A Death of One's Own:

Understanding Dying Well For Patients Receiving Palliative Care

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It is the thought of doing the best you can today, and making today really count, and being really positive, and then letting it go and doing the same thing again tomorrow.

K.M.

Abstract

This thesis investigates individual differences in understandings of dying well from the perspective of patients receiving palliative care. Dying well has traditionally been researched from the health professional's perspective, and this has produced a relatively uniform understanding. The present research addresses gaps in the literature specifically with respect to addressing the palliative care patients' perspective, and the investigation of individual differences in understandings of dying well.

Q-methodology was used in the present research to develop accounts of dying well. In this approach a number of statements about a construct are sorted onto a response hierarchy, with the resulting data subjected to a weighted average procedure and factor analysed in a by-participant factor analysis. In the present research, interviews were conducted with patients and hospice nurses to develop a series of themes, or statements, about the notion of dying well. Following a number of guidelines, these themes were then reduced to a manageable set of statements for pilot testing on further patients and health professionals. The final set of 40 statements (Q-set) was established for the task of Q-sorting. Forty patients were recruited from Arohanui Hospice, Palmerston North, to carry out the Q-sort. This task involved placing the statements on a quasi-normally distributed response hierarchy from *most important* to *least important*. The resulting Q-sorts were then factor analysed in a by-participant factor analysis, which grouped participants, rather than statements, together on the basis of their correlations. A weighted average procedure was undertaken to produce exemplar Q-sorts for each factor, and these exemplars represent an amalgamation of the similarities between participants. The exemplars were then interpreted in combination with interviews carried out during the Q-sort process.

Four factors, or accounts, of dying well for patients receiving palliative care resulted from this analysis. These were labelled as: religious-oriented, independent-oriented, idealised, and family-oriented accounts. The placement of the statements in the religious account reflected the relative importance placed upon God and religious faith. In addition, statements reflecting personal control were rated least important. This was in contrast to the next account, independent-oriented, where statements reflecting control and independence were rated as most important. The third account, idealised, indicated a death denying position, and an idealised notion of the dying experience. Family-oriented, the final account, emphasised the importance of family above all else, including superseding the needs of the individual.

Focussing specifically on patients' perspectives has addressed an apparent gap in the literature, and identified an alternative perspective on the notion of dying well. Uncovering four different accounts suggests that there are individual differences in understandings of dying well for patients receiving palliative care. The nature of these differences implies that there is neither total idiosyncrasy nor total uniformity in patients' understandings. This thesis concludes with a discussion of limitations of the present research, possible future directions for research, and a discussion of the potential clinical implications of the findings.

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[Dying]
It’s finding a different way to live in the world, that’s what it is, and if you can do that, it’s not so bad.

S.G.

Chapter 1:
Introduction

That we will die is a universal certainty. The nature of how and when we die, and whether or not we die as we would wish, for most of us, is much less certain. For those who have a terminal illness, the circumstances of dying become more salient and considerably more real. How terminal patients die will depend upon the type of illness they have, their personality style, their age, their environment and a variety of other factors. How terminally ill patients would choose to die, or what dying well means for them, is generally understood in terms of shared cultural knowledge about what constitutes a good death. This research investigates the extent to which there are individual differences in patients' understandings of dying well.

People can live with a life-threatening illness for several years. Many, particularly those with incurable cancers, will reach a phase when curative treatments are no longer effective and these individuals will move into the terminal, or palliative, phase. At this time in their illness, patients in New Zealand are commonly referred to a hospice programme to receive palliative care. Curative treatments that take place in a hospital setting are traditionally aggressive treatments aimed at eliminating or containing the disease. This differs from palliative care which is primarily pain relieving. Hospice is not exclusively employed in managing physical pain, it also aims to attend to the emotional, spiritual, and social needs of the terminally ill individual. Hospice therefore, is not simply a 'bricks and mortar' structure, it is a philosophy of care that provides the context in which individuals can understand, and perhaps achieve, a good death.

Hospice has an extensive history dating back several thousand years, with modem hospice the current manifestation. Chapter Two details various factors that have influenced the development of the modem hospice movement, and have thus impacted on the notion of dying well. Such factors include societal influences, advances in medical technology, and the increasing institutionalisation of hospice. The aims of palliative care within the New

Zealand hospice movement are also introduced as they serve to frame the context in which a good death occurs.

One key aim of current palliative care is to employ "a holistic approach that integrates the physical with the social, psychological and spiritual aspects of care" (Ministry of Health, 2000, p. 2). Although a good death is not an explicit objective of palliative care, there is an underlying assumption that should the above aim be met, a good death will be achieved.

The notion of a good death has been conceptualised in a number of ways, including: definitions, lists of components, categories of components, qualitative accounts, and social practices. Chapter Three includes an analysis of these concepts, and a review of research findings. Following from this, Chapter Four critiques the literature from Chapter Three, particularly in terms of the choice of sample, and other methodological difficulties.

There are a number of ways in which dying well could be investigated, and many varied approaches have been tried. The present research used Q-methodology to investigate patients' understandings of dying well. This approach produces structured accounts of these understandings via a form of factor analysis. Each account therefore represents a different way in which dying well is understood by the patients. As Q-methodology is not a commonly used technique and can be used in a variety of ways, the methodology is explained in broad terms in Chapter Five. Chapter Six describes the methods and procedures used in the present study, including details of the particular Q-analysis adopted.

Chapter Seven outlines the results of the statistical part of the analysis that led to the identification of four accounts of dying well. The subsequent four chapters (Chapters Eight to 11) offer detailed descriptions of each of the accounts. Each of these chapters uses qualitative data obtained from the participants to reflect upon and further develop the understandings identified.

Finally, the discussion chapter, Chapter 12, outlines the contribution the findings make to existing knowledge of a good death, particularly in terms of identifying the patients' perspectives on understanding dying well, and also in terms of establishing individual differences in understandings. This chapter also addresses some difficulties that arose from the research, it suggests future research that might be undertaken to extend the current knowledge of dying well, and discusses potential clinical implications of the findings.

While I thought that I was learning how to live, I have been learning how to die.

Leonardo da Vinci
(1452 - 1519)
Notebooks

Chapter 2:

Hospice Philosophy and Principles of Palliative Care

This chapter will focus on the influence of early hospice on current hospice philosophy and palliative care principles. These principles and philosophy provide the context within which the notion of dying well has developed, the health professionals' perspectives have been formed, and the patients' views are practised. Specifically, the chapter will explore the influence of religion on the development of hospice, and the role of medical technology in determining hospice practices. Increasingly hospices are being drawn back into the hospital fold, and this has come at a cost of institutionalisation and additional bureaucracy. These elements are also discussed in relation to their impact on dying well.

Although hospice is often thought of as a fairly modern movement, in fact its history dates back more than 3000 years. Like the development of other hospitable establishments, hospice is born of religious and humanitarian traditions of caring for those in need (Siebold, 1992). The emergence of hospice has come about in three loosely defined stages. *Ancient hospice* provided shelter and mainly spiritual care for pilgrims, travellers, crusaders, the sick and the dying. In *pre-modern hospice*, care was still largely spiritual but was almost solely for the sick and dying. Exclusively for the dying, *modern hospice*, sees all aspects of the human condition considered - emotional, physical, social and spiritual. Appendix A includes a historical account of the development of ancient and pre-modern hospice, and provides additional background information to the hospice movement.

Societal Influences on the Development of Hospice and Hospice Philosophy

Religious Ideals

Many ancient hospice establishments were run by religious orders and provided food, shelter and spiritual care, but not medical attention (Manning, 1984). As religious fervour grew, the notion of providing hospitality became a religious duty (Manning, 1984; Munley, 1983; Siebold, 1992) rather than an altruistic act. This early involvement of religion was fundamental to the development of hospice, and continues to permeate the hospice movement today. As Clark and Seymour (1999) eloquently note, world-wide modern "hospices have sought self-consciously to rekindle the tradition of devotion, caring and the ethic of service which was enshrined in the religious foundations of their predecessors" (p.66).

Much of the religious focus of today's hospices is attributable to Dame Cecily Saunders, the founder of the modern hospice movement and St Christopher's Hospice in London. St Christopher's, established in 1967, is the hospice upon which other hospices worldwide, have been modelled. The power of Dame Cecily Saunders as the charismatic leader of this movement should not be underestimated, nor should the strength of her own underlying belief system (Clark & Seymour, 1999). Saunders is a devout Christian and the strength of her convictions is stated most succinctly by her biographer Shirley Du Boulay who states: "St Christopher's is the incarnation of a religious ideal - Cecily's religious ideal. Her spiritual journey is expressed in St Christopher's; St Christopher's reflects the spirit of its founder. They cannot be separated" (1984, p. 155). Based upon this influential leader, this religious ideal has continued to pervade hospice throughout the world.

Today's society however, is becoming increasingly secular, with the role of religion less pervasive. Increasingly, the ideology of individualism extends throughout our modern society and consequently the impact of religion on modern life has been considerably weakened. Hospice's foundation of religious (and predominantly Christian) principles is less aligned with current societal beliefs, and hospice therefore has the potential to isolate itself from sectors of society by not keeping pace with our increasingly multifarious world. Dying well may or may not be achievable within a system that is inconsistent with an individual's own beliefs.

Without sidelining its religious underpinnings, increasingly the hospice movement is attempting, at least in principle, to attend to *spiritual* beliefs, where spiritual beliefs are much broader than religion. Barnard (2000) suggests that whilst medical advancements have increasingly been incorporated into hospice practices, changes in spiritual beliefs have not equally been included. Accommodating broader spiritual beliefs within hospice will increase opportunities for patient autonomy and choice to be respected (Ministry of Health, 2000). Hospice, and hospice philosophy, is attempting to attend to changing societal beliefs by redefining palliative care. This should in turn, increase opportunities for dying well, as death practices become more in line with individual beliefs.

The recent New Zealand Palliative Care Strategy – Discussion Document (2000) is an example of policy attempting to keep pace with change. This document, although having a strong funding focus, attempts to advance improved guidelines for the provision of palliative care within New Zealand. It defines palliative, or hospice, care as below.

> *Palliative care operates from the time it is acknowledged that the aim of treatment is no longer curative and that a person's death is very likely. It is the active total care of people by a multidisciplinary team when a person's disease is not responsive to curative treatment, and:*
>
> - *affirms life and regards dying as a normal process*
> - *aims to neither hasten nor postpone death*
> - *aims to provide relief from distressing symptoms*

- *integrates physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care*
- *offers help to the family/whānau/carers during the person's illness and their bereavement"* (Ministry of Health, 2000, p. 2).

This New Zealand definition has attempted to emphasise our multi-cultural heritage and address the needs of New Zealand Māori, and with this, include more diverse spiritual beliefs. In terms of the religious underpinnings of this definition, it could be argued that the first two points, in particular, relate to religious principles regarding the sanctity of life. The fourth point openly includes a spiritual component, but de-emphasises it by including the more modern focus on integrating aspects of care. Whilst definitional changes are attempting to keep pace with changing society, how are these definitional changes implemented in clinical practice?

The Ministry of Health (2000) document continues by attempting to address the implementation issue by specifying the *aims* of palliative care. These are to:

- *respect patient autonomy and choice (for example, over treatment options)*
- *provide care that includes support for those people close to the person who is dying*
- *use a holistic approach that integrates the physical with the social, psychological and spiritual aspects of care*
- *promote open and sensitive communication between health care professionals and the person who is dying and their family/whānau*
- *provide care that is culturally appropriate*
- *provide care that is people centred* (p. 2).

Although these aims do not expressly address the provision of dying well or a good death for patients, there seems to be an underlying assumption that if the aims are met then the patient (and family/whānau) will be satisfied with the service provided, and to some extent, a good death will have been achieved.

Individualism and Collectivism

Ancient and pre-modern hospices were born of a tradition of collectivism where value lay in close-knit families and communities. Western society however, increasingly favours the ideology of individualism. In line with the Ministry of Health's (2000) definition, respecting the patient's autonomy and choice follows this ideology, and most certainly requires that the patient be asked what it is they want.

The remainder of the points in the Ministry of Health's definition seem to focus on a type of collectivism that may run contrary to the individualism promoted in the first point. Religious beliefs, particularly of promoting the importance of family above the self, may be responsible for the endorsement of collectivism within the hospice movement. There appears to be no recognition within hospice philosophy and practice that these ideologies are contradictory. In attempting to create an ideological stance that meets the needs of all, hospice appears to have included competing elements. In terms of the dying experience then, how might the competing ideologies impact upon the individual who is dying? It could be argued that if an individual's ideology is consistent with hospice's ideology then dying well may be easily facilitated and achieved. Without a similar ideology to hospice, it is difficult to see how a good death is achievable.

Advances in Medical Technology

Up until the late 1960s hospices in the US and Europe discouraged medical interventions. The main proponent of the change to addressing medical issues was Dame Cicely Saunders (Siebold, 1992). Her vision encompassed the pre-modern hospice traditions of providing care and hospitality to the terminally ill, but significantly augmented this care with the addition of much needed medical treatment (Buckingham, 1983). This redefinition of the role of medical treatment is the cornerstone of the modern hospice movement. In the Ministry of Health's (2000) definition of palliative care outlined above, the role of medicine is clearly acknowledged through the inclusion of references to physical aspects of care, as well as in the reference to curative treatments in the opening statement. Medical treatment, or more specifically, pain management, has in fact surpassed religion to become the core focus of palliative medicine and care. Perhaps unsurprisingly, symptom management and control is the feature most identified by nurses as important in end of life care and a good death (Payne, Langley-Evans, & Hillier, 1996). Paradoxically, the ever increasing use of more advanced medical technologies in palliative care has needed to be offset against the traditional hospice philosophy of employing only palliative treatments. "Curative" medical treatments are increasingly being used within the palliative setting. For example, radiation therapy is used within curative approaches as well as for pain management in advanced cancer (Twycross, 1997). This blurring of the line between curative and palliative treatments can lead to ambiguity in practices. The increasing medicalisation of palliative care has not come without a price. Social, psychological, and spiritual care, all, parts of hospice's holistic approach have suffered. The dominance of symptom management as a first line of intervention for terminal patients has brought hospice care closer to that of hospital care. This is becoming problematic as hospice attempts to maintain its identity, but also reconcile the philosophy of hospice care with the medicalisation of the hospital movement (Clark & Seymour, 1999).

Institutionalisation Within Hospice and Palliative Care

As most hospices, including St Christopher's, were originally developing predominantly via the charitable trust sector, they tended to be separate physical structures in a community setting. At this time they were largely in-patient units and were seen to be an appropriate environment in which an individual could die peacefully. In the mid-1970s however, there was a shift towards giving hospice a more 'continuing care' focus. Whilst tending to remain structurally separate, they began to be built within hospital grounds and also to draw upon national health service financial resources (Clark & Seymour, 1999). This has, in addition to the specialisation and increasing medicalisation of palliative care, brought hospice into the mainstream medical (i.e. hospital) realm. This has lead to the routinisation of hospice care, and with this, comes bureaucracy (James & Field, 1992).

In terms of the provision of care for patients, and particularly in the aspirations for dying well, it is perhaps the hospice staff who are most keenly affected by this increasing institutionalisation. They must attempt to reconcile the needs of the patient in the context of hospital policy, both economic and philosophical, and also adhere to the philosophy of hospice. Hospice was founded on a principle of breaking the traditional rules of medical practice, but with increasing demands being made from various quarters, hospice is becoming rule bound (James & Field, 1992). This is presumably leading to less flexibility in the choices available to patients. Despite attention being given to the patient's autonomy and choices, with the increasing institutionalisation of palliative care, individual preferences for dying practices seem to be smothered in favour of upholding institutional values.

Summary

Modern hospice has come a long way from its ancient and pre-modern counterparts. However, the underlying philosophy of providing hospitality and care, and to a large extent, spiritual care, has remained. The early religious focus and the changing societal ideologies, in addition to the more recent medical advancements and increasing institutionalisation, provide not only the context of hospice, but also the context of dying well. These factors influence both the development of the idea of dying well and establish a context in which it can occur. These increasing pressures on hospice and hospice philosophy to meet the demands of the changing society, may well be played out in the dying process.

There is increasing tension within hospice regarding the provision of care in a diverse society with increasingly secular and individualistic philosophical beliefs. In addition, medical technology has revolutionised the modern hospice movement, and currently, the provision of medical care, particularly by way of symptom management, has now become a key feature. The philosophy of hospice and palliative care has begun to pay attention to all areas of functioning including physical, psychological, social, and spiritual, in order to provide holistic care for the dying. The current struggle for hospice is to provide patient autonomy and choice, but to do this within the context of increasing medical technology and institutionalisation. These factors play an important part in influencing the development and understanding of the concept of dying well. In addition, although the aims of palliative care do not include the achievement of a good death as a goal, there does seem to be an underlying assumption that if the aims are met then a good death will have been achieved.

This is what we were taught as children, that when God created Death he created two sorts, Lily Death and Moon Death. The choice is ours, depending on the way we live our lives. The lily is gregarious. It thrives amongst its own kind. It sends out shoots which replace and survive it after death. The moon is solitary and childless. It has no offshoots. But when it dies, it rises to live again. . . . We choose the nature of our death by the way we live our lives.

Jim Crace
Sins and Virtues

Chapter 3:

Conceptualising a Good Death

Since the late 1960s death has become an increasingly popular topic for psychological research. However, the task of understanding the nature of a good death, has not received so much attention. The little research that is available is comparatively diverse, and has approached the concept from a number of different perspectives, and these are addressed in this chapter.

Definitions of a good death are scarce, but provide a useful starting place to investigate the construct, and this is introduced in the first section. The following section addresses research that has focused on identifying the components of a good death – which elements are important or necessary to facilitate the process of dying well. Others have extended this type of research by seeking to understand how the different components of a good death might be systematically grouped or categorised.

For other researchers, the focus has been on how individuals construct accounts of a good death through qualitative research, and this is discussed in the fourth section. The final section examines research that has attempted to contextualise a good death and to identify what roles it is performing in social and societal terms.

Defining a Good Death

Good Death Terminology

Good death derives from the Greek *Kalos Thanatos*, meaning "beautiful death, the ideal or exemplary" (Liddell & Scott, 1897, p. 737, as cited in Kellehear, 1990). This differs from *Eu Thanatos*, which equates more with "dying well, that is painlessly and easily" (Partridge, 1959, p. 189, as cited in Kellehear, 1990), which is where the word euthanasia originates. Despite clear links between a good death and euthanasia (Council of Scientific Affairs, American Medical Association, 1996), end-of-life decisions (Singer, Martin & Kelnor, 1999), and intensive care units (Johnson, Cook, Giacomini & Willms, 2000), the present research addresses only good death within the palliative care context. Before attempting to define a good death, it is helpful to first consider the terminology that has been used to describe a good death. Good death (Beresford, 1997; Gazelle, 2001; Katz & Sidell, 1994; Kaufman, 2000; Sadler, 1992) has variously been called dying well (Neuberger, 1999, 2000; Richardson, 1977), appropriate death (Weisman, 1972, 1993), hopeful death (Anderson, 1989), decent death (Institute of Medicine, 1997), healthy death (Smith & Maher, 1993), dignified death (Weber, 1995), peaceful death (Callahan, 1993), good enough death (McNamara, 2001; Young & Cullen, 1996), coping with death (Rando, 1984, as cited in Smith & Maher, 1993), correct death (Berger & Luckmann, 1975), and adaptation to death (Barton, 1977, as cited in Smith & Maher, 1993). Knowledge of a good death has predominantly come from history (Ariès, 1974), sociology (Kellehear, 1990), medical anthropology (McNamara, Waddell & Colvin, 1994), medicine (Kübler-Ross, 1969; Weisman, 1972, 1993), and more recently from nursing (Kristjanson, et al., 2000; Payne et al., 1996). Psychology has contributed very little to our understanding of a good death.

Current literature vacillates between using the term “good death”, which reflects the last few moments of life, and “dying well”, which considers an extended amount of time up to and including the physical death. Both of these terms do appear to be used interchangeably. In introducing the material that follows, I have used the terminology that the respective authors have chosen for their research.

Definitions

Very few researchers have attempted to define a good death, but some of those that have are discussed. Smith and Maher (1993) defined a healthy death “as a death that has positive effects on the dying person, the dying person's family, and the dying person's principal caregivers" (p. 22). This definition moves away from the individual as the focus of a healthy death, and highlights the perceptions of others who are involved. However, they do not go on to elaborate what these "positive effects" are, and who is deciding whether the effects are sufficiently positive.

Nimocks, Webb and Connell (1987) suggest that "the degree of 'goodness' of [the] death experience is the extent to which the interactants accept the impending death, receive mutual emotional care and support, mitigate the dying person's discomfort and isolation and/or complete all 'unfinished business'" (p. 329). It is difficult to know specifically who the "interactants" are in this definition. Like Smith and Maher's (1993) definition, the focus of a good death is much broader than the patients themselves, and appears to emphasis the role of the "interactants".

A third definition is offered by the American Institute of Medicine (IOM). They defined "a *decent or good death* as one that is: free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (1997, p. 24, emphasis in original). There is a lot of flexibility in this definition, particularly in "*avoidable* distress", "in *general* accord", and "*reasonably* consistent", which makes it appear less of an idealised good death than a practicable good death. This clearly has some value in terms of the provision of care from the health provider's perspective (which is the source of the definition), but offers restricted control and choice to the patient. Furthermore, this definition does not give the patient's wishes precedence over the family's wishes, or perceive the family as able to provide for the patient. This third definition sees both patient and family receiving care and is therefore in contrast to the previous definitions which focus on what must be done, rather than who must do it. Possibly the most influential writer on a good death, who has come from the medical discipline, has been Avery Weisman (1970, 1972, 1988, 1993). His definition developed out of his clinical experience in working with the terminally ill. In surprisingly non-medical terms, he coined the term "appropriate or befitting death", which he describes as "a death that someone might choose for himself - had he a choice" (1972, p. 36). The first clause of this sentence seems fundamental to the investigation of a good death - that an individual chooses. There are two possible readings of the second clause, one more charitable than the other. Firstly, few get to choose the 'how' of their death, be it a chronic illness, accident, or cardiovascular accident. An alternative explanation is that the reality of dying in an institutional setting currently, is that individuals are not given any control over decision making at this critical time, and "had he a choice" reflects the limited control the individual has within the highly structured setting of the current medicalised approach to dying. It is not clear from Weisman's writing what his position on this is.

Weisman (1993) goes on to describe four necessary characteristics of an appropriate death, and then several conditions that help facilitate such a death. The four necessary characteristics are awareness, acceptance, propriety and timeliness. Awareness refers to the patient being aware that there is nothing more that can be done to prevent the advancement of the disease. Although in the past, discussing a terminal diagnosis with a patient has been avoided (Glaser & Strauss, 1966), most of the current literature is in favour of open communication about impending death (Nimocks, et al., 1987). Weisman is in agreement and extends this by, rather harshly, stating that: "denial of an incipient demise is apt to be foolhardy" (p. 192).

Acceptance, the second characteristic, he describes as being "very inconstant" (1993, p.192). Patients can show differing levels of acceptance according to whom they are speaking. For example, showing acceptance to family and friends to prevent them suffering, and showing denial to doctors in order to encourage continued treatment (Hinton, 1971). It is difficult to use the word 'acceptance' without Kübler-Ross' (1969) work coming to mind. The fact that Weisman considers acceptance inconstant is an important advancement on Kübler-Ross' work where acceptance is considered the ultimate stage. This view allows more flexibility and an ability to move between beliefs.

Propriety, the third characteristic, "refers to the non-medical features of illness that distinguish a good death from something more objectionable" (1993, p. 192). These features are established from the perspective of the patient, and do not involve outside judgements of another. This can include controlling the numbers of visitors, the place of death, the decision-making process, and the "protection of individuality and decorum" (1993, p. 193).

The final characteristic of an appropriate death for Weisman (1993) is timeliness, which refers to "when is the best time to die" (p. 194). He suggests that often the very elderly, by virtue of being very elderly, are seen as failing to achieve a timely death for not dying earlier. For others, dying may last for an inappropriate length of time, either too long or too short, that causes some inconvenience to family or inheritors. If some individuals seem to live too long and others die too soon, then Weisman argues that there must be a time that is just right "indicating that further existence would be meaningless and that death now would be particularly significant" (p. 194). This is perhaps the most problematic of Weisman's characteristics. He seems to suggest that timeliness relates to others (inconveniencing them) and not solely to the dying individual. There is also a hint that the dying individual should, somehow, take responsibility over the timing of their own death, so that they do not inconvenience others. This seems unattainable in a practical sense. However, perhaps Weisman believes that a good death is unrelated to attainability. This is not clear from his writing. Even if a good death were achievable, it is unclear who is making the decision about whether a death has been timely or not - how then can it ever be known?

Weisman (1972) also identifies several conditions that will facilitate an appropriate death. These include: being relatively pain free, experiencing limited suffering, having social and emotional needs met, operating on as high a level as possible, resolving conflict, having remaining needs satisfied, relinquishing control to trusted others, and making decisions about maintaining or abandoning significant others. These characteristics are supported and extended upon by later literature, which will be discussed in the following sections.

One of the core difficulties of Weisman's (1972, 1993) work seems to be the incompatible desire to allow the patient to be idiosyncratic and yet still attend to the needs of others. In describing awareness, he talks about patients being "foolhardy" if they are in denial, which implies a judgement from someone other than the patient - something Weisman argues strongly against in propriety. In addition, when discussing propriety, he notes that this concept is based on "what a patient decides is right and proper and on what seems befitting according to the pertinent community's expectations and standards" (1993, p. 193). This again suggests an outside source, and more complex yet, a community, providing some structure on which to make a judgement of good or bad, appropriate or inappropriate, other than the patient's own expectations and standards. Even though a person may live within a community, the values that they hold may or may not reflect exactly the community's values, and ultimately, Weisman's definition suggests that the community will decide. Timeliness seems totally driven by outside forces, and the dying person is impossibly involved in timing their own 'punctual' death. These characteristics seem inconsistent with the original statement of "a death that someone might choose for himself" (1972, p. 36).

Stephen (1991-92) reviewed Weisman's approach and identified three principles she considered prevailed in his research: 1 - consistent functioning; 2 - what is appropriate is idiosyncratic; and 3 - components that enhance the opportunity to achieve a better death. In terms of consistent functioning, several discordant patterns of functioning contribute to an inappropriate death. First, a pattern of functioning that is discordant with past functioning will have an adverse impact. Second, a pattern of functioning that is discordant with one's view of oneself, and, thirdly, discordant with a significant other's view, will also be a factor in an inappropriate death. However, consistent functioning as Stephen describes it, seems to be an untenable position. What an individual perceives as discordant may often conflict with what significant others assume is discordant. Furthermore, reflecting on past functioning requires a consistency that may not be apparent.

The second principle, that the individual's perspective is essential in providing an appropriate death, seems to be a point that is largely lost in the remaining literature that will shortly be reviewed. Stephen (1991-1992) emphasised the need to avoid hypothesising about what the patient might want, by actively asking the dying person what is important to them.

Components that are important to an appropriate death, the third principle in Stephen's (1991-92) approach, are the same as those listed earlier. These components seem to have become the focus of almost all later research.

In much good death research, authors have investigated perceptions of both good and bad deaths. There is sometimes a sense in this research that a good death is the mirror image of a bad death (Abramovitch, 2000). For example, pain is bad; therefore lack of pain is good. This view seems to place good and bad deaths at opposite ends of a continuum. This means that the absence of bad characteristics would imply a good death. In the present research this particular line has not been pursued predominantly since it seems reasonable to consider that good and bad deaths represent qualitatively different phenomena, rather than different ends of a continuum. It seems possible that a death can be perceived as both good and bad, either by an individual or across different perspectives, and also that a death or dying may have good and bad aspects co-existing. Furthermore, there may be aspects of a good death that bear no relationship to a bad death. Finally, it is necessary to consider what we can know about certain aspects of death. We can never know whether the patient thought the death was good or not. For example, patients experiencing a "bad" symptom, such as delirium, cachexia-anorexia, or haemorrhage, may or may not be experiencing bad death, from their perspective. Thus the standpoint taken in the present research is that a good death is qualitatively different to a bad death and not simply the opposite, or "not a bad death". For this reason, limited reference is made to research on a bad death.

Components of a Good Death

A great deal of good death research has tended to take a taxonomic approach. This has meant investigating the nature and number of components that are necessary for, or facilitative of, a good death. This tradition was perhaps first introduced through historical research on the nature of a good death. Further research, particularly from within the medical discipline, has further fostered this particular approach. In light of the philosophy of hospice care to address the physical, psychological, social and spiritual needs of the patients, the components have been artificially grouped in this way, and are presented below.

Historical accounts are a useful place to begin to explore the notion of a good death from a components perspective. Phillippe Ariès (1974, 1981, 1993), a French historian, investigated western attitudes to death, and detailed the nature of a good death in Europe in the Middle Ages. He identified five components of a good death. First, the individual had an awareness of their impending death through knowledge of their own bodily processes rather than through a discussion with a health professional. Second was the public expression of grief from the patient. Third, forgiveness of those who the patient had wronged was sought, which facilitated the bestowing of God's blessing on the patient. Fourth, the patient sought forgiveness and pardoning of sins from God, whereby an absolution would be performed by an appropriate representative of God (commonly a priest). The final component was waiting for death once the patient was no longer communicating (Ariès, 1974). The order in which these components occurred was apparently not important, but their existence as necessary components of a good death was. As the predominant religious belief at this time in Europe was Catholicism, the focus on forgiveness and atonement is unsurprising.

Ariès (1981) suggested his conclusions about attitudes to death in the Middle Ages in Europe were applicable to all "Western Christian cultures" (p. xiv). A New Zealand researcher applied Ariès' findings to the Pakeha (New Zealand European) treatment of death from 1850 to 1910 (Cleaver, 1996). Cleaver concluded that Ariès' work was indeed relevant to Pakeha attitudes during this period which reflected European attitudes to death.

What might have been appropriate in the Middle Ages is unlikely to relevant today. With less focus on western Christian ideals, the notion of a good death has been further developed. The number of characteristics necessary to achieve a good death ranges from a few (Field, 1984) to many (Bolton, 1981), and these characteristics frequently overlap. Good death characteristics can be grouped conceptually in a variety of ways. However, given the hospice philosophy of attending to the patient's physical, psychological, social, and spiritual needs, it seems appropriate to introduce them in these categories. What therefore follows is an overview of the types of characteristics that have been suggested as components of a good death by researchers from a range of disciplines.

Physical characteristics

Given that the majority of research has been carried out within medical settings and with health professionals, it is perhaps unsurprising that pain control or being pain free, are the most common physical features of a good death (Bolton, 1981; Callahan, 1993; Emanuel & Emanuel, 1998; Field, 1984; Gelo, O'Brien, & O'Connor., 1997; Hunt, 1992; Kristjanson et al., 2001; Low & Payne, 1996; Payne et al., 1996; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000; Wilkes, 1993). Physical symptom control, particularly of nausea, vomiting, and diarrhoea, or having no distressing symptoms and no suffering, are also important (Bolton, 1981; Emanuel & Emanuel, 1998; Field, 1997; Hunt, 1992; McNamara et al., 1994; Taylor, 1995; Wilkes, 1993). Also, in Steinhauser, Christakis, et al.'s study (2000), the notion of the patient being kept clean was important.

Psychological characteristics

The most widely reported psychological characteristic of a good death is acceptance (Bolton, 1981; Hunt, 1992; Kristjanson et al., 2001; Payne et al., 1996; Taylor, 1995; Wilkes, 1993). Acceptance itself is ill-defined, and seems to be loosely based upon the 'final stage of dying' identified by Elisabeth Kübler-Ross (1969). At times acceptance refers to the acceptance of the certainty of death (Bolton, 1981), acceptance of diagnosis (Hunt, 1992), family acceptance (Payne et al., 1996), or just general acceptance or accepting (Kristjanson et al., 2001; Taylor, 1995; Wilkes, 1993). These multiple meanings of acceptance are problematic in the sense that it is often assumed that the author and reader are employing the same definition, when in fact they may not.

Other psychological characteristics that have been identified as important include: being at peace with self (Low & Payne, 1996); having hope (Hunt, 1992), maintaining mental capacity (Wilkes, 1993), having a healthy attitude to death (Smith & Maher, 1991, 1993), having control and making decisions (Bolton, 1981; Bradbury, 1993; Hunt, 1992; Katz & Sidell, 1994), having come to terms with life (Bolton, 1981), resolving conflict and having affairs in order (Bolton, 1981; Kellehear, 1990), and living life to the full (Hunt, 1992; Low & Payne, 1996).

Social characteristics

Involvement of family and friends in the dying process is a commonly identified characteristic (Hunt, 1992; Katz & Sidell, 1994; Taylor, 1995; Wilkes, 1998). They should be present at the time of death (Kristjanson et al., 2001; Payne et al., 1996; Steinhauser, Christakis, et al., 2000; Wilkes, 1993), be accepting of the patient's diagnosis (Hunt, 1992; Payne et al., 1996), and be prepared for the patient's death (Steinhauser, Christakis, et al., 2000). Some research has elaborated on this characteristic to include three types of interaction involving family (Taylor, 1995). Patient-to-family interactions were naturally highlighted, and concerned the dying patient feeling supported by family. Secondly, family-to-family interactions, where outer family members support those closer to the patient, were also important. Finally, nurse-to-family interactions where identified. These were characterised by nurses and family being mutually supportive. These three levels of interaction certainly broaden the role of family in the dying process beyond which they are normally considered. Interestingly, however, introducing the nurse-to-family relationship may imply collusion, but is framed as in the best interests of the patient.

Social characteristics can also include the role of nurses and other health professionals in terms of providing support for the patient and family (Taylor, 1995), encouraging adequate communication (Kristjanson et al., 2001), and being someone who the patient feels comfortable with and can trust (Steinhauser, Christakis, et al., 2000).

Spiritual and cultural characteristics

Some researchers acknowledge the role that religion plays at the end of life, such that the death should be in line with religious principles and practices (Abramovitch, 2000; Gelo et al., 1997; IOM, 1997; Payne et al., 1996). Others have taken a broader view and introduced the importance of spiritual and existential beliefs, establishing a sense of purpose and meaning in life (Callahan, 1993; Emanuel & Emanuel, 1998), and finding a spiritual dignity (Callahan, 1993).

Cultural characteristics are occasionally acknowledged as important in achieving a good death. Following cultural rules, addressing cultural perceptions, and a death that occurs in line with cultural beliefs are mentioned (IOM, 1997; Katz & Sidell, 1994; Low & Payne, 1993). However, there is a tendency for both culture and spirituality to be overlooked or have a nominal status.

Other characteristics

A significant proportion of the research carried out with regard to a good death refers to the final moment or hours of a person's life. Thus, many of the characteristics refer specifically to this time. These include a death that is: peaceful, quiet, calm, tranquil, dignified, quick, and beautiful; and where the individual is: comfortable, with family and/or friends, with nursing staff, not alone, in their chosen environment, not afraid, ready to die, saying goodbye to significant others, and goes in their sleep; and this takes place without: tubes, aggressive treatments, agitation and anxiety (Bolton, 1981; Gelo et al., 1997; Hunt 1992; Katz & Sidell, 1994; Kristjanson et al., 2001; Low & Payne, 1993; McNamara et al., 1994; Payne et al., 1996; Taylor, 1995; Wilkes, 1993).

The range of characteristics established by the research is diverse and covers several domains of functioning. The listing of characteristics in this way gives a sense of the feature that might be important at the end of life. Although some of this research has established notions of dying well that have attempted to combine these various characteristics in a meaningful way, this primarily taxonomic approach has a number of problems associated with it.

Combining Components of a Good Death

Several studies have attempted to combine components of a good death into categories. They have done so using a variety of methods, including conducting factor analyses and conceptually grouping components.

In a quantitative study by Low and Payne (1996) a 12-item questionnaire was created, which was established on the basis of in-depth interviews with palliative care professionals. The researchers then administered the questionnaire to 50 palliative care professionals, and factor analysed the results. Three factors of a good death were uncovered which were labelled: lack of patient distress, patient control and role of staff. Lack of patient distress included the following components: family acceptance, dying in the presence of close people, being at peace, continuing previous interests, having no physical pain, having no anxiety, and dying in place of choice. The second factor, patient control during the dying process, included following appropriate cultural rules, dying in place of choice, cultural perceptions of a good death, patient control, and dying in the presence of close people. The authors describe this factor as "giving patients back some control of their lives and … following the rules governing their cultural beliefs" (p. 239). Role of staff, the final factor of a good death, included a comfortable process, having a peaceful death, no anxiety, and no pain. In this view the staff are responsible for attending to the physical and psychological needs of the patient.

Kristjanson et al. (2001) and Leichtentritt & Rettig (2000) both used domains of functioning (e.g. physical, personal, social) to describe the combining of the components into groups. Kristjanson et al. (2001), through interviews with 20 palliative care nurses, described five groupings which they labelled: patient-related features, family-related features, team- (i.e. staff) related features, illness-specific features, and attributes of the death scene. Similarly, Leichtentritt & Rettig (2000), who interviewed 26 elderly Israelis, labelled their groupings: personal, interpersonal, social, cultural, and physiological domains of life. Despite having similar labels, only one grouping of statements corresponded – illness-specific and physiological. The illness-specific category included components of lack of suffering, having no loss of dignity, and symptom control. Likewise, the physiological domain referred to maintaining independence and self-reliance, maintaining mental capacity, and avoiding physical pain and suffering.

Patient-related factors for Kristjanson et al. (2001) covered only one component, that of being ready or accepting of death. The family-related factor included having family members who were trusting, prepared, communicative as well as present at the time of death were key to the connected good death. This was quite different from Low and Payne (1996) where the patient remained the focus, whereas here the focus appears to be on the relationship between the nurse and the family, and the patient is somewhat ancillary. The third category, team-related factors, included the following components: having rapport and being supportive of each other, being communicative, anticipating symptoms, having adequate time with patients, and knowing the patients and family. Again, this was very different to Low and Payne's (1996) role of staff, which was framed more in terms of what nurses could do for their patients to aid them in dying well. The final factor was attributes of the death scene. This included the patient being supported by staff, family and friends, the death being peaceful, calm, quiet, beautiful, and the patient having a look of readiness. Interestingly, there was no mention of being at home in this account, a characteristic that frequently features as part of a good death final scene (Bolton, 1981; Hunt, 1992; Porta, Busquet & Jariod, 1997).

Although comparable to Kristjanson et al's (2001) categories, Leichtentritt & Rettig's (2000) have a more nebulous quality. Interpersonal death, their second category, included accepting the imminence of death, others accepting their death, and "separating from the world by stating one's wisdom" (p. 240-241). Personal death combined spiritual consolation, dying a natural death, integrity of self and ritual, and sharing the dying experience or choosing to isolate others. The fourth category was social death. This included dying at an appropriate age, completing tasks, addressing social norms, and considering the "consequences of behaving in a deviant manner" (p. 241). Finally, cultural death included respect, "continuity of heritage" (p. 241), leaving a legacy, and religion under a Jewish state. Despite the appearance of these groupings as somewhat reconfigured characteristics, there is an attempt in this study to exemplify each of the groupings, and then integrate them not only under a generic category, but also to situate them within a good death timeframe. It was noted that a good death covered several time periods including past, present, and future, and the underlying principle was that of maintaining continuity throughout. This idea of providing an overriding framework for a good death is an advance on previous research, which is similar to the research that follows.

A final study in this section attempted to go beyond mere components, aiming to "gather descriptions of the components of a good death" (Steinhauser, Clipp, et al., 2000, Abstract, para 1). However, the categories appear more focused on aspects of the death, rather than the domains of functioning approach undertaken by the two studies outlined above. Steinhauser, Clipp, et al. (2000) carried out focus group and individual interviews with 75 participants including hospice nurses, social workers, chaplains, hospice volunteers, physicians, patients, and recently bereaved family members. Focus groups were organised by role, and participants asked to reflect upon their experiences of good and bad deaths encountered within their role. Their research identified six categories of a good death; pain and symptom management, clear decision-making, preparation for death, completion, contribution to others, and affirmation of the whole person.

Pain and symptom management was the first category. They noted the importance to the patient of considering both current and future pain. This suggests that the patients are not simply concerned with the here and now but have concerns about what future pain or symptoms may arise, giving this component a more process oriented impression.

The second category, clear decision-making, reflected a desire for clear communication with physicians. In addition, by being involved in the decision-making process, patients felt empowered. However, what was of particular interest in this section was the differing emotions experienced by different parties when there was no clear treatment preference. Steinhauser, Clipp, et al. (2000) stated that "patients felt disregarded, family members felt perplexed and concerned about suffering, and providers felt out of control" (Clear Decision

Making, para 3). Although these feelings were indicative of a bad death, the fact that the parties were experiencing things differently seems equally likely to be apparent in a good death as well.

Preparation for death, the third category, also had different perceptions for the patient, family and non-physicians. Both patients and family sought information about what changes to expect over the course of the illness. However, for patients this seeking of information carried additional meaning - decisions concerning after death events, such as funerals were necessary . By contrast, the non-physicians highlighted their own need to reflect upon their own death and to realise how this might influence their future work practices.

Achieving meaningfulness at the end of life, and having spiritual beliefs, were the core characteristics of completion, the fourth category of a good death. This included "life review, resolving conflicts, spending time with family and friends, and saying goodbye" (Steinhauser, Clipp, et al., 2000, Completion, para. 1). For some participants, these were individually oriented pursuits, whilst for others there was more integrated involvement of the family. This again suggests that the various parties differ in what they see as important during the dying process.

The above four categories reflect to a large extent, findings already present in the literature. The remaining two categories however, Steinhauser, Clipp, et al. (2000) suggest, are new developments in our understanding of a good death. The first of these is contribution to others, whereby the patient is making some active attempts to influence the lives of others. This can include helping others, giving gifts, or just the sharing of knowledge.

Affirmation of the whole person is the final category of a good death. Patients are understood in terms of "the context of their lives, values, and preferences" (Steinhauser, Clipp, et al., 2000, Affirmation of the Whole Person, para. 1). This understanding is said to affirm the individual, and this notion is highly regarded by the family. From the caregiver's perspective, the need was seen to develop personal relationships with the patient as part of affirming the individual.

In summary, research has addressed the notion of categorising components of a good death and has produced varying results. Low and Payne (1993) established three categories, lack of patient distress, patient control, and role of staff that seemed to relatively narrowly define the construct. Leichtentritt & Rettig (2000) and Kristjanson et al. (2001) drew upon domains of functioning to label their categories, whilst Steinhauser, Clipp, et al. (2000) chose rather more pragmatic labels. One of the possible benefits of constructing a good death in terms of domains of functioning, is in clinical practice. An organisational structure as to what is important in achieving a good death may prove beneficial in developing policy and practice and facilitating the implementation of palliative care strategy.

Qualitative Accounts of a Good Death

Some researchers have drawn upon qualitative methods to better describe and understand the phenomenon of a good death. Predominantly, rather than asking what constitutes a good death, these researchers ask about *perceptions* and *meanings* of a good death.

Young and Cullen (1996), who interviewed 14 terminally ill patients, appeared to aim to create qualitative accounts rather than to construct categories of a good death. However, the overall structure of their book, seemed to provide similar categories to Kristjanson et al. (2001). Young and Cullen focussed on the patient (physical and psychological features), the family or carer, the medical staff, and on religion and afterlife. They did not attempt to construct these categories on the basis of the conversations of the patients, it seemed more of an organisational structure. In fact, they appeared to aim to maintain the individuality of the patients throughout and made few inferences about shared themes. This approach, whilst important for its in depth focus on the patient, seems to become lost within individual variation.

Leichtentritt & Rettig (2001) used dramaturgy analysis of interviews with 26 elderly Israelis "to recognize the meaning-making strategies individuals use while constructing the good death experience" (p. 86). They used this approach to develop an understanding of a good death by creating a drama or play with scenes, directors, players, and a script, on the basis of interviews with frail elderly Israelis. Despite this alternative approach, this research revealed similar characteristics to those already conveyed in the literature. But in addition, they did find a framework within which good death could be understood, albeit the same chronological framework previously identified in their research.

Leichtentritt & Rettig (2001) found that the first dramatic episode included two scenes, the first of which saw the participants engaged in preparations for dying within the timeframe of the last few months and weeks of dying. The main performers in this scene were the participants and their families, with the participants taking "active" roles (i.e. parent, spouse, provider) while family members took "passive" roles (i.e. helper, companion). In scene two the participants had moved the drama forward, and described the preparations required in the last few days of dying. Here there were "intense mental, emotional, and financial preparations for death" (p. 95). The "action area" or scene for the good death was either home, hospital or hospice. Furthermore, some participants specified their desire for the death to occur in bed or in a private single room. Participants were again the main performers, with the "backstage staff" including medical professionals, lawyers, family, etc, forever present.

The second dramatic episode referred directly to the last few moments of life, and to the physical death and deathbed scene. Whilst the purpose of the previous episode had been to establish the quality of life, this episode focussed on the quality of death. Some participants took the "playwright's" approach, the remainder were "directors" whereby they directed the scene following medical or biblical practices. The death predominantly took place at home or in a hospice, although some participants desired to be alone. For those who did not wish to be alone, roles were allocated to various others present, including elevating significant others to the main role, and the self to a supporting role.

Constructing the funeral was the theme for the third episode, with the purpose being "to establish a ceremony that is consistent with one's identity and roles in life" (Leichtentritt & Rettig, 2001, p. 97). Again, the main role was fulfilled by the family, who were mourning, and the participant took a secondary role.

The final phase, the "epilogue", more than an episode, was a descriptive account of how things should be after the funeral. Wanting to be remembered was the core focus, with emphasis also placed upon establishing continuity, "honoring one's unique identity and heritage, and establishing a beginning, or allowing for the continuation, of various kinds of legacies" (Leichtentritt & Rettig, 2001, p. 99).

One of the advantages of using an approach such as this is that it is able to provide a sequential account that allows not just for the time *of* death, but also the time *up to* death. This is one way in which the various aspects of a good death can be meaningfully related to each other - using a chronological framework.

Keeping in mind that the research was conducted on elderly and not terminally ill patients, their account provided interesting descriptions of the relationships between people at the different stages in the 'dying' process, which was an advance on previous research. What may be of further interest, although perhaps outside the scope of this approach, would be to establish what function is served (if any) by patients taking on and assigning others to the various roles (actor, director, playwright) in this drama. For example, by taking on the role of a director, does the patient feel empowered, in control, but not the focus of attention? So what does it mean to the patient to direct others? How might it help them understand or construct their own dying experience? Understanding why patients make certain choices to improve the "goodness" of their death, would aid our understanding of the dying experience.

Whilst it is possible to see the steps involved in the unfolding drama, it is less certain how this drama might differ across individuals. The authors clearly outline examples of the existence of multiple scenarios of a good death, however, they seemed to make little of it, and ultimately produce a universal account of a good death. Despite minimising these differences, there was evidence of considerable individual variation within the work - this warrants further investigation, and is addressed, in part, by the present research.

Other attempts to create rich understandings of a good death have used narrative analysis (Gelo, et al., 1997; Taylor, 1995) and "scripts" of a good death (Hunt, 1992). Taylor (1995) asked 10 hospice nurses "to tell a story about someone in their care, who they perceived had experienced a good death" (p. 210). Three overriding perceptions and 10 ideas for promoting a good death were identified.

The three perceptions of a good death were: death as a continuous social event, death perceived as good from various perspectives, and death is good if it goes well overall. The first perception, death as a continuous social event, was distinguished from death as an "absolute physiological moment" (p. 211). Death, for the nurses, extended from "time of initial contact to the last memory" (p. 211), and included the funeral. Here, death is considered an ongoing process rather than a discrete physiological event. This process focus also allows for the inclusion of the funeral and bereavement phase, which is an extension beyond which good death is normally considered.

The second perception of a good death suggests that the death is perceived as good if, overall, all parties involved perceive it as good. In developing this account Taylor (1995) notes that the nurses draw upon a number of different viewpoints. These include their own views, the feedback given by friends and family of the dying person, and the "assumed or verified perspectives of the person dying" (p. 211). By considering many different views, this perception aims to be encompassing although, having "assumed" perspectives of the dying person may lead to an evaluation of a good death that is not actually in line with the patient's view. This perception also seems to imply an uneven weighting of the views of participants in the dying process, whereby the patients' view need only be assumed or verified, never elicited. In this way the nurses' and families' views are, in fact, more important than the patients' views. This perception of a good death may be better phrased in terms of the family, friends and health professionals perceiving that the patient's death was good.

The third perception, death is good if it goes well overall, allows for some negative occurrences, but focuses mostly on the positive. This perception is potentially useful for the nurses psychologically, as good death becomes more achievable, and allows for some flexibility. However, it is unclear who is making the evaluation of whether the things that occur are good or bad. Implicitly, it would seem to be the nurses, and practically the judgement of 'overall' would have to be made after the patient's death, and consequently can not include their perspective.

This research offers a quite different way of looking at the good death experience, and offers interesting descriptions of the perceptions. However, like the categorising of the components outlined above, no attempt was made to investigate the relationship, if any, between the three perceptions. It is difficult to envisage them being mutually exclusive, although combining all three may be problematic. Death as a continuous social event may be seen as the context for the remaining two. It provides the foundation upon which the various perspectives and overall goodness are laid. The relationship between these last two seems somewhat awkward. One aspect deals with perceptions of the various parties (all parties agree it was good), the other with the practicality of it being mainly good overall. The timing of the goodness evaluation is clearly crucial. It appears to be a retrospective evaluation, which suggests that the patient's voice may be completely lost.

Taylor (1995) identified 10 components of a good death, and these have already been included within the earlier components section of this chapter. However, in reflecting on her study, she highlights two important observations on these components that warrant mentioning. Firstly, she acknowledges that the 10 components are not prescriptive, but that they are in fact *possibilities* of the types of things that are important in conceptualising a good death. Secondly, she suggests that good death manifests differently in different circumstances and in different familial contexts. These two reflections begin to suggest that for each individual their situation and life experiences may well encourage different interpretations of what it means to die well, a point addressed by the present research.

Hunt (1992) follows a similar style to Taylor (1995) in that she investigated "scripts" for dying, and ended up with themes of a good death. She recorded conversations between "symptom control team nurses" (p. 1297), patients and relatives, and analysed the scripts for "elements". Six elements identified included controlling physical symptoms, open acceptance of the cancer diagnosis by both family and patient, "preservation of hope and desire to live" (p. 1298), enjoying life, and having a peaceful death at home. Interestingly, despite using 'scripts' that included the voices of patients and relatives, the understanding of a good death identified draws almost exclusively on the nurse's position. The "elements" uncovered are similar to those already identified, however, Hunt offers some interesting observations on these themes.

With regard to controlling physical symptoms, she notes that the ways in which nurses imparted this knowledge was by assuring the patient that their pain would be managed. However, this was tempered by the reminder that they could not cure the cancer. Similarly, in terms of maintaining hope and the desire to live, Hunt noted that the "nurses endeavoured to balance the realistic acceptance of the terminal stage of illness and yet to give patients hope" (p. 1299). Nurses also wanted the patients to keep mobile, although within their own limitations, and to fight back, until it was "appropriate to allow them to 'give up'" (p. 1300). There is a seemingly untapped overriding theme of balance that is exemplified in this research. The nurses seem to be continually attempting to maintain a balance, in these instances, between assurance and false expectations, acceptance and hope, and fighting and giving up. This idea of balance may be a fruitful avenue for future research on nurses.

Hunt (1992) notes in her conclusion that

> *[o]ther than carrying on their lives as 'normal', none of the patients presented 'scripts' for dying which were 'individualistic' or at variance with those presented by the nurses. On the contrary, patients and relatives sought guidance from the nurses and seemed to strive to live up to what was expected of them while showing little inclination to express anger or fears of dying (p. 1302).*

This seems problematic. Firstly, if patients are striving to live up to nurses' expectations, which all nurses seem consonant with, then patients are unlikely to produce variant scripts. Secondly, and more importantly, does striving to live up to the nurses' expectations suggest that patients are achieving a good death because they were doing it "right"? Hunt seems to be suggesting that a good death is equivalent to doing things "right", and, by implication, a bad death is where the patient does it wrong by not following the nurses' approach. Naturally, these assumptions have implications for the type of care provided to patients that seems to have little focus on the patients themselves.

Whilst Leichtentritt & Rettig (2001), Taylor (1995), and Hunt (1992), all attempted to create a global understanding of the good death construct, a final narrative analysis took a more specific approach and investigated the role of Christian religious beliefs in understanding a good death (Gelo et al., 1997). Narrative analysis techniques were used with 15 frail elderly residents in a nursing home, most of whom were Roman Catholic or Protestant.

The participants identified the importance of having a priest present at the time of death, for the death to occur at a time of God's will, and with God offering comfort and strength, and answering prayers. God assumed many roles including that of father figure, absolute controller, judge, forgiver, initiator of death, provider of strength, banisher of fear, and one that offers reassurance. Participants in this research did acknowledge the idea that they would ultimately have "to face God's judgement and potential punishment" (p. 24), which provided some anxiety, however, faith in God appeared to overcome this anxiety.

This research provides an interesting investigation into the role of one particular aspect of a good death – religion – specifically Christian religious beliefs, in the dying process. This adds a specific focus to the qualitative accounts identified by other research in this area.

Qualitative accounts including dramaturgy and narrative analysis have been used to better describe and understand the phenomenon of a good death. This research has tended to approach this task by asking about *perceptions* and *meanings* of a good death, rather than what constitutes a good death. Using these approaches, components were sometimes identified as a consequence, as was a chronological structure for understanding the experience of dying well. There are social factors, however, that can provide a structure for understanding a good death, and these are discussed below.

Social Issues in a Good Death

Whilst the previous research has attempted to answer the questions of what is a good death, and how do people perceive a good death; the next body of research to be discussed has a different focus. Researchers, predominantly from outside of psychology, have made attempts to understand a good death within various social contexts. Sociologists have provided a foundation for understanding a good death. In addition, other disciplines have attempted to understand the social rules of a good death and how the practices of a good death have become institutionalised. Despite appearing rather disparate approaches to a good death, they all offer different and interesting ways of considering the construct.

Sociological approach to a good death

Kellehear (1990) carried out often-cited research investigating the sociology of a good death from the perspective of 100 terminally ill Australian cancer patients. He used a theoretical model, based on his review of the literature, including five features of dying with five underlying principles. The five features he identified included: awareness of dying, social adjustment and personal preparations, public preparations (including legal, financial, religious, funeral, and medical), work, and farewells. He further identified five principles:

preparing to die, preparing to live with dying, relinquishing some social roles, readjusting other social roles, and reaffirmation of social order.

As this research was conducted from a sociological perspective, its core focus was the social life and social experience of the dying, rather than any psychological foci. Despite this, the features and principles are all in line with research from other disciplines, as outlined in the components section.

One key feature that does not appear to have been addressed by other research is that of work. Kellehear (1990) states that perhaps the reticence in addressing work as an important aspect of the dying process has come from the fact that the majority of people who die in industrialised countries, by virtue of being over 65, are retired. With increasingly lengthy dying processes from diagnosis to death, and continually improving medical technology, the need to address work issues may however, become more pertinent. Kellehear identified four aspects of the work experience that related to a good death: worker disengagement, work social relations, work preparations for death, and women and housework. The decision to remain at work was not simply financial, but also for morale, and the process of disengagement was perceived as better if it occurred gradually. Work social relations referred to the workplace making appropriate adjustments to accommodate the dying person. Work preparations reflected practical issues of setting up a "work funeral fund" and other financial arrangements. Finally, women and housework, reflected similar disengagement practices as those in paid employment. Aside from a reference to work affecting morale, it is unclear what these work-related practices *mean* to the individual, and how might they facilitate a good death. This may be an appropriate topic for investigation in future research.

Institutionalising a good death

McNamara and colleagues (1994) have introduced the idea that a good death has become both idealised and institutionalised. The hospice movement has been the originator and purveyor of the idea of a good death, and has been instrumental in the maintenance of the concept. However, hospice itself is continually developing and as Siebold (1992) points out, hospice is, paradoxically, trying "to humanize the care for the dying and their families and introduce new forms of medical technology to ease the pain of death" (p. 82). Increased technological developments, coupled with increased bureaucratisation and professionalism within hospice, are providing a challenge to those charged with the responsibility for providing a good death (McNamara et al., 1994).

McNamara et al. (1994) interviewed 22 hospice nurses about their perceptions of a good death. Although many of the themes established are similar to those already mentioned in the taxonomic approach, the authors attempted, on the basis of what the nurses said, to understand the ideology of a good death. Good death performs two ideological functions:

> *Firstly, the occurrence [of a good death] affirms the socially responsible individual who quietly slips away once all that could be done is seen to have been done. Secondly, it benefits hospice in-patient and community administrative structures by supporting their philosophies and goals and by facilitating the smooth running of the organizations (McNamara et al., 1994, p. 1504).*

The good death ideal seems to establish uniformity and stability within the hospice context by delineating what is appropriate behaviour. But this also provides a largely inflexible structure in which individual variation has no place (McNamara et al., 1994). Hospice itself has served to institutionalise the good death ideal such that it has become routinised and expected. Despite this, nurses acknowledge that a good death is not easily achieved. Attaining the idealised goal of a good death has implications for both the nurses and the patients. For the nurses, they appeared to shoulder a great deal of the responsibility for ensuring a good death. As might be expected, a good death has positive psychological consequences for them, and a bad death, presumably negative. For the patients, there is a desire and an expectation that they achieve this idealised death, which may not be realistic given the course of their particular illness. In addition, they may wish to appear a "good" patient and thus subvert their own desires and wishes to meet the recommended ideal.

Idealising a good death, McNamara et al. (1994) argue, maintains the organisational structure as well. "Bad death drains resources" (p. 1506), compared with the good death that benefits many. Hospice has been responsible for the institutionalising of a good death and is now experiencing difficulties maintaining this ideal in the context of increasing medical technology, which often runs contrary to its palliative philosophy.

Social rules of a good death

One of the difficulties inherent in having a routinised and idealised good death is that the nurses apparently prefer not to impose a good death understanding on the patients, but rather to identify what the patient wants (McNamara et al., 1994). Despite this, McNamara et al (1994) states that: "while nurses respect the right of individuals to pursue their own path, they hold firm in the belief that death is made 'good' by peaceful acceptance on the part of the patient" (p. 1506). The patient is allowed to have a variety of beliefs but ostensibly only those that fit in with the ideology of a good death. There are some underlying social rules that appear to be influencing this argument. McNamara et al (1994) state, as above (p. 50) that the good death "affirms the socially responsible individual" (p. 1504). Responsibility is placed upon the individual to behave well and subvert their own desires should they not fit the ideology. These 'good' individuals are often easier to manage. They, at least on appearances, have endorsed the hospice philosophy, and are 'good' patients, making them easier to care for. This serves to re-affirm the philosophy, and encourages its perpetuation.

There are also elements of social control that become apparent in this argument. Hart, Sainsbury, and Short (1998) rather strongly suggest that:

> *the ideology of the good death legitimates a new form of social control within which socially approved dying and death are characterized by proscribed and normalized behaviours and choices. This ideology dominates the social management of dying and death within the hospice movement and increasingly within the broader community, and powerfully constrains the choices of dying people (p. 65).*

So, whilst there may be different ways in which individuals want to approach their dying experience, there are greater forces which will constrain their options should these fall outside of those endorsed by the hospice and community.

In Ariès' (1974) work discussed earlier, it was noted that a good death in the Middle Ages seemed to perform a social role. He suggests that the notion of a good death was used by the ruling class as a means of fighting against the growing religious doubt in the under-classes. In fact, pre-modern hospices sometimes acted on a similar level whereby social control was facilitated by the imposition of middle class values and behaviours on the poor (Clark & Seymour, 1999). The power of the ideology of a good death appears to have great potential to limit the choices of the individual.

Acceptance is one notion that appears to be widely endorsed by both hospice and the broader community. When considering notions such as acceptance, the idea that this is an appropriate characteristic for a good death depends somewhat on who the good death is for. Katz and Sidell (1994) state the following:

> *Accepting that death is inevitable gives dying people the opportunity to say and do all the things that they have left undone, to make preparations for their funeral,* ***if that is what they would like to do****, and to make arrangements for those they leave behind. It allows for the saying of goodbyes and the affirming of affections . . .* ***But does acceptance make the death 'good' for the dying, or is it just more comforting for those left behind?*** *(p. 19, emphasis added).*

The phrase "if that is what they would like to do" is particularly important here and it is unfortunate that it seems only associated with arranging the funeral and not all other aspects of a good death. Whose needs are being met when preparations are made and goodbyes are said? How much of the account of a good death is merely a reflection of rules for socially appropriate behaviour applied to the good death setting? It is good to be organised, bad not to be organised, good to be accepting, bad to be in denial, and so on. How much of our understanding of a good death is being influenced by the hospice as a means of social control?

There may be an apparent benefit in the notion of having, for example, a peaceful death, rather than a battling one. However, if we believe in the maxim that the manner in which we live reflects the manner of our death, then it is reasonable to consider that 'raging against the dying of the light' as Dylan Thomas would have it, is just as appropriate a dying experience as dying in one's sleep (Home, 1995).

Understanding the sociology of a good death, how the concept has become institutionalised, and some of the social rules involved in dying well, has advanced our knowledge beyond components and taxonomies towards some much wider issues. Notwithstanding this advancement, some important issues appear to have been overlooked in developing understandings of a good death.

Summary

Although not a great deal of research has addressed the notion of a good death, that which has, has approached the task from a number of different perspectives. Much research has established a number of components that constitute a good death, and others have advanced this research by categorising the components in a variety of ways. Yet other research has identified qualitative accounts of dying well, however, the accounts established create a view of a uniform good death that is representative of all, rather than allowing for individual differences. The final research focus attended to social issues inherent in the concept of a good death. This research widened the general reach of the good death notion, and situated it within a social context further developing our understanding. Whilst these perspectives have been useful to advance and develop current knowledge of a good death, they are not without their methodological problems.

It’s a strange thing dying.

M.A.

Chapter 4:

Problems with Good Death Research

Following the review of research that has investigated a good death in the previous chapter, this chapter addresses some of the methodological concerns that are raised. Methodological problems are discussed with specific reference to the divisions from the previous chapter, including components, categories of components, qualitative accounts, and social issues. This is followed by a discussion of who is an appropriate source of information about a good death for the patient. Finally, elements that are missing from the current research are briefly discussed.

Methodological Problems in Good Death Research

Specific conceptual and methodological concerns arose from each of the components approach, the categories of components approach and the qualitative research, and these are discussed in the following section. Furthermore, the question of who should be researched with regard to understanding dying well is considered in some depth. Problems associated with drawing upon the views of health professionals, family members, and non-terminally ill patients are discussed, and potential reasons why patients are not commonly researched are considered. Finally, this chapter addresses what matters appear to be missing from current research on dying well.

Problems with the components approach

Rather than explore in-depth notions of a good death, there is a tendency in the literature to summarise a good death as a list of characteristics. This is in large part due to the types of research questions asked, i.e. what the characteristics of a good death are. Within the quantitative paradigm, this approach has led to a focus on frequencies of the occurrence of certain characteristics (Taylor, 1995), and a listing and re-listing of the same or similar characteristics. This has added little to our current understanding of a good death.

The listing of characteristics gives the health professionals' perception of a good death a medicalised, syndrome-like quality. For a diagnosis of a disease a certain number and combination of symptoms must be apparent. This diagnostic approach seems to have been incorporated by hospice in relation to a good death, such that certain characteristics must be apparent before a death is deemed good. It is therefore tempting to suggest that a 'perfect good death' would contain all of the characteristics outlined earlier in Chapter Three. However, not only are some of the characteristics incongruous, very few of these characteristics have been established from the viewpoint of the person who is dying.

This taxonomic approach is also problematic in that it raises several questions: how many characteristics must be apparent before a good death is achieved?; are a certain combination of characteristics necessary?; and, if a patient gets four out of 10 essential characteristics instead of the 'necessary' five - does this mean they had a bad death, a below average death, or a poor death, and who is deciding? There is an inflexibility and arbitrariness in this very quantitative approach, which seems to leave very little room for the patient's opinion of what is important to them at the end of their life.

Problems with combining components

Several problems are apparent in these attempts to combine various components of a good death. Firstly, components appear to have been re-categorised rather than connected in a meaningful way. Also, different individuals seem to construct the various categories in different ways, and this idea needs exploring further. Finally, given the vast number of characteristics identified in the first section of the present research, there were notable absences in the combining components research.

The outlined research has been able to identify ways in which the characteristics of a good death might be meaningfully grouped together. Some researchers observed that different participants within the dying process were more likely to endorse some categories of components over others. For example, Steinhauser, Clipp, et al. (2000) found that their physician participants did not mention the category that referred to *contribution to others*, whereas this was important to other people involved in the dying process. Unfortunately, they did not elaborate on why this might be. This finding, however, suggests that patient, families, physicians and non-physicians see a good death from unique perspectives. Therefore, they may create different understandings of dying well when they are considering their own perspective. This may appear obvious, but given the scarcity of research on patient understandings, for example, it seems to need reiterating.

An additional problem with the combining of components is the initial comprehensiveness of the components. That is, if the entire domain of components is not covered, it is impossible to identify comprehensive categories. For example, none of the combined components research mentioned dying at home as a component of any category. Dying at home is a characteristic that occurred frequently in the research on components of a good death (Bolton, 1981; Hunt, 1992; Porta, et al., 1997). In order to be considered as a comprehensive account of the categories of a good death, it would seem appropriate to have a large number of the characteristics present. Or, perhaps some consideration of why particular elements did not appear would be of interest.

One advantage in investigating the combining of categories using a factor analytic strategy is that the variables, or items, are grouped together on the basis of correlations among items, rather than on a purely conceptual basis. However, factor analysis does have certain important considerations to be addressed. Firstly, achieving simple structure is an important process in producing an interpretable structure. Items that load on more than one factor can be problematic for the factor structure and attempts are normally made to minimise them. This was problematic for Low and Payne's (1993) study, as four of their 12 questionnaire items loaded moderately highly (> .46) on more than one factor. Other important considerations include obtaining an adequate sample size, specifically, at least five participants for each variable or item. Again in Low and Payne's study (1993), using a 12-item questionnaire, 60 participants would have been required, 10 more than were used.

Overall, however, ascertaining how the components of a good death might be categorised has facilitated consideration for how the construct might be organised. An advantage of constructing a good death in this way is that it provides potential targets for clinical interventions.

Problems with the qualitative accounts

Because the studies outlined above produced quite different results, many concerns about these approaches have already been introduced. However, one overriding criticism seems apparent with the qualitative accounts - this has already been alluded to but deserves reiterating. Despite most of these studies in some way observing that participants in their research had different views, each identified a structure that encompassed *all* participants' experiences. Understanding a good death in terms of a structure has a great deal of utility. It is particularly useful in a practical sense, such as providing guidance to health professionals on what aspects of care they should best attend to. However, this seems to leave little room for individual differences in understandings of dying well.

One potential problem for the narrative accounts of a good death (Gelo et al., 1997; Taylor, 1995) is the apparent lack of narrative focus. Punch (1998) suggests that there are at least four different styles of narrative analysis including "identifying the structural features of narratives" (p. 223), understanding the function of the narrative, considering the narrative within the context of "power structures and social milieux" (p. 223), and "how informants use language to convey particular meanings and experiences" (p. 223). Understanding dying well in terms of the narrative analyses styles would certainly add to current understandings of a good death. However, some of the studies do not appear to have employed these styles of analysis.

A good death has been researched using a variety of techniques, including searching for components, combining components, and describing qualitative accounts, however, these are not without their problems. Perhaps an even greater problem for current good death literature is the apparent lack of focus on the patient's perspective.

Who Should Be Researched?

Much of the dying well research has been carried out on significant others involved in the dying process. These have included nurses (Kristjanson et al., 2001; Low & Payne, 1996; McNamara et al., 1994; Taylor, 1995; Wilkes, 1993), physicians (Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000), non-physician health professionals (Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000), as well as family members (Hunt, 1992; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000). Although these people are clearly important in the process, they themselves are not dying. The following sections outline why these groups are not necessarily always the most appropriate source of information on what the patient wants at the end of life. Beginning with health professionals, two possible reasons to reconsider the nurses' views are identified: the fact that nurses are not patients and the influence of the nursing role and hospice philosophy on the nurses' practices. Family members are similarly highlighted in terms of not themselves being the patient, and the family's needs being addressed over and above the patient's needs. Concerns about investigating a good death from the perspective of the non-terminally ill patients are also discussed. One overriding feature that is problematic with research on individuals other than terminally ill patients, is that inferences are made about the patients needs without them being consulted. This section concludes by considering why patients may not be participating in good death research, and possible gaps that exist in the current notions of dying well.

Health professionals

Addressing how health professionals, and nurses in particular, perceive a good death has been the focus of much of the core good death literature. This is problematic because nurses[1] are not dying patients. Given the different situations of the dying and the carer for the dying, they are unlikely to have the same perspective. Nurses are medicallytrained professionals whose role is to care for sick people. Hospice nurses have a wealth of experience dealing with, and witnessing, both good and bad deaths. This means however, that although they have a wealth of information, their views will not necessarily reflect patients' views. Given nurses' training, their experience, and the medical model under which they operate, it is perhaps unsurprising that they commonly endorse the physical

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[1] As nurses are the population most frequently studied, I will use the term 'nurses' rather than 'health professionals' to avoid confusion. If any other professional is implied, this will be explicitly stated. I will also use the pronoun her where necessary, as the majority of nurses are female.

characteristics as being of primary importance. For example, managing pain and controlling other physical symptoms are common characteristics of a good death identified by nurses (Payne et al., 1996; Steinhauser, Christakis, et al., 2000). Patients, on the other hand, may not be operating under a medical model, they have different life and death experiences, and this is their own death. Whether these physical characteristics are as important to patients, or are indeed, at all important, cannot and should not be inferred from nurses' accounts. It seems reasonable to suggest that there may be a disparity between what health professionals and patients consider constitutes a good death.

There is little consideration in the literature of how the nurse's role as caregiver might influence her perceptions. The nurses' role may also influence the importance placed on other non-physical characteristics of a good death, such as being at peace or having a peaceful death. A patient who is peaceful demands few nursing interventions and is easy to manage. Thus nursing staff may perceive a good death as including being at peace, as there are advantages in terms of the nursing care necessary (Payne et al., 1996). However, this may not reflect the perceptions of the patient.

Acceptance and surrendering to death were also identified as important by nurses, with both supported by the literature (Hunt, 1992; Taylor, 1995; Wilkes, 1993). To a nurse, there are many benefits of an accepting patient, particularly in the dying individual being considerably easier to deal with and manage. According to Taylor (1995), neither acceptance nor surrender are imposed upon individuals, these ideas are simply acknowledged. However, it is not difficult to envisage that subtle encouragement towards acceptance and surrender occurs, particularly since these ideas, especially acceptance, are so pervasive in our broader understandings of death.

Furthermore, nurses commonly identify pain and symptom management as key features of a good death. This also has the ability to affect caring practices - being able to effectively manage symptoms means the nurse can feel as if she is doing her job properly. Taylor (1995) suggests that the nurses are "central to the facilitation of those circumstances in which a death might be judged as good" (p. 215). However, without understanding the patients' desires the nurses' practices may in fact contravene patients' wishes.

Dying at home is another characteristic of a good death identified by nurses that may be influenced by both their professional role and by the philosophy of hospice care. Although some researchers have used the term 'dying in the chosen environment' (Katz & Sidell, 1994; Payne et al., 1996; Wilkes, 1993), many seem to suggest dying at home is the desired outcome (Bolton, 1981; Hunt, 1992; Porta, et al., 1997). There are obvious benefits to inpatient hospice nurses who would therefore not be required to nurse the patients, but there are also greater economic and philosophical forces at play. Economic pressures are apparent throughout the health care system, including hospices. Having a patient die in the hospice has the potential to be more expensive than having them die at home, thus there may be an economic preference for patients to die at home. Furthermore, the modem hospice philosophy, particularly since Cicely Saunders' involvement in the late 1960s, endorses dying at home as a desired altemative over dying in a hospital or hospice setting, on the basis that the environment is familiar and presumably loving (du Boulay, 1984). While the health professionals may see dying at home as appropriate in terms of care provision, economics, and philosophy, patients may well have equally valid economic, philosophical or care-related reasons for preferring to die in the hospice, or elsewhere. The point is that the patient must be provided viable options for the place of death.

Family members

In arguing for an appropriate death, Weisman (1972) states:

> *Obviously, appropriate death for one person might be unsuitable for another. . . . What might seem appropriate from the outside might be utterly meaningless to the dying person himself [sic]. Conversely, death that seems unacceptable to an outsider might be desirable from the inner viewpoint of the patient* (p. 37)

This quote is pertinent to family members, health professionals, and others involved in a patient's care. What might be appropriate for one may not be appropriate for another. Although family usually has intimate knowledge of the patient, because of the difficulty often experienced in talking about death, it is possible that some particular issues have not yet been discussed. Thus, family members, who are likely to be in a state of heightened emotionality, may well make decisions that can often reflect their own discomfort with a situation, rather than in any practical sense of acting in the best interests of the patient. Hinton (1971) notes that

> *the intense feelings of those facing a great loss can cause them to believe, sometimes quite erroneously, that the dying must be experiencing considerable distress either physical or mental; and if the bereaved are asked for retrospective accounts of such emotionally charged situations their current version is liable to be distorted either by the ease of partial forgetting or the exaggeration of some particular stress" (p. 38-39).*

In deferring to the family, it is also necessary to consider their role and motivations in the dying process. For example, with respect to dying at home, the family's view can often reflect their own ability or inability to provide appropriate care for their loved one in the home environment. Thus it can reflect their own needs and not necessarily the patient's wishes.

Nurses commonly identify family factors as important to a good death (Payne et al, 1996; Kristjanson, et al., 2000; Taylor, 1995). Often the family is deferred to in terms of decision-making, and in determining the wishes of the patient. For example, nurses aim to be "always respecting and adhering to the families' wishes" (Kristjanson et al., 2000, p. 136). There are several possible explanations why the nurses might feel the family involvement is important. Firstly, the patient may be in a state where they are unable to express their own needs and desires, and thus the family, who presumably know the patient best, can do their best to represent the patient's own wishes. Secondly, deferring to the family allows the family an element of control and responsibility which may make them feel productive in a situation that is predominantly out of their control. Furthermore, the burden of responsibility that nurses commonly shoulder is diffused somewhat by including the family. Thirdly, there seems to be an underlying belief that if the patient dies a good death, in that it is in accordance with the family's wishes, then the family will experience a better grieving process. This third belief requires some explanation and expansion. Whilst there is certainly some discussion on this matter (see Abramovitch, 2000), there appears to be no specific empirical evidence to suggest that a good death contributes to better family grieving. In fact, Young & Cullen (1996) suggest a patient's "good death can make for a bad bereavement" (p. 152).

This notion that a good death equates with good grieving may have its origins with religious ideas of a good death. Abramovitch (2000), in talking about Jewish and Hindu good and bad deaths, notes that when religious rituals are unmet there are implications for the soul of the dead person, and the family who are left behind. In particular, if some ritual or consequence is not performed, not only would the soul not be admitted to the kingdom of heaven, for example, it would remain in the physical realm and haunt the family for generations. The rationale behind performing the appropriate rituals seems more in terms of preventing a bad death and bad consequences, than necessarily facilitating a good death. As argued earlier, it may not be appropriate to consider a good death merely as the antithesis of a bad death. However, it is easy to see how a lack of a bad death has erroneously been perceived as having good consequences for the bereaved family.

Notwithstanding this potential explanation of the relationship between good death and better family grieving, Kristjanson, Sloan, Dudgeon, and Adaskin (1996) investigated families' perceptions of palliative care and how these influence family functioning and family health before and after death. They found that "family's care experience during the palliative care phase has a bearing on family members' health and the family's ability to function during the early bereavement period [three months]" (p. 18). It is noteworthy that this study looked at "family care experiences and perceptions" and not the nature of the patient's death as being either good or bad. However, it was noted that the quality of life of the patient was related to the family members' health status. From this they suggest that "the strong correlation [$r = -.73$, $p < .01$] between the patient's symptom distress and her/his quality of life suggests that alleviation of patient symptom distress may indirectly affect the health status of the family members who witness the patient's distress and care" (p. 18). On the basis of this finding they further suggest that "in the care of the terminally ill patient, family members should be considered as pseudo-patients in and of themselves with vital attendant needs" (p. 18). This seems to be an overvaluation of the correlational relationship that borders on causative. In addition, the greatest predictor of health status at time two was, unsurprisingly, health status at time one. No investigation was undertaken correlating patients' distress to family health at time two, nor controlling for health status at time one. Perhaps a more important finding from this study relates to the family's experiences and expectations of care. The research does not preclude the idea that if the family changes their perceptions and expectations they can have better grieving *and* patients can have a better death.

Non-terminally ill patients

Some researchers have investigated the concept of a good death from the perspective not of those who are terminally ill, but from those who are close to death: frail elderly (Gelo et al., 1997), "older adults" (aged over 60, Leichtentritt & Rettig, 2001, p. 87), and the seriously ill (Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000). Although these groups may be closer to death than other age groups, there would seem to be some core differences between them that may affect the psychology of a good death. Most terminally ill patients have been expressly told their life expectancy resulting from their illness. They 'have a date'. Despite the fact that they may outlive that date, they still have been given a date. Whilst other groups may have a sense that they will die in the near future, this differs from the knowledge that a terminally ill person holds about their future demise. In addition, terminal illness is normally managed within a hospice setting that includes a model of care, and an expectation of death. Elderly people may be living alone, or in a rest home which has a quite different philosophy, and less of a medical focus.

Perhaps most fundamentally different is that terminal illness can affect all age groups. Young and old alike may develop a terminal illness. Although young terminally ill individuals may experience many similarities with other groups, their shorter life span is likely to colour their experience in ways that differ from the elderly population.

Inferring patients' needs from others' accounts

It is important to state that there is nothing erroneous in the health professionals' or the families' perceptions of a good death per se. The difficulty arises when these perceptions of a good death are used to make inferences about the patients' perceptions, needs and desires. Given that the role of health professionals and family members is so different from the role of patient, it seems unlikely that their perceptions of a good death will be similar. Furthermore, that patients themselves have had different life experiences from each other may mean that they too, have differing understandings of a good death. For these reasons it seems essential to ask the patients what a good death means to them to establish not only what their wishes are but also whether their views do in fact differ from the health professionals' and family members.

Why are patients not considered for research?

Why is it that researchers are so reticent about asking patients for their own perspective on dying well? There is a small amount of research that has addressed patients' views, although this has tended to be in comparative terms, that is, comparing patients' and nurses' views (Payne et al., 1996). There are several potential reasons why patients may have been excluded from this type of research, with the foremost, quite probably, ethics.

Working with a dying population is ethically challenging, but not impossible. It is particularly difficult to carry out controlled trials in an ethical way with this type of population (Payne, 2001) and this may have deterred researchers. It may be seen as inappropriate to carry out lengthy interviews or administer lengthy questionnaires to individuals whose time is comparatively more precious than others'. However, as strain placed upon participants should be minimised as part of any research project design, this seems a limited argument.

Owens and Payne (1999) recommend using qualitative approaches in order to minimise “the power imbalance between researcher and researched” (p. 158). Such collaborative approaches ensure that there are benefits to both the researcher and the participants.

Concern for the truth

Perhaps there is also a concern for not getting at the ‘real’ picture when speaking with patients. Hinton (1971) notes that patients will give different accounts to the various significant others depending on what they think the person needs to know, how the person has reacted to previous discussions, wanting “to show their appreciation and not disappoint” (p. 37), and other assorted reasons. This does not seem sufficient reason, however, to exclude this important group’s point of view.

Following on from Hinton’s (1971) comments, there is a sense that patients, particularly in this time of high distress are seen to not really know what they want. Just because this is a difficult time does not mean this population should not be studied, or that they are unable to verbalise their needs or requirements. Of course perhaps much closer to the physical death, there may be times when the patient is unable to respond, and in these instances it may be useful to obtain the opinion of others, with the realisation that this may not reflect the dying individual’s view.

Given the extent of the research that has addressed health professionals’ views of a good death, it seems obvious to suggest that health professionals’ opinions are easier to obtain than patients’. Although this may be true, with health professionals’ views indeed of great value and a large source of information, this should not preclude acquiring patients’ opinions.

Who is the good death for?

Throughout the literature addressing the notion of a good death one is often left wondering who is the good death for? Research on health professionals seems to suggest it is predominantly for the surviving family rather than for the patient. Some have gone so far as to suggest that "others [i.e. family, health professionals] often experience a strain as great, if not greater, than the one who is dying" (Hinton, 1971, p. 37). Toynbee (1968, as cited in Shneidman, 1971) advocated that

> *if one truly loves a fellow human being, one ought to wish that as little as possible of the pain of his or her death shall be suffered by him or by her, and that as much as possible shall be borne by oneself (from Shneidman, 1971).*

Although these quotes clearly emphasis the depth of suffering that families might experience, it does not, by implication, mean the death should be **for** them. Contrarily, Shneidman (1971) notes that, particularly in Toynbee's view, death has become romanticised. He states:

> *In cases of absolutely sudden and precipitous death, all of the total sum of dyadic [i.e. two people] pain is borne by the survivor (inasmuch as the victim has no opportunity to experience any of it); but in protracted dying, as occurs in most cases, the present pain and anguish involved in the frightening and lugubrious anticipations of being dead may well be the sharper for the dying person than the pain suffered then and afterwards by the survivor. The algebra of death's suffering is a complicated equation* (p. 9).

However, the question of who suffers most is an interesting one that has not yet been addressed by the literature. In addition, the question of whom a good death is for, also needs addressing. The current good death literature focuses predominantly on health professionals' views, less on families' views, and very little on patients' views. Perhaps it is time that the focus of research attention shifts toward investigating the understandings of the person with the terminal illness. Until such time as the role or perspective of the dying person is understood it seems futile to be approaching the problem through peripheral parties.

What is Missing from Current Good Death Research?

In the current literature that addresses a good death there are three noticeable absences: sexuality, spirituality, and process issues. Although the role of sexuality in the cancer and illness context is receiving increasing attention (Horden, 2000), there has been little mention of sexuality within the terminal illness context, and none in respect to dying well. Several explanations are available for why sexuality may not have featured thus far. Firstly, sexuality and sex are often confused. The World Health Organisation's (WHO) defines sexual health as "the integration of the somatic, emotional, intellectual, and social aspects in ways that are positively enriching and that will enhance personality, communication, and love" (WHO, 1974, as cited in Harwood & O'Conner, 1994). Sex, however, defines the physical act of intercourse (Harwood & O'Conner, 1994). During their illness patients may well be physically weak but may still wish to express their sexuality. Cline (1996) notes that the double taboo of sex and dying may prevent any frank discussions of desire for sexual contact or other expressions of sexuality taking place.

Secondly, sexuality may not in fact be important to people at the end of their lives. Thirdly, as much research on a good death has focussed on the final hours of life, expressions of sexuality may not be considered appropriate. Both these issues are addressed by Cline

(1996) through interviews she conducted with 80 women (not all terminally ill) about the dying experience. She found that sex is considered “frivolous” when someone is terminally ill and that many people believe that individuals who are dying are past being interested in sex. The women in her study often did want sex, and also to express their sexuality but their partners were often unwilling, or the staff thought it inappropriate. This suggests a final reason for sexuality not being discussed in relation to dying well, that health professionals may be uncomfortable bringing up issues of sexuality with their patients. Whatever the reasons, it seems important to consider the role that sexuality may play within the context of terminal illness.

Similarly, spirituality appears to have been marginalised in good death research. Whilst religiosity often appears to have a part, spirituality does not feature as strongly, with one key exception, Steinhauser, Clipp, et al. (2000). Spirituality is not easily defined, but one author suggests “spirituality reflects an expended consciousness beyond a biopsychosocial awareness and gives meaning and purpose to a person’s life as they transcend their everyday experiences” (Thomas & Retsas, 1999, p. 191). Religiosity, on the other hand, is more about belonging to a particular system of faith, such as Christianity, Buddhism, and Muslim (The Concise Oxford Dictionary, 1976). This distinction is important as it has the potential to influence desires for and beliefs about a good death. The role of spirituality therefore needs to be explored in relation to a good death.

The terminology “a good death” can sometimes be viewed as if it only encapsulates the last few hours of life. However, one recent article has attempted to incorporate a longer time frame and outlined three time periods up until death (Leichtentritt & Rettig (2000). Whilst it is important to understand a good death in terms of the final few hours of life, it is equally, if not more important, to establish what is important to people during their last months.

Understanding the dying experience over this extended time period gives more of an idea of the processes involved rather than a very time limited approach.

Summary

This chapter has addressed the methodological problems that have arisen out of the current research literature on a good death. Issues concerning the various ways in which good death has been considered, as components, categories of components, and descriptive accounts were discussed. Other questions arose from the choice of non-terminally ill participants in addressing the question “what is a good death?”. Whilst it is important to understand what others’ perceptions are - for they provide a valuable perspective as well as a starting point for other research - making inferences about patients views on the basis of these findings seems inappropriate. Reasons for not addressing patients directly may include problems of ethics, a concern for reality and truth, a belief that patients do not really know what they want, and easier access to health professionals. Finally, understanding whom the good death is for, and addressing issues of sexuality and spirituality, are important considerations for future research.

Darkling I listen; and, for many a time
I have been half in love with easeful Death,
Call'd him soft names in many a mused rhyme,
To take into the air my quiet breath;
Now more than ever seems it rich to die,
To cease upon the midnight with no pain,
While thou art pouring thy soul abroad
In such an ecstasy!

John Keats
Ode to a Nightingale

Chapter 5:

Q-Methodology

Q-methodology is a little known and therefore little understood technique that developed out of the 1930s factor analytic tradition. Because this methodology is widely unknown, it is appropriate to present an introductory chapter outlining the fundamentals of Q-methodology. Following this, a more detailed description of the particular strategy used in the present study appears in Chapter 6, the method chapter.

This chapter is divided into three main sections. The first outlines the reasons for choosing Q-methodology in the present research, and is followed in section two by a condensed version of the fundamentals of carrying out a Q-method study. As with many alternative methodologies, there has been debate as to where Q-methodology can be situated epistemologically and ontologically, and this will be discussed in the final section. This chapter is intended to introduce only the basics of Q, and more comprehensive accounts of the history and development of Q-methodology can be found in alternative sources (e.g. Brown, 1980, 1993; Kitzinger, 1987; W. Stainton Rogers, 1987).

Choosing Q-Methodology

A number of research methods may be used in developing understandings of particular constructs. Traditional quantitative methods, such as those using surveys, questionnaires, or experimental designs with large samples, can be applied to investigate understandings. Qualitative methods, which focus more closely on individual cases, can also be used and tend to provide more descriptive results, uncovering different ways in which people perceive a construct. Although research has investigated what a good death is using a variety of methods, few have attempted to develop a comprehensive understanding of the construct and investigate individual differences from the perspective of patients. Q-methodology offered an alternative approach that had the potential to meet the research objective of investigating individual differences in understandings of dying well for patients receiving palliative care.

Stenner, Dancey, & Watts (2000) argue that the strength of Q-methodology lies in its exploratory potential. Given the current status of dying well as a somewhat uniform concept, an exploratory technique such as Q-methodology has the potential to challenge current knowledge and explore alternative understandings of dying well. This method is not intended to test hypotheses, however, the results of a Q-methodological study can be useful in terms of generating new theories, and investigating different viewpoints. Q-methodology enables the researcher to explore the commonalities and idiosyncrasies in perceptions of a construct, and therefore was suitable to investigate individual differences in understandings of dying well.

The choice of method in the present research was partly constrained by the relatively small number of participants available. Most quantitative methods require large participant numbers, whilst qualitative methods are more suited to smaller numbers. Fortunately, Q-methodology is flexible in the number of participants required. Brown (1980), a key proponent of Q-methodology, suggests 30 participants are sufficient to produce interpretable results. With small numbers, then, Q-methodology was appropriate.

The nature of the participants, being patients receiving palliative care, was also influential in the selection of a research method. Quantitative methods can often restrict the involvement of a researcher by detaching them somewhat from participants. Given the delicate nature of the topic of the present research, it seemed unethical, or at least inappropriate, to act in such a detached way. Notwithstanding this, carrying out lengthy in-depth interviews, as qualitative researchers often do, may have proved physically and emotionally exhausting for these participants. Thus, Q-methodology provided an opportunity to combine the practicalities of the quantitative method with the personal contact of a more qualitative approach, without being disconnected from, or overburdening, the participants (McNaught & Howard, 2000).

Finally, Q-methodology purported to offer an approach that kept the participants themselves as the core focus (Brown, 1980; Febbraro, 1995; Senn, 1996). Participants are not only able to feel heard but also to experience an outcome by seeing the visual result of their efforts in the completed task. Q-methodology had much to recommend it, but the emphasis placed on identifying individual differences was perhaps the key benefit.

Before discussing Q-methodology in more detail, it will be useful at this stage to consider what is involved in a Q-method study. Following is an introduction to the fundamentals of Q-method, and for ease of understanding, an example study is outlined. This was a study carried out by Stenner and R. Stainton-Rogers (1998) on jealousy.

Steps for Carrying out a Q-Method Study

Overview of Q-method

The aim of a Q-method study is to uncover a range of different understandings of a construct, such as jealousy. First, views on the topic are sought from a variety of people during an interview process. This process generates a number of statements about the construct (called a *concourse*), which is reduced to a manageable set of statements (called a *Q-set*). This phase is a generative stage that develops the statements for use in a later phase.

This later stage, which generates the data, involves participants individually sorting the Q-set statements onto a forced choice, quasi-normally distributed response hierarchy, a process called *Q-sorting.* The *Q-sort response hierarchy* contains a person's ranking of the statements from *most disagree* at the left end to *most agree* at the right end. Figure 1 shows Stenner and R. Stainton-Rogers' (1998) response hierarchy structure for a 55-item Q-set. The shape of the response hierarchy is quasi-normal and can be adjusted to fit the number of statements in the Q-set.

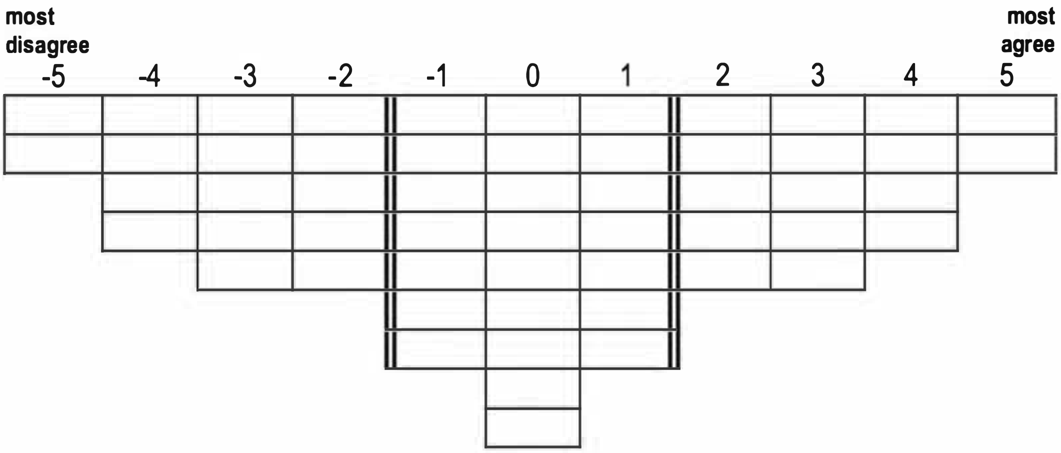

Figure 1: Q-sort Response Hierarchy for 55 item Q-set Used by Stenner and R. Stainton Rogers (1998)

The Q-sorts for each participant are then factor analysed to produce a number of factors. In Q-factor analysis, factors are groups of participants who responded similarly on the Q-sort task. This differs from R-factor analysis where factors are groups of variables. Stenner and R. Stainton Rogers' (1998) study produced 10 factors. The resulting factors are then subjected to a weighted average procedure. This procedure converts the resulting factor data into a Q-sort for each factor, called an *exemplar Q-sort*. Each exemplar Q-sort reflects the similarities in the responses of the participants who belong to that factor. These exemplar Q-sorts are then interpreted as accounts, aided by qualitative data obtained from the participants (Wamer, 1998).

It should be clear that there are a number of delineated steps in a Q-methodological study. Having now provided an overview of the process, the following three sections offer more detail on the development of the Q-set, the Q-sort task, and the statistical analysis used in Q-methodological studies. Both this outline and the method chapter, draw on the key work of Brown (1980) who has explicated the process in great detail.

Developing a Q-set

The first requirement of Q-methodology is that the area of interest is well defined. As with a great deal of research, inadequate or over-inclusive sampling of the area of interest can lead to failure in uncovering important factors or to the identification of spurious factors (Fabrigar, MacCallum, Wegener, & Strahan, 1999). For this reason, in Q-factor analysis, a great deal of attention is paid to the development and selection of statements for the Q-set.

In developing a Q-set, the intention is to establish a comprehensive set of statements that represent the various facets of a construct. Initially, relevant literature is consulted, interviews are carried out, and opinions sought from a variety of people who have knowledge of the construct of interest. For example, Stenner and R. Stainton-Rogers (1998) elicited material from interviews, a review of academic, literary, and popular literature, taped discussions, and a "videoed role play . . . [of] scenes of jealousy" (p. 74). Transcripts from these sources are then thematically analysed and the resulting themes are reduced to a manageable set, usually of up to 100 themes: the Q-set (R. Stainton-Rogers, 1995a). In the jealousy study for example, 55 were selected from several hundred. These themes, or items or statements, are reduced in such a way as to ensure the many facets of, or opinions about the construct of interest are covered without redundancy. Once the Q-set is established, the task of Q-sorting can commence.

Carrying out the Q-sort

Whilst the development of the Q-set involved seeking information from the literature and from knowledgeable others, the main Q-sort task tends to be carried out with a different group of participants. Stenner and R. Stainton-Rogers (1998) were not interested in targeting a particular population's views on jealousy and therefore used a relatively standard technique to recruit their participants: advertising in a local newspaper. Other research has purposefully sought out people who the researchers believed would have differing views on the topic of interest (e.g. Kitzinger, 1987; W. Stainton-Rogers, 1987, 1991).

Some researchers, prior to undertaking the main Q-sort phase, suggest carrying out pilot testing of the Q-set (Block, 1978; Curt, 1994). This allows the researcher to ensure the statements are widely understood, and that the number of statements is suitable for the population sampled.

The Q-sort procedure itself involves two key phases. First, the Q-set of statements is sorted by the participants into three relatively equal sized groups: one group includes the statements they consider to be those they *most agree* with, a second group are those they *neither agree nor disagree* with, and the final group are those they *most disagree* with. This procedure is undertaken to simplify the subsequent ranking task.

The second phase requires the participants to rank the statements in order of agreement, a process facilitated by placing them on the Q-sort response hierarchy. To rank the statements participants work with one of the three groups of statements at a time (e.g. those they originally grouped as *most disagree* in phase one above) and decide upon the relative importance of the statements within that group. For example, with the *most disagree* group, participants are asked to select the two statements they most disagree with, and place these in the two far left spaces in column -5 (see Figure 1). They are then asked to select the next four statements that they most disagree with and place these on the response hierarchy in column -4. This proceeds until the response hierarchy is complete. No ranking takes place within the columns, as this additional procedure has been shown to be no more discriminating than ranking by columns alone (Brown, 1980; Thomson, 1980).

An additional and crucial feature of the Q-sort procedure is the dialogue that goes on between the participant and the researcher during completion of the Q-sort. Participants are encouraged to talk about the importance of the statements to them, comment on why they placed statements in certain positions, or make any other comments about the statements that they choose. Interviews during the Q-sort are often tape-recorded for transcription. The key purpose of this interview process is to facilitate the later interpretation of the factors, using the participant's own words.

In summary, the Q-sort phase of Q-method involves each individual sorting a number of statements that reflect opinions about a topic onto a quasi-normally distributed response hierarchy, thus obtaining a representation of how the subject matter is constructed by each participant. It is this phase that generates the data for statistical analysis.

Q-method statistical analysis

The next step in carrying out a Q-method study is Q-factor analysis. McKeown and Thomas (1998) state "factor analysis is fundamental to Q-methodology since it comprises the statistical means by which subjects are grouped – or, more accurately, group themselves – through the process of Q-sorting" (p. 49). It is useful to consider where Q-factor analysis fits with other similar techniques, thus the following section outlines some differences between Q and R-factor analysis, and cluster analysis. This is followed by a discussion of Q-factor analysis procedures, and finally, the weighted average procedure that produces the exemplar Q-sort is outlined.

Q and R-factor analysis, and cluster analysis

Because factor analysis is so essential to Q-method, some time is spent below detailing the approach. This section outlines the fundamentals of Q-factor analysis, and makes some comparisons between various aspects of Q and R-factor analysis and cluster analysis, in particular drawing attention to how they differ. Steven Brown's (1980) text, *Political Subjectivity*, is the key text that Q-methodologists follow, particularly as he has honoured the original tradition of Q-method as espoused by its founder, William Stephenson. In general, the data analysis carried out in the present research follows Brown's (1980) guidelines.

Factor analysis is a technique in which the key aim is to identify the underlying structure of a construct, which is represented as a set of so-called factors (Hair, Andersen, Tatham, & Black, 1995). This technique is often used to reduce a large number of variables or items representing a construct, to a smaller set of factors, which describe the components of the construct. For example, as in Low and Payne's (1996) research, a 12-item good death questionnaire was reduced to three factors of a good death.

It is possible to conduct a factor analysis in at least six different ways (Gorsuch, 1983). The most common way is a by-variable analysis in which variables are grouped together, on the basis of their correlations, as factors. This is R-factor analysis, which textbooks on multivariate methods usually outline (e.g. Hair et al., 1995). An alternative method is a by-participant analysis where participants are grouped together as factors, on the basis of their correlations. In this way participants that have responded similarly (i.e. are correlated) 'load' onto the same factor. This is Q-factor analysis. The difference between Q-factor analysis and R-factor analysis statistically, begins at the data matrix. Whilst in R-factor analysis the columns are variables and the rows participants, in Q-factor analysis this is transposed so the columns are participants and the rows variables. However, it is not simply the transposition of the data matrix that differs, but the underlying methodology itself.

In Q-factor analysis, the aim is to create accounts or understandings of subjective positions on a topic (Brown, 1980). Thus, the focus of the interpretation is the account generated and not the participants who make up the accounts (Stenner et al., 2000; Warner, 1998). According to Brown (1980), Q-factor analysis "is a method for determining how persons have classified themselves . . . [by investigating the extent to which their Q-sorts] fall into natural groupings by virtue of being similar or dissimilar to one another" (p. 208). Thus the Q-sort is self-referential and is not validated against "real" or "true" accounts. This differs from the objective position of R-methodology, where scorable traits or attitudes exist which people hold in varying amounts (Warner, 1998). This suggests that Q and R-factor analysis can be used to address different research questions.

It is important to reiterate that although Q and R both use factor analysis, the methodologies are based on different principles. Brown (1980) states: "Q and R represent fundamental methodological distinctions that reach into the logic of inquiry and theories of human behavior, culminating in a concrete way in the differing kinds of data that are offered up for analysis" (p. 208). It *is* possible for an R-methodologist to use the Q-factor analysis technique of beginning with a rotated factor matrix (albeit with some additional restraints); however, Brown would argue, these methods ask, and answer, different questions.

There are other methods that group by participants, including cluster analysis (Hair et al., 1997). Although both Q-method and cluster analysis involve grouping individuals together, this is undertaken in different ways. In Q-factor analysis, groupings are made on the basis of maximising *similarities* between the profiles of participants' responses. With cluster analysis the researcher is maximising *distances* between participants' responses (Hair et al., 1997). This difference between the two methods can be displayed diagrammatically, as in Figure 2 below.

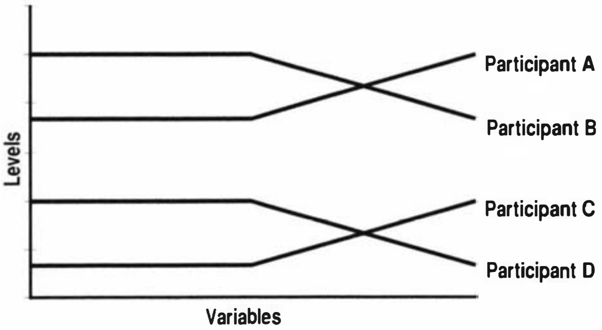

Figure 2: Comparison of Participant Responses on Q-Factor Analysis and Cluster Analysis

In Q-factor analysis, participants A and C, and participants B and D, have responded similarly in that they have a similar profile to each other. In this case each pair (A & C, and B & D) would be grouped together to make a factor. In contrast, in cluster analysis, A and B would be grouped together as a factor, as would C and D, as these participants are, respectively, close together in terms of *level* on the y-axis, and this maximises the distances between the pairs of respondents (Hair et al., 1995).

In Q-factor analysis it is, therefore, not important what the levels of responses were, but what the *relative* levels were. Contrarily, cluster analysis focuses on the levels at which the participants were placed across the variables. It is noteworthy that Canadian researchers found that "Q-factor analysis is a more useful method [than cluster analysis] for the purpose of classifying patients" (Morf, Miller & Syrotuik, 1976, p. 64). This suggests that Q-factor analysis may be more appropriate than cluster analysis in some instances.

Q-factor analysis and cluster analysis are also used for different purposes. Q-factor analysis gives the researcher an account or understanding of a particular construct from the participants' perspective, on the basis of participants performing similarly on a Q-sort. Cluster analysis is generally used to group participants "based on characteristics they possess" (Hair et al., 1995, p. 423) in order to predict group membership. Although predicting which group participants might belong to on the basis of, say, disease type, may be of interest, the present research aimed to establish the different understandings or accounts of dying well from the perspective of those who have a terminal illness. Thus Q-factor analysis was a more appropriate technique in this instance.

Q-factor analysis procedures

Several conceptual and statistical procedures are employed when considering the factor analysis technique involved in standard R-methodology. For example, a usual initial requirement is that the simple correlation matrix exhibits 'factorability', i.e. some internal structure. This can be assessed by establishing if there are a "sufficient" number of correlations above .30 (Hair et al., 1995). Other procedures include Bartlett's test for sphericity, KMO measure of sampling adequacy, and low partial correlations. Although in a practical sense these tests can be applied to Q-data, Brown (2001) argues that philosophically they are unnecessary. He claims: "all such procedural rules can be jettisoned in order to make room for a process which takes as its sole responsibility the examination and understanding of subjectivity" (Listserv, 2001).

Another issue, that of sample size, is controversial in both Q and R-factor analysis (Fabrigar et al., 1999). In R-factor analysis there are various recommendations ranging from ten participants per variable (Nunnally, 1985, as cited in Brown, listserv, 2001) and five participants per variable, with a minimum of 100 participants (Gorsuch, 1983), down to 1.3 participants per variable (Arrindell & van der Ende, 1985). In applying Nunnally's criterion to Q-factor analysis, with a sample of 40 participants, this would require 400 statements to be sorted, which is likely unmanageable, particularly for terminally ill patients.

Arrindell and van der Ende (1985), in reference to R-factor analysis, recommend that a more appropriate criterion for establishing sample size is to make the number of participants proportional to the number of factors extracted. This makes sense in Q-factor analysis also, as the greater the number of factors (i.e. understandings) the greater the number of statements needed to distinguish between the factors (Brown, 1986, listserv). Although they recommended the ratio of 20 statements per factor, this may be too rigid for Q-factor analysis as this means, for example, that a four factor solution would require 80 statements. The important thing, Brown (1986, listserv) maintains, is that the statements themselves are sufficiently diverse as to be available to represent any individual's point of view. If this is so, then no matter what the participant to statement ratio, the view can be expressed.

Factor vs. Principal Components Analysis

A fundamental decision in Q-factor analysis (or R-factor analysis) is whether to conduct a Factor Analysis (FA) or Principal Components Analysis (PCA) to decompose the correlation matrix. FA is principally used to identify latent constructs, whereas PCA primarily focuses on data reduction (Fabrigar et al., 1999). Although the analysis processes of FA and PCA are similar, FA decomposes only shared variance, whereas PCA uses total variance, which is made up of shared, unique and error variance. For this reason, for example, FA is considered an effective technique when investigating a new questionnaire with unknown error variance, because it uses only shared variance. However, it is common practice (at least in R-FA) to carry out both methods and examine the differences between the various solutions in order to find the most appropriate factor or component structure.

It is notable that the majority of Q-method studies carried out previously use the PCA method (e.g. Stenner et al., 2000; Kitzinger, 1987). One notable exception is Steven Brown (1980) who prefers the centroid FA method (with manual rotation of factors) as it allows the researcher more flexibility to find a solution that is informed by theory. There is no "statistically correct" solution with the centroid method, which Brown sees as a virtue in developing a factor solution. However, Brown often uses the centroid technique in a more theoretically driven way, when he is testing to establish if a hypothesised structure exists.

Numbers of factors

There are a number of different methods that are employed in R-factor analysis to determine the appropriate number of factors to be extracted. These include: latent root (eigenvalues), percentage of explained variance, scree test, a priori theory (Hair et al., 1995), statistical significance and interpretability (Brown, 1980; Schmolck, 2000). Brown (1980) focuses almost exclusively on the latter two criteria and predominantly on interpretation, and criticises the applicability of the remaining methods. Brown's criticisms are briefly outlined.

The latent root or eigenvalue method is the most commonly used method for extracting factors in R-factor analysis. It is based on the principle that "any individual factor should account for the variance of at least a single variable if it is to be retained for interpretation" (Hair et al., 1995, p. 377). Thus those factors with an eigenvalue over one are included. Brown (1980) argues strongly against this criterion in its application to Q-factor analysis. He suggests that since eigenvalues are a sum, they are highly susceptible to small participant numbers. This anomaly can create large numbers of "significant" factors that may encourage redundant or spurious factors. R-factor analysis is, of course, equally susceptible, but given that Q-method often uses small sample sizes, using the eigenvalue method to select the number of factors is not ideal.

The second criterion is percentage of explained variance, which consists of two parts: total explained variance and cumulative variance. Each factor has an amount of variance associated with it that is successively added to the next to create a percentage of total explained variance. The aim of this procedure is to establish the "practical significance" of the factors, and a very loose guideline is to aim for 60% explained variance (Hair et al., 1995). Another common criterion is that each factor should contribute at least 10% of total explained variance to be included in the solution. Brown (1980) again argues against these criteria being used in Q-factor analysis, using the same basis as described above, that eigenvalues are a sum influenced by the number of participants. As the percentage of total explained variance for a factor is equivalent to 100 times the eigenvalue divided by the number of participants in a Q-analysis, the small sample sizes generally used in Q-method studies affect the outcome (Brown, 1980).

Extracting factors on the basis of the scree test is the third criterion. A scree test involves plotting the eigenvalues on a graph and establishing, irrespective of the eigenvalue being greater than one, where the graph makes a transition between a steep slope and a levelling out (Hair et al., 1995). This test is based on the idea that having extracted the first factor (in PCA), the remaining factors contain more unique variance than the previous factors. Thus in trying to build an optimum model that contains predominantly shared variance, the scree test helps define the point at which the unique variance is beginning to usurp the shared variance

(Hair et al., 1995). This criterion is based upon the maximising explained variance idea that Brown (1980) criticised above.

A priori criteria are used when the researcher has a hypothesis about the number of factors that will eventuate. This method is appropriate for both Q and R-factor analysis. Brown (1980), like others (i.e. R. Stainton-Rogers, 1995a), argues that using statistical criteria for obtaining "significant" factors may result in insignificant factors being found (i.e. the over-inclusivity of eigenvalues), or theoretically important factors being excluded (i.e. the under-inclusivity of cumulative variance). He therefore promotes the use of "theory and judgment" (p. 43) in the establishment of the appropriate number of factors. He also recommends using less than seven factors, and aiming for around four. He believes that these guidelines should encourage a parsimonious, and interpretable factor solution. Brown (1980) acknowledges the arbitrary nature of these figures, but suggests that "experience has indicated that the 'magic number of 7' is generally suitable" (p. 223).

One of the most important criteria that Brown (1980) advocates is that of interpretability. No matter how many factors the solution has, each factor needs to be interpretable and make some sense within the context of which it is being investigated.

Rotating the factors

Interpretability of a factor structure can be achieved and enhanced with the use of rotation. Two types of rotation are commonly used in R-methodology: orthogonal or oblique. Orthogonal rotation forces the factors to be uncorrelated whilst oblique rotation allows the factors to be correlated (Hair et al., 1995). Most Q-methodologists have predominantly employed orthogonal rotation (usually Varimax) (e.g. Kitzinger, 1987; Stenner et al., 2000;

Warner, 1998) as it encourages simple structure, which enhances interpretability (McKeown & Thomas, 1988).

Weighted average procedure and factor interpretation

Having selected the type of factor analysis, established the appropriate number of factors, and rotated the factor matrix, the next step can be addressed. A weighted average procedure is undertaken on the basis of the factor loadings (i.e. the correlation of a Q-sort with a factor). This procedure generates an "exemplar" Q-sort for each factor. This exemplar represents an amalgamation of the shared views held by participants in each factor. It is this common understanding, as characterised by the exemplar, that is then interpreted, aided by discussions carried out with participants during the Q-sort procedure.

To exemplify this, Stenner and R. Stainton-Rogers (1998) established 10 factors, each representing a different view of jealousy. The understandings of jealousy were characterised by the following titles: anti-possessive critique of aggressive male jealousy; innocent victim jealousy; natural, helpless jealousy; female over-reaction through personal insecurity and inadequacy; guilty, confused and jealous; the powerful and consuming jealousy of unrequited love; jealousy through emotional weakness and immaturity; and young 'self'-developing and 'self'-protective jealousy. Each factor was constituted by a sub-group of participants whose views of jealousy were used to aid the description of the particular factor.

Q-Methodology and Paradigms

Q-methodology has been used in a variety of ways and in the context of different epistemological positions. Stephenson saw Q-methodology as a positivist technique that was able to objectively measure individuals' subjective understandings of themselves. Positivism and objectivity were the underlying paradigms of most psychological research from the 1930s to 1960s, and many saw Q-methodology as a technique that focussed on an individual's private world. Non-Q-methodologists, therefore, saw this method as a step backwards towards introspective research and away from discovering the favoured universal rules of behaviour (Kitzinger, 1987). Q-methodology was considered unscientific. Despite the apparent rigour of the quantitative technique used in Q-methodology, and Stephenson's belief in a positivist empiricist philosophy, Q-methodology was widely disregarded (Febbraro, 1995).

By the 1960s individualism was the predominant ideology and Q-methodology was used in a way that was consistent with this ideology, but inconsistent with Stephenson's original intentions. In light of this, the methodology began to be compartmentalised and aspects of the approach were detached from each other. Psychologists working with clinical populations drew upon the teachings of Carl Rogers and his client-centred approach, and applied the Q-sort technique in isolation from the broader Q-methodology. Clients created a Q-sort of themselves as they believed they were (in their current state of mental illness) and this was correlated with a "real" (i.e. objective) Q-sort designed by experienced clinicians to represent wellbeing in mental health (Dymond, 1954). Another variation on Q-methodology at this time was to correlate a client's Q-sort of their "actual" self with their "ideal" self, where moderately high correlations indicate sound mental health and very high correlations indicate schizophrenia (Butler & Haith, 1954). The focus on the Q-sorting procedure in these ways became less about understanding the subjective viewpoint of the individual, and more about objectively measuring their dysfunction (Kitzinger, 1987). This moved away from the philosophy Stephenson had first proposed and made use of only part of Q-methodology.

The 1980s brought about further developments in the use of Q-methodology, this time as a feminist research technique. Feminist researchers saw the Q-methodology focus on the individual rather than variables as more in line with feminist beliefs and thus began to employ this method. Febbraro (1995) suggests that at least three feminist Q-method perspectives have used Q-methodology within different paradigms: feminist empiricism, feminist standpoint, and feminist postmodernism/social constructionism. In feminist empiricism researchers "recognized the potential of Q-methodology, as a sophisticated quantitative technique, to legitimize the scientific status of feminist research" (Febbraro, 1995, p. 147). This clearly maintained Stephenson's positivist approach. Women's ways of knowing the world within the context of a patriarchal society are emphasised in the feminist standpoint position. Q-methodology was seen to access these different ways of knowing the world. Finally, feminist social constructionism, "seeks to deconstruct scientific objectivity and to legitimize multiple versions of reality" (Febbraro, 1995, p. 148). Q-methodology was used to generate alternative accounts of constructs that were not accessible using traditional methods. Warner (1998) has since used this method within a feminist/post-structuralist framework. Despite widely varied epistemologies the methodology was applied in ways that were consistent with the different positions.

Social constructionists in general, particularly those researchers based in the United Kingdom (e.g. Curt, 1994; R. Stainton-Rogers, 1995a, 1995b; W. Stainton-Rogers, 1991), have also utilised this technique to develop understandings beyond our current knowledge. This approach maintains a focus on subjectivity, particularly in its rejection of the use of external criteria to validate findings, on the basis that there are no external criteria for an individual's point of view (Febbraro, 1995). Emphasis is placed on the potential diversity of understandings of a construct and the idea of a universal truth about a construct is disputed. Still other UK researchers (Stenner et al., 2000) refer to Q-methodology as a "pattern analytic [technique] suitable for discovering account taxonomies" (p. 441), which could place it more in a critical realist domain.

To a certain extent, the use of Q-methodology has come full circle. In the UK, Q-methodology is predominantly used as a social constructionist technique. However, the American Q-methodology movement has found its impetus in Steven Brown, a political scientist and previous student of Stephenson's. Brown has re-established Stephenson's tradition of Q-methodology as a combination of the Q-sorting technique and Q-factor analysis, with the revisited aim of objectively measuring subjectivities (Kitzinger, 1987). This firmly situates Q-methodology as a positivist technique.

What this section has highlighted is the variety of ways in which Q-methodology can, and has, been used within various paradigms, including positivist, feminist, and social constructionist. Whilst the methodology has been used within various epistemological frameworks, Febbraro (1995) argues that the technique itself is not inherently positivist, feminist or social constructionist. She states:

> *Q-methodology is neither ideologically, epistemologically, nor metatheoretically 'neutral'. . . . Q-methodology does not carry within it or entail any particular or inherent political agenda, whether emancipatory or oppressive. Rather, the ideological meaning of Q-methodology – or any methodology, science, logic/mathematics or language, must be derived from the social and political contexts of its use (Febbraro, 1995, p. 149).*

Not only has Q-methodology been used within different epistemological and ideological paradigms, it is has been used to investigate a wide variety of issues. In terms of health related issues, researchers have investigated irritable bowel syndrome (Stenner et al., 2000), chronic pain (Eccleston, Williams, & W. Stainton-Rogers., 1997), health beliefs (Stainton Rogers, 1987, 1991), women's mental health and childhood sexual abuse (Warner, 1998), and abortion (Werner, 1983). Other social issues have also be explored using Q-methodology, including unmarried mothers (Endres, 1989), male identity (Horward, 2000), lesbian identities (Kitzinger, 1987; Kitzinger & R. Stainton-Rogers, 1985), self-perception (Knight, Frederickson, & Martin, 1987), privacy (Kozlowicz & Cottle, 1993), women's experiences of pornography (Senn, 1996), rebelliousness (Stenner & Marshall, 1995), and jealousy (Stenner & Stainton Rogers, 1998). The variety of issues investigated using this approach provides evidence for its versatility, and suggests its appropriateness for researching other issues, namely, dying well.

Given Q-methodology's flexibility as a technique, it can, and has, been used within a variety of paradigms. The present research has predominantly followed the work of Brown (1980) and employed Q-methodology as a variant on positivist techniques, called *operant subjectivity.* Brown (1997) clarifies this position by suggesting that:

> *Science deals with operations associated with confrontable events, and in Q methodology self and subjectivity are rendered operational through Q technique. In the process of Q sorting, the person operates with statements or other measureable stimuli by rank-ordering them under some experimental condition. The operation is subjective inasmuch as it is me rather than someone else who is providing a measure of my point of view, and the factors which emerge are therefore categories of operant subjectivity (Stephenson, 1977).*

> *The factors are also* naturalistic *in the sense that they are naturally occurring events: The statements, unlike scale items, are naturally rendered (usually in the course of interviews) and in no way implicate variables or pretend to be a test of anything, and the Q sorts are a function of the person's understanding; hence, the factors which emerge from this process must, of necessity, be a natural consequence of all that preceded, and relatively uncontaminated by the scientist's intrusions* (p. 12, emphasis in original).

Using Q-methodology in this way the individuals' subjective views are "rendered operational" such that the accounts that are uncovered represent individual's subjective understandings of dying well.

This chapter has outlined the methodological and pragmatic reasons for choosing Q-methodology for the present research, and presented an overview of the fundamentals of carrying out a Q-methodological study from developing the Q-set to interpreting the exemplar Q-sorts. The following method chapter outlines in more detail the Q-methodological process employed in the present research.

If you have seen any man die think that yourself shall go the same way. Wherefore be eveready and live so that death find you never unready.

Colin McCahon

Chapter 6:
Method

This chapter outlines the various stages involved in the present research, from developing the concourse and Q-set, through pilot testing the Q-set statements, to carrying out and analysing the Q-sorts. Initially, concourse themes were uncovered using various sources including: interviews with hospice health professionals and patients receiving palliative care, consulting relevant literature, and other media sources. A detailed refinement process was then undertaken to reduce the large number of statements to a manageable Q-set. Pilot testing involved a number of individuals involved in health care engaging in the Q-sort. The amended Q-set was then used with 40 participants who were patients receiving palliative care at Arohanui Hospice, Palmerston North. Finally, the resulting data were factor analysed, and four accounts identified and described. Each of these phases in this research will now be discussed in detail.

Development of the Concourse

The aim of this phase was primarily to gather from a variety of sources a concourse of themes on dying well, from which a manageable Q-set could be drawn. Three main sources were used: interviews with health professionals, interviews with patients receiving palliative care, and relevant literature/media. The transcripts and literature were thematically analysed to produce the concourse of statements.

Health professionals

When developing a concourse it is important to establish a full range of themes that pertain to a construct (Brown, 1980). In order to generate as many diverse themes as possible participant selection is considered "theoretical, rather than random" (Warner, 1998, p. 103). Choosing to interview health professionals may seem inappropriate given that the primary focus of the present research was patients' understandings. However, in order to establish a comprehensive concourse of the different themes of dying well, it was appropriate to draw upon the views of health professionals. They have a wealth of information on numerous deaths that they have encountered whilst working with the terminally ill making them a valuable source of information. Even though health professionals and patients may differ in their role in the dying process, the themes that they produce may be similar. Furthermore, because access to patients was relatively limited, drawing upon health professionals meant the number of patients drawn upon could be reduced. Thus health professionals played a useful role in developing the statements for the concourse.

Choosing to interview the health professionals before the patients provided an opportunity for the researcher to hear first hand accounts of dying well from those with experience in the area. Furthermore, this allowed the researcher to check the interview questions with the health professionals and ensure that these questions would be appropriate and sensitive questions that patients would feel comfortable answering.

The majority of health professionals were sought from the local hospice, Arohanui Hospice, Palmerston North. Hospice nurses were approached by the Medical Director of the Hospice, who explained the aims of the project, and invited the nurses to participate. All of the nurses approached agreed to take part. This produced nine interviews with a variety of hospice nurses including day and evening shift, part- and full-time, hospice unit and liaison nurses.

A further three hospice-related professionals known to the researcher were interviewed, and they generated four additional candidates who were also contacted and interviewed. These seven participants included: an ex-hospice nurse, now a clinical psychology graduate student; an ex-oncology community nurse (providing community based care for all cancer and palliative care patients in the MidCentral Health domain) also involved in cancer health promotion for the Cancer Society of New Zealand Manawatu Branch at the time of interview; a pharmaceutical sales representative responsible for a morphine-based pain relieving agent, who chose to speak of her recent personal experience of loss; two hospital and hospice chaplains; a night district nurse; and a hospital and hospice social worker. Selection criteria were based upon possessing some previous or current experience working in or with a hospice/palliative care environment and having an interest in participating. No participants were rejected, and none refused to participate. However, one interview produced material that was not suitable and thus was not included in the analysis.

This group of 16 individuals included only two males, which reflects the uneven gender distribution in the nursing profession in particular. The lack of male health professionals may be problematic, as some research suggests that women and men having different views on the dying experience (Cline, 1996). However, there is currently no research that has investigated the existence of gender differences specifically in understandings of dying *well*.

Six participants, without prompting, chose to speak of their personal experience of a family member or friend's death, in addition to discussing the patients they dealt with on a regular basis. This is unlikely to be problematic and, in fact, was perhaps beneficial. As the purpose of this phase was to gather information on various understandings of dying well, their decision to talk about family and friends provided additional information.

Procedure

Sixteen interviews with various health professionals were conducted by the researcher, and these lasted approximately between 20 and 90 minutes. As this phase was entirely generative, the interviews were conducted in a relatively informal manner. Despite this informality, participants were fully informed of the research goals and offered the right to withdraw at any time or to not answer questions, if they chose. Furthermore, verbal consent was sought to tape-record the interviews. Although no written consent was documented, verbal consent to take part was sought and obtained for every interview.

A semi-structured interview (see Appendix B) was carried out with each participant. Each interview began with an explanation of the aims of this preliminary stage and a brief synopsis of the researcher's background. The purpose of the interview was then explained. Particular emphasis was given to the importance of the individual's personal perceptions of dying well. This emphasis highlighted the fact that their views were not intended to be representative of the views of their peers or organisations. Further emphasis was given to the context of dying well, focusing on the time from referral to the hospice until death, and not just the last few hours or moment of death.

The data-gathering phase of the interview began with a factual question about the participant's work as a hospice health professional in order to provide some background information and encourage discussion. Following this, interviewees were asked to discuss examples of dying well or a good death they had been involved with in their work. This question often generated lengthy responses and only limited questioning was required thereafter. However, a number of prompt questions were available including prompts related to family and family conflict, as well as examples of bad deaths, to stimulate further and diverse dialogue. At the conclusion of the interview, participants were asked if they had any questions or further comments, and then thanked for their time.

The researcher was responsible for transcribing and thematically analysing all of the interviews with health professionals. The thematic analysis involved each text being reviewed in depth and all phrases identified that indicated the importance or lack of importance of some aspect of dying for the individual. All transcripts were thematically analysed before progressing to interviews with patients.

Patients receiving palliative care

Having established a grounding in dying well from the health professionals' perspective and guidelines for appropriate interview questions, the data-gathering stage could continue with the patients. However, prior to the commencement of any interviews with patients ethical approval was sought and obtained from both the Manawatu-Whanganui Ethics Committee and the Massey University Human Ethics Committee.

In light of the aim of the present research to address patient understandings of dying well, a number of hospice patients were sought. Potential patients were approached by the Medical Director of the Hospice and invited to take part. In order to be admitted to the hospice programme patients must be in the final 12 months of their lives. They are generally cancer patients (approximately 95%) although non-cancer patients (i.e. end stage renal, cardiac, neurological, and respiratory diseases) may also be admitted.

Selection criteria to participate in the study primarily emphasised practical considerations. These included being physically well enough to take part, being interested in taking part, and not being severely cognitively impaired by disease or medication. Ten patients who met these criteria were approached by the Medical Director and all agreed to take part. One participant became too unwell to be interviewed and another participant was selected to replace him. Final participants included six females and four males whose ages ranged from 42 to 77 years (M = 59.3, SD = 10.7). All participants had cancer, with primary sites including ovary, colon, bowel, renal cell, skin, thorax (upper chest and neck), and pseudomyxoma peritoneii (not strictly a cancer). The average length of time from date of referral to the hospice to the interview was 5.1 months (SD = 5.2, Range = 0.4 to 16.3, Mdn = 3.0). Two participants were single, and the remaining eight were either married or widowed.

Procedure

Once the participants had agreed to take part, the Medical Director gave the participant's phone number to the researcher. She then contacted each participant and arranged an appropriate time and place to meet. During this phone discussion a brief overview of what the participant could expect of the interview was given.

A semi-structured interview (see Appendix C), similar to that used with the health professionals, was used with the patients. After the researcher introduced herself, the purpose of the project was again explained to the participants. Participants were given an information sheet to read (see Appendix D) and time to read it. Once completed, participants were given the opportunity to ask questions. At this stage the participant was asked to read and sign a consent form (see Appendix E). Once this was signed, and if audio taping had been agreed to, taping began.

Before commencing the data-gathering phase of the interview the researcher reiterated that the participant's personal views were of interest and that anything they said would in no way affect their continuing care. In addition, they were reminded that if they wanted to stop at any time they should let the researcher know. Initially, participants were invited to talk generally about their diagnosis and illness. Although participants were well aware of the research topic, it was felt that by talking about something factual to begin with, a better rapport could be established between the researcher and the participants. Such a rapport provided a solid basis upon which to ask the more difficult questions later in the interview.

Furthermore, this general discussion gave a starting point in chronological terms that allowed participants to work their way (if they chose) from diagnosis through the hospice referral to their current situation.

For the most part, after briefly discussing their illness, participants began to discuss what dying well meant for them. Several prompts however, were prepared to facilitate further discussion if necessary. These included asking about the things that participants felt would improve their life in the immediate, in terms of their relationships with their family, health professionals, workmates, and others. In addition, prompts related to any conflicts being experienced, issues of spirituality, and anything positive that was happening for them at this time were also provided when necessary. Finally, participants were asked if they had any questions or further comments, and then thanked for their time and valuable contribution. Participants were each sent a card within a couple of days of the interview thanking them again for taking part.

Most (n = 7) interviews were carried out in the patient's home; the remainder were in the hospice (n ■ 2) and one at the researcher's home. Two patients remained in bed for the entire interview (one at home and one in the hospice). Interviews ranged in length from 20 minutes to four hours (in this case the interview was carried out over two sessions).

All patient interviews were carried out, transcribed, and thematically analysed by the researcher. Some participants indicated on the consent form that they would like to receive information about the results of this phase of the study. A letter and a summary of the results was sent to participants who had requested information (see Appendix F).

Relevant literature and media

Additional themes were sought from relevant literature and available television documentaries. In terms of professional texts, psychological, health and medical literature was reviewed and analysed with regard to characteristics of a good death or dying well. Although this literature often presented research that had addressed health professionals' views of dying well, themes were sought for the same reasons as those outlined earlier with regard to health professionals.

In addition to the relevant literature, a convenience sample of two television documentaries was also thematically analysed. *The Human Body* was a British Broadcasting Company (BBC) series that looked at human development from birth to death. The final episode takes the viewer through the remaining weeks of life of a man with stomach cancer. A second documentary, a New Zealand programme called *My Name is Jane*, followed a respected New Zealand artist from her initial cancer diagnosis to her subsequent death. Both the man and woman in these programmes spoke often of the things that were important to them at this time in their lives.

Summary of concourse development

The function of this phase was to generate a concourse of diverse themes of dying well from which a smaller number of representative statements could be selected. For this purpose, interviews were carried out with health professionals and patients, and relevant literature was reviewed. All interview transcripts were thematically analysed, and approximately 850 themes emerged from the various texts. This group of themes or statements became the basis for the next phase, development of a manageable Q-set of statements that addressed the issue of dying well for patients receiving palliative care.

Q-sort Response Hierarchy

The Q-sort response hierarchy is developed in conjunction with reducing the concourse to the Q-set. There are some guidelines available for the selection of numbers of statements for the Q-set, which therefore dictates the number of statements on, and the relative shape of, the response hierarchy. These are outlined below. However, the participants themselves were a key consideration in the present research, in the establishment of the number of statements for the response hierarchy.

In terms of selecting numbers of statements some guidelines are given. However, the selection of statements in the present research was also limited by the restricted abilities of the participants. R. Stainton-Rogers (1995) suggests that the concourse be approximately three times the size of the Q-set. Employing this guideline would have produced a Q-set of more than 70 statements. The palliative care context required that the set be much smaller than this. Limitations on ability to concentrate, level of complexity of the Q-sort, and a concern to make the Q-sort not too burdensome with respect to time, were practical issues that placed restrictions on the number of statements desired for the Q-set. Other recommendations suggested ensuring at least 60 statements for "statistical stability and reliability" (Kerlinger; 1973, p. 583); and that the number of statements be twice the number of participants plus two (Thompson, 1981; as cited in Carr, 1992). Kerlinger (1973) does note he has carried out studies with 40 statements that have achieved "good results". However, neither of these recommendations provided any further practical guidance on item number selection, nor was there any apparent theoretical or statistical basis, other than that noted above, for these recommendations.

In light of the fact that a response hierarchy is developed along side the selection of statements, a response hierarchy that could accommodate 48 statements was established and is shown in Figure 3. This number seemed manageable for participants, and also reflects the application of the principles of developing a Q-set that are outlined in the development of the Q-set section.

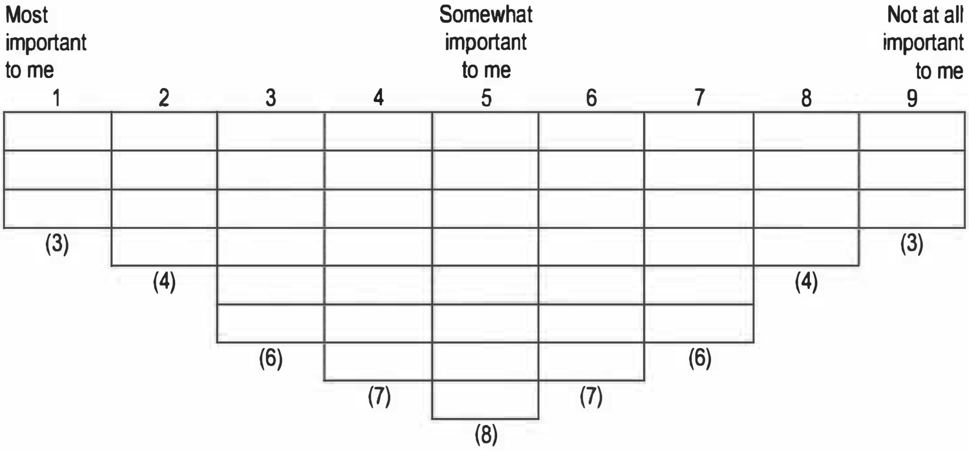

Figure 3: Q-sort response hierarchy for a 48 item Q-set

Another key issue arose in developing the response hierarchy. A decision needed to be made as to the response anchors, in Figure 3 labelled *most important to me*, *somewhat important to me*, and *not at all important to me*. Much Q-methodology research uses a continuum from *most agree* to *most disagree* to investigate different views on a particular construct, making the scale (and construct) two dimensional. However, several factors influenced the decision to consider dying well as a unidimensional construct.

Firstly, the established literature tends to view good and bad death as being at opposite ends of a continuum. For reasons outlined earlier (see p. 29), a unidimensional approach to a good death allows for good and bad deaths to be approached as qualitatively different phenomena. Consequently, good and bad deaths can be considered different constructs, rather than two faces of one construct. The present research focused on a good death, and viewing good death as unidimensional allowed for it to be investigated without explicit reference to bad death. There was also a certain practical component within this decision. Asking terminally ill patients what constituted a bad death, even within the context of asking about a good death, raised concerns of upsetting the participants.

Furthermore, the Q-sort needed to be made as simple as possible in order to accommodate the cognitive difficulties and decline frequently associated with terminal illness and pain relieving medication. Disagree/agree continuums can make a Q-sort more abstract and verbose (for example, see Brown (1980) or W. Stainton-Rogers, 1991). It was felt that a unidimensional *important to me* scale made the Q-sort more tangible for the participants and, more importantly, easier to understand and carry out.

Development of the Q-Set

Many authors who have undertaken Q-method studies offer strategies for reducing the concourse to a manageable Q-set. However, each writer appears to have their own preference and thus no one author appears to address all strategies. For this reason, the following section summarises the available literature on strategies to reduce the concourse, and describes how they were used in the present study. These strategies seem to fall into three broad categories: editorial and content-related refinements, structural modifications to fit the response hierarchy, and technique-driven sampling strategies.

Editorial and content-related refinements

Editorial and content refinements involve making relatively superficial changes to statements to ensure that they are clear and concise, easily understood and not duplicated. Many of these recommendations are not dissimilar to methods utilised in developing a good questionnaire from interview themes. Q-methodologists recommend beginning by removing duplications (Stenner & R. Stainton-Rogers, 1998; Stenner, et al., 2000). In the present study, approximately 100 direct duplicates were found and removed.

Double-barrelled propositions should be either removed or separated into two separate statements to avoid confusion (Stenner & R. Stainton-Rogers, 1998; Block, 1978). For the most part these propositions had already been separated when obtaining themes, however, some remained. For example, "[God] saved me and gave me a whole new Christian family" [27][2]. This became separated into statements about the role of faith in God and support from fellow Christians. This separation therefore allowed two separate, although related, ideas to be established.

Expressions that were problematic and ambiguous were identified and either reworked or removed (Stenner & R. Stainton-Rogers, 1998; Stenner, Dancey, & Watts, 2000). For example, having "key people around to lift me up" [27]. Through the context of this statement it was clear that the individual was speaking in an emotional sense, rather than practical. However, without the context the statement was ambiguous. The wording was thus changed from "lift me up" to "make me feel good". Although changes are often necessary, attempts were made to maintain, as much as possible, the original language of the participants. Brown (1980) sees maintaining original language as important because it minimises "the sociopsychological equivalent of Heisenberg's principle, i.e., a situation in which the act of measurement overly affects the phenomenon being measured" (p. 190).

Statements need to be expressed in everyday language and be devoid of psychological or medical jargon (W. Stainton-Rogers, 1987). For the most part the statements were direct quotes from individuals and thus the psychological jargon was limited. However, medical

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[2] The number in square brackets denotes the interviewee's identification number.

language did feature, obviously more in the nurses' dialogues, although it was still minimal. For example, a patient experiencing "respiratory disease" [8] was altered to "breathlessness", a more common, non-medical, term. Minimal modifications were made to improve the clarity of the statements whilst still reflecting the voice of the participants.

Statements that occur in interviews can often be lengthy, involve elaborate clauses and require some contextualisation. However, statements that are brief, precise, direct, clear and simple are recommended for the Q-set (W. Stainton-Rogers, 1987; Block, 1978). For example, a detailed account of a personal family dispute was paraphrased into a statement that reflected the theme of the account, "resolving family conflict". Yet, even brief sentences may not be clear. For example, "I see myself dying" is brief but ambiguous. Even with contextualising, it was difficult to establish what the participant had meant.

Ensuring the statements were applicable and appropriate to all the participants was also an important issue. For example, expressions related to specific family members were removed or made more general. For example, a father being unable to express his feelings becomes "family members not being able to express their feelings". This allowed for the possibility that the father in particular may not be the family member unable to express his feelings. Unfortunately, there may in fact be different connotations associated with different family members' perspectives on addressing feelings, that are not able to be accessed by reducing the statement in the way outlined. However, it was more important to select statements that all participants could relate to, rather than introduce redundancy. Other circumstances that may not have related to all participants, such as having a pregnant wife, having children, having a spouse or partner, being employed, were also reworded, if possible, or otherwise removed.

Block (1978) suggests that in order to prevent the mere replication of the dominant discourse, statements should be equal in terms of their social desirability thereby allowing other views to emerge. This was not a simple task. As it transpired, some statements with high social desirability had to be excluded if they could not be adequately rewritten. For example, "to have time to explore what dying well means to me" is highly socially desirable given that the researcher was at the time enquiring precisely about this topic.. It is also a somewhat pointless statement in this context given that individuals have been selected on the basis that they want to explore their understandings of dying well. Statements low on social desirability, e.g. "that someone else seems worse off than me", were also removed.

Structural modifications to fit the Q-sort response hierarchy

Recommendations for modifications to fit the Q-sort response hierarchy tend to be based upon the structure, rather than the content, of the statements as a group. In this section, issues concerning ensuring the statements are sufficiently comprehensive, and having a ratio of positive to negative statements, are discussed. In addition, the role of different categories of statements (i.e. 'how?', 'why?', and 'what?' statements) is discussed.

Of core importance in selecting the Q-set was the achievement of a balance between the statements such that there were a range of statements that were representative, comprehensive, and able to be ranked in a variety of spaces on the response hierarchy (Stenner & R. Stainton-Rogers, 1998; Brown, 1980; W. Stainton-Rogers, 1991; R. Stainton-Rogers, 1995a; Stenner, et al., 2000). Due to the large number of statements in the concourse it was necessary to provide some overall categorisation of these statements in order to facilitate and simplify the reduction process. Four categories were decided upon: physical, psychological, social, and other (which included spiritual and practical considerations). Categorising in this way follows the philosophy of hospice and palliative care (see p. 9). Establishing categories of statements simplified the process of obtaining a Q-set that covered many domains of peoples' lives.

Q-methodologists recommend aiming for a balance between agree and disagree statements with a ratio of neutral to positive to negative statements of 2 : 1 : 1. While this may be practical and indeed necessary for some research, it did not seem appropriate for this particular construct. The aim of the present research was to investigate individual differences in understandings of a good death. Even the phrasing "good death" indicates broadly positive ideas, suggesting statements are likely to be framed in a positive way. Thus the suggestion to follow a 2 : 1 : 1 ratio distribution was not followed for a number of reasons. Firstly, substantial manipulation or fabrication of the statements would be required in order to fit this distribution. This moves away from one of the guiding premises of maintaining the language of the participants from whom the original statements were derived (Brown, 1980). In addition, creating negatives complicated and made unintelligible some of the statements. For example, [*it is important to me*] "that my family are not trustworthy" [10], would be unlikely to be positively endorsed. Also, [*it is important to me*] "to not know others who are going through the same experience" [14] is difficult to follow. This suggested a ratio approach was not ideal, and was therefore not employed.

Finally, R. Stainton-Rogers (1995b) recommends not combining "discursive domains", meaning that statements should only come from one of the following three categories: representational (what things are like), theoretical (why things are like they are) and conductual, policy-oriented or strategic (what should be done about things). This is to keep the possibility of confusing concepts to a minimum (Warner, 1998). All three categories had been collected during the interviews. However, the discursive domain the present research addressed was “what things should be like” - an apparent combination of representational and conductual. The conductual discursive domain, with its focus on the future, seemed appropriate, as it provides a facility for making recommendations to appropriate bodies about potential changes. However, the focus on the description of what things are like, of how individuals actually want things to be, seemed to fit more closely with the representative idea. The results will describe how dying well was represented for these individuals, which is also more aligned to the interview discourses. Finally, those statements that addressed theoretical rather than representational discourses, for example, explanatory statements were removed. Statements such as a participant having done something “because I was much younger when I first got sick” [26] involved some explanation and were therefore removed.

Sampling strategies

In terms of employing sampling strategies to reduce the concourse, two particular methods were identified in the Q-methodology literature: structured and unstructured sampling.

Structured sampling

Structured sampling consists of using a theory to impose structure on the selection of the statements. For the present research, the overarching tenet of palliative care involves addressing the physical, psychological, social and spiritual needs of the patient. This principle was able to be used to categorise the statements, as mentioned earlier, and thus provide an overall structure for the statements. Once a structure was in place, the statements were easier to manage - they were in smaller and more coherent groups, and the issue of the total and relative number of statements to be selected could then be addressed.

The guidelines with respect to the number of statements necessary for a Q-set have already been outlined in the Q-sort response hierarchy section above. However, as mentioned, the Q-set and response hierarchy are developed in conjunction with each other. As the philosophy of palliative care was driving the division of the concourse into categories, it was appropriate to also use these categories to create an overall structure for the statements. Thus 12 statements per category (physical, psychological, social and other) were explored, as 48 statements seemed manageable and provided appropriate coverage of the established themes. The 48-item response hierarchy is shown in Figure 3 on page 116.

Finally in terms of structured sampling, statements that are most different from each other *within* the categories are selected. This procedure ensures the comprehensive coverage of the construct. However, this assumes that the categories themselves are sufficiently comprehensive. Aiming for diversity within each category should ensure that the statements are "conceptually independent" or at least relatively different from each other (Brown, 1980; Carr, 1992; R. Stainton Rogers, 1995a). Statements were thus not necessarily selected solely on the basis of frequency of occurrence within the interviews but for diversity, amongst other things.

Unstructured sampling

An alternative to structured sampling is unstructured sampling. This was not the approach chosen for the present research, however, it is briefly presented here for completeness. In this approach statements are selected at random without considering notions of comprehensive coverage of the construct. One advantage of this method is that it is a more transparent process than structured sampling, with this process being easily reproducible, albeit with a different group of randomly selected statements. This unstructured approach seems appropriate to a concourse that has equally represented categories (i.e. relatively equal numbers of statements in each category). Randomly selecting statements from a large concourse should mean that categories are evenly represented by equivalent numbers of statements. The dying well concourse in the present research did not have evenly represented categories. Had unstructured sampling been used, categories may have been over and/or under-represented, which would then not appropriately map the construct of interest. For this reason, the structured sampling approach seemed more appropriate.

Having sorted the statements into four categories following the structured sampling approach, decisions on selection of statements for the Q-set were ready to be made. Selection of the Q-set statements should be a collaborative process (Block, 1978). For this reason the researcher and her supervisor spent some time discussing the inclusion and exclusion of all the statements. Attention was paid to ensuring statements were not duplicated, double-barrelled, ambiguous, or included psychological or medical jargon. Also statements that were not applicable to all participants were removed, as were those statements high in social desirability. As noted above, 48 statements were selected, with 12 for each of the four categories (see Appendix G).

Developing Appropriate Q-sort Materials

The aim of this phase was to develop and construct the Q-sort materials in such a way that they would be able to accommodate the various levels of physical restrictions experienced by the patients. Given the poor health and physical weakness of many of the participants the materials needed to be developed to accommodate these specific restrictions. Typically the Q-set statements have been printed onto an A4 sheet of paper and the participants asked to cut out their own statements (W. Stainton-Rogers, 1994), presumably to prevent individual statements becoming lost. Furthermore, participants have been seated at a table where they can spread out all of the statements and sort them on to the response hierarchy. Many of the participants to be interviewed in the present research were expected to be relatively unwell, probably more comfortable in a reclining position, either in bed or in a reclining chair and unlikely to be able to sit at a desk. For this reason, the materials needed to be designed in such a way that they could be used with the participant reclining and without the use of a large flat surface. The statements needed to be able to be secured to the response hierarchy, yet still moveable if the participant changed their mind about the placement of the statement. To accommodate these circumstances a steel board and strip magnets were used. This allowed the statements to be secure yet moveable, and also allowed the participants to remain reclining for the duration of the process as the board could be held at any angle, or rested on the arms of a chair.

Two steel boards, one 700mm x 250mm, the other 700mm x 500mm, were constructed and painted white. On the first board, black felt pen was used to draw vertical lines at 230mm and 460mm, such that the surface was evenly divided into three segments, as shown in Figure 4.

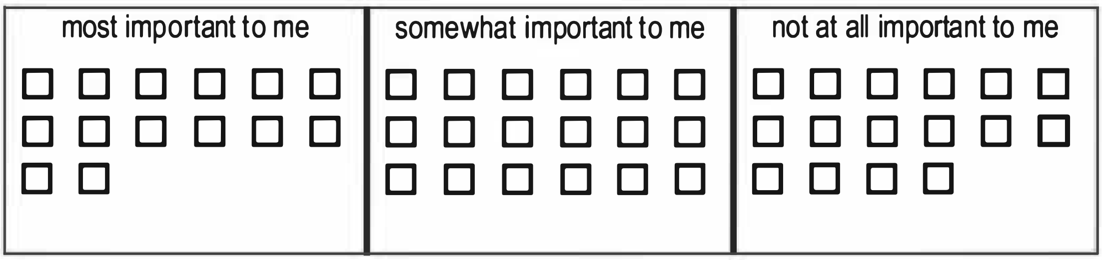

Figure 4: Statement Sorting Board with Example Q-set Statement Placements Shown

On the surface of the larger board the response hierarchy, shown earlier in Figure 3, was drawn. A sheet of strip magnet was then cut into 48 pieces, each measuring 70mm x 50mm. The 48 statements were then printed on to individual sticky labels, which were then fixed to the fridge magnets. Three further magnets were cut and these held the label information for the response hierarchy (i.e. most important to me, somewhat important to me, not at all important to me). Nine smaller magnets (1cm x 1cm) were also cut, and these contained numbers one to nine which provided anchors to aid the further distinction between statements. These were also placed on the response hierarchy, as shown in Figure 3. Finally, the random number generator tool in Microsoft Excel was used to allocate a number to each of the statements. These numbers were then written on the magnetic statements in red ink.

Pilot Testing the 48 Statement Q-Set

Pilot testing aimed to test the 48 statements on selected individuals. Establishing the comprehension of the statements, the ease or difficulty of the Q-sort, and identifying any other problems were core objectives. To test these objectives systematically, three separate groups of participants were sought. The first group included patients receiving palliative care. A second group consisted of health psychology staff and students, and a third, hospice-related health professionals. At the completion of each group's testing any recommended alterations were considered and changes made if appropriate.

Pilot testing with hospice patients

Establishing the patients' ability to comprehend and complete the Q-sort without undue stress were core aims of pilot testing with the hospice patients. In addition, this proved to be an opportunity for the researcher to test the adequacy of the instructions given and gain practice in administering the Q-sort.

Five hospice patients, three men and two women, were selected by the Medical Director of the hospice for the pilot testing. All participants had cancer: colon, bowel and breast, and their ages ranged from 50 to 85. Interview times ranged from 45 minutes to two hours.

Procedure

Participants were initially approached by the Medical Director or the Nurse Manager of the hospice and invited to take part. At the time of invitation, those willing to take part (none declined) were given an information sheet to read which outlined the project (see Appendix H). Willing participants' names were then forwarded to the researcher who telephoned to make a time to meet with them. For the most part, participants were also called an hour before the meeting time to see if they were well enough to participate. As a result, occasionally postponements were made.

With regard to the meeting itself, at the beginning of the meeting the researcher explained the nature of the project and gave a brief summary of the data-gathering phase. Following this the Q-sort was explained to the participant so they knew what was involved and they were invited to ask any questions they might have. Having addressed any concerns, they were then asked to sign a consent form (see Appendix E).

All meetings were tape-recorded. For the first part of the Q-sort, participants were handed the 48 statements (in numerical order) and asked to sort the statements into three groups: those most important to them, those somewhat important to them, and those not at all important to them (see Figure 4). The three division headings were placed at the top of each of the divisions to orient the participant.

During this grouping task the participants were asked to comment on the readability and intelligibility of the statements, and offer any general comments about the process. The researcher noted any comments the participant made.

Participants were asked to review the statements they had placed in the first group (most important) and decide which were the three most important. These three were then placed on the response hierarchy (see Figure 3) in the far left column. Participants were then asked to select the next four most important and place these on the response hierarchy. This continued until all statements from the first group had been placed on the response hierarchy. This process was then repeated for the *not at all important to me* group.

Finally, the empty places on the response hierarchy were filled by the remaining statements. During this process participants were again asked to comment on the Q-sort and offer any suggestions in improving the way in which it was carried out. Having completed the Q-sort, participants were asked for any final comments and the placement of the statements was noted by the researcher on the scoring hierarchy (see Appendix I). All participants were then thanked for their time, and a card was sent within a week of this meeting to thank them again for their assistance.

Recommendations made by participants and subsequent revisions made

On the basis of the comments made by the participants several statements were altered in some way, and others were removed completely. Most changes suggested were editorial (e.g. changing "that at the time of my death I am at home" which participants felt was cumbersome, to "that I die at home") or content driven (e.g. changing wording from "sensitive to the needs of my new situation" to "sensitive to the needs of my illness"). Participants also recommended changing the statement headings to *most important*, *quite important*, and *least important*, to clarify the distinctions. Although "to me" was dropped from the statement anchors, it instead was emphasised in the introduction to the task given by the researcher.

Most participants felt the Q-sort was too long and thought that removing some statements would make the Q-sort more manageable. Having incorporated many of the recommended stylistic changes, the number of statements was reduced by eight to 40 to meet the manageable requirement. Statements were removed on the basis that participants found them difficult to understand, ambiguous, or repetitive. For example, "that I have a purpose" was removed as participants saw it as too similar to "that my life has meaning". Also, "that things are not left unsaid", was removed as many participants asked "what things?", suggesting a lack of clarity for this statement that was difficult to quantify.

The task of sorting onto the response hierarchy was noticeably more difficult the greater the number of statements in the groups. Thus the instructions were also modified such that the participants were asked to make the groups of statements "roughly even", i.e. having at least 10 in each.

In terms of the materials, three key problems were identified. Firstly, the board was too large and too heavy. This was solved by reducing the size of the statements to 60mm x 35mm (although maintaining the 16pt font size), which thus reduced the height and width of the response hierarchy. Reducing the number of statements also reduced the height of the response hierarchy by one statement. This allowed a new board to be constructed which was somewhat lighter and considerably smaller at 660mm x 420mm. Secondly, the printing on the labels began to wear off and the labels became difficult to read. Thirdly, the magnets were extremely adhesive and participants found it difficult to lift the statements off the magnetic board. One solution fixed both of these problems. The statements were laminated on both sides. This meant the printing did not come off the labels and the adhesion to the steel board was reduced allowing the statements to be slid across the board and yet remain sufficiently adhesive to stay fastened to the board. In addition, this lamination process provided an edge to the statements sufficiently large to allow a fingernail to slip under the rim and lift the statement easily from the board. Finally, the board was laminated with Coverseal to further reduce adhesion.

Pilot testing with hospice health professionals and health psychology students and staff

The pilot testing of the statements for comprehension continued with a selection of hospice health professionals, health psychology students and staff. One hospice doctor, one hospice nurse manager, five Massey University School of Psychology staff and students, and the husband of a graduate student, were asked to complete the Q-sort, as outlined above, with the modified 40 statements. Five participants were male, and four female, and all aged from early 20s to late 50s. All five psychology staff and students were involved in health psychology research, three as PhD students, the remaining two as academic staff: one an Associate Professor, the other a Senior Lecturer.

The procedure was identical to that of the patients' except that it incorporated the recommendations for revisions outlined above. Participants were also asked to comment on the readability and intelligibility of the statements and offer any general advice they felt was relevant to the Q-sort. Resulting comments, again, related largely to editorial issues and any changes deemed appropriate were made.

At the completion of this phase the final 40 statements were discussed once more by the researcher and her supervisor. Only minor changes were made.

Q-Sort Study

Participants

Hospice patients were recruited by a number of hospice health professionals including the Medical Director, Nurse Manager, Hospice Liaison Nurse and Hospice Doctors. Approximately 75% of those approached agreed to take part. Only one participant did not complete the entire Q-sort, and thus this data was excluded.

Forty participants completed the Q-sort. Participants were mainly over 60 years old (77.5%), NZ European (85%), and married or widowed (70%). There were relatively equal numbers of males and females (females 43%). However, participants were diverse in cancer type (bowel/colon 27.5%, lung 15%, breast 12.5%, stomach 7.5%, prostate 7.5%, and other 30%). Full details are given in Appendix J.

Procedure

The procedure outlined below repeats that of the final stage of the pilot study but for clarity the process in its entirety is documented here.

At the time of recruitment, potential participants were given the information sheet (see Appendix K) to read and invited to ask any questions they may have. Those willing to take part were informed that the researcher would contact them in the next few days. Participants' names and contact details were given to the nurse manager who contacted the researcher on an as and when required basis. The researcher then telephoned participants and arranged a time to visit them either in their own home or at the hospice. As Arohanui Hospice is part of Mid-Central Health it is mandated to service the Manawatu and

Horowhenua regions (see map in Appendix L). This meant travelling between 12 and 145 km to conduct the 40 interviews.

Background information to the project oriented the participants to the project. To each participant the researcher outlined the two stages of the exercise, sorting and completing the response hierarchy. If participants had not received the information sheet they were given one to read. Otherwise participants were asked if they still wanted to take part, and if so, they were requested to read and sign the consent form (see Appendix E). No one declined to take part at this stage.

For the 19 participants who for the purpose of aiding interpretation of the factors, were asked and had agreed to tape-recording of the procedure, taping began here[3]. Instructions were then given to participants regarding the first part of the Q-sort, namely dividing the statements into three roughly equal sized groups. Participants were given the 40 statement Q-set and asked to sort them into three groups, those that were most important to them, quite important to them, and least important to them. They were instructed to have "roughly even" groups, such that there was a minimum of ten in each group. If this was not met in the first sort, participants were asked to look at the oversubscribed group and select those that could be removed and placed at a lower (or higher) level. For the most part, the minimum of 10 per group was obtained on the first sort. Participants were encouraged to talk about the statements and reflect upon any specific meanings they had to them.

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[3] For participants who were particularly unwell I decided not to tape the interviews as it felt too intrusive. Only one participant [78] did not want her interview tape recorded. For all participants, I took notes on relevant comments they made.

For the Q-sort, participants were first asked to consider the statements they had placed in the most important group, select the two they felt were the very most important, and place these in the top two positions on the response hierarchy. The final 40-statement response hierarchy is shown in Figure 5. Participants were advised that the placement was not binding and they could change their mind and the placement of the statements at any time.

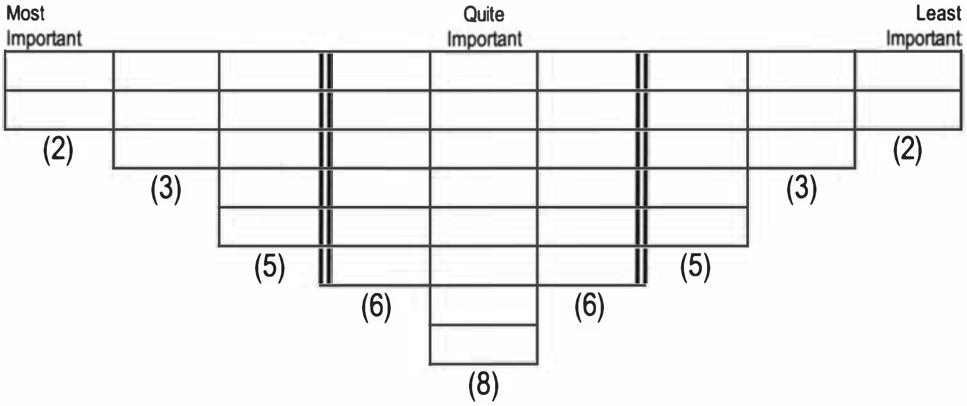

Figure 5: Final Response Hierarchy for 40 Item Q-set

Within the same group of statements they then selected the next three most important and placed these on the response hierarchy, and so on until the first group was completed. Next, they considered the statements from the *least important* group, and selected the two least important for placement on the response hierarchy. Again, the next three least important were chosen and placed on the response hierarchy until none remained. Finally, the participant considered the statements in the *quite important* group and placed them, according to their degree of importance, on the response hierarchy.

Participants were asked to review the overall response hierarchy and comment on their satisfaction with how they had completed the Q-sort, and to make any changes they deemed necessary. Some time was spent by the researcher reflecting on this task with the participant, to ensuring they were happy with the final product and that it represented their views, as they wanted it to. Once they were satisfied, the statement placement was recorded on a response grid (see Appendix M). Participants were then asked to provide some basic demographic information (see Appendix N).

Throughout the Q-sort process the participants were encouraged to comment on the statements, reflect upon any issues that arose in response to the statements, and make any other comments they felt appropriate. This interview data was used to elaborate on the factors that were generated in the factor analytic process that followed.

At the conclusion of the interview many participants commented that they had enjoyed carrying out the task, and liked that they had a "visual picture" (i.e. the board with the statements on it) of what they had done. Participants were thanked for their time, and each was sent a card again thanking them for their contribution within a week of completing the task.

Data analysis

Computer software

PQMethod 2.0 (Schmolck, 2000) is a free software program that was downloaded from the internet (http://www.rz.unibw-muenchen.de/~p41bsmk/qmethod/index.htm) in order to input and analyse the Q-sort data. It has a number of advantages over standard statistical packages, such as Statistical Package for the Social Sciences 10.0 (SPSS 10.0, 1999). In particular, it provides useful results files not available in standard packages. However, it is limited in that it only performs Principal Components Analysis (PCA) and centroid factor analysis extractions with varimax and manual rotations. Thus both SPSS and PQMethod were used for extracting and rotating solutions, and Microsoft Excel (version 5.0) was also used to convert some of the results to a similar format to PQMethod.

Q-factor analysis procedures

Much attention was given in the previous chapter to the Q-factor analysis approach. This section addresses what was actually done in the present study.

Although much Q-method research uses only PCA with varimax rotation without strong justification, the decision was made to trial a number of solutions, as might be performed in an R-study. This meant that both PCA and FA were explored. Examining the differences between the various solutions is useful to establishing the most appropriate factor or component structure.

Brown (1980) focuses almost exclusively on statistical significance and interpretability criteria, and predominantly on the latter, to establish the number of factors likely to create the simplest structure. He heavily criticises the use of standard R-methodology procedures for establishing the number of factors, such as latent root (eigenvalues) and percentage of explained variance in Q-analysis. However, despite his criticisms, these methods seem to provide useful *guidelines* to investigating different solutions. Whilst the present research follows Brown's work fairly closely, particularly in emphasising the interpretability of solutions, these "standard" guidelines have also been employed as additional features in informing the decision making process.

The next step in the procedure is considering the rotation method to be used. It is reasonable to assume that, in the present research, the factors that are constructed may be correlated, and thus an oblique rotation would be appropriate. Allowing accounts to be correlated means that they are able to resemble each other, or show more commonalities than if they are forced to be independent. However, forcing them to be independent of each other by using an orthogonal rotation may improve the structure of the factors such that a simpler solution is established. Simpler in the sense that the factors are more distinct from each other and therefore represent discrete understandings of dying well. As with deciding on the number of factors, trialling different solutions using the different rotational strategies was carried out.

In R-factor analysis the rotated component matrix (in PCA, pattern matrix in FA) is predominantly used for interpretation of the factors. It is generally hoped that a variable (i.e. Q-sort in Q-factor analysis) will load predominantly on one factor and minimally on all others, thereby approximating simple structure and enhancing interpretability (McKeown & Thomas, 1998). Often a loading of 0.30 or above on a second factor is considered indicative of "impurity". Brown (1980) recommends performing a test to determine "pure factor representatives" (Brown, 1980, p. 262) using the equation 2.58(1/SQRT(N)), where N is the number of participants. This method suggests that a loading is "pure" and "representative" if only one loading of a Q-sort on a factor is greater than this value (which is 0.41 with the sample size of 40 Q-sorts). PQMethod performs a similar calculation, although two criteria need to be met. The first criterion is: $a^2 > h^2/2$ (where a is the factor loading, and h is the explained variance). This expression means that the factor explains more than half of the shared variance. The second criterion is: 1.96(1/SQRT(N)), which is a less stringent form of Brown's (1980) pure factor test, where the loading is significant at $p > 0.5$, rather than Brown's $p > 0.01$. Those Q-sorts that do not meet these criteria are found to lack "purity" and can be excluded from the weighted average procedure described below (Schmolck, 2000). The present research employed the two criteria available in PQMethod to establish the "purity" of the factors.

In R-factor analysis, the factor loading matrix is often of interpretative interest. In Q-factor analysis, it is used more as a source for the next stage, weighted averaging, than for its interpretative value in itself. The weighted average procedure incorporates relative loadings of the Q-sorts, so interpreting the factor loading matrix is not common in Q-factor analysis.

Weighted average exemplar Q-sort

Q-factor analysis has an additional step over standard R-factor analysis. The result thus far is a rotated factor matrix that shows the factor loadings of each participant (or Q-sort) on a factor. In order to facilitate the interpretation process, a weighted average procedure is undertaken. Here each Q-sort is weighted such that its contribution to the construction of an exemplar Q-sort is reflected by its correlation with the factor (i.e. factor loading). An exemplar Q-sort represents the combined common views of the participants that loaded highly on that factor. Thus each exemplar Q-sort represents a different account or understanding of dying well. Spearman's formula (1927, as cited in Brown, 1980) for calculating factor weightings is $w = f/(1-f^2)$, where f is the factor loading. Following this, the absolute value of the reciprocal of the largest weighting is multiplied by the weighting. The resultant weighting is then multiplied by 10 and rounded to the nearest whole number. The factor weights for the defining sorts (i.e. those Q-sorts or participants who loaded high on the factor) are multiplied by the raw score (i.e. the column on the response hierarchy), and then summed across items (statements).

As the factors contain different numbers of Q-sorts it is useful to convert these total summed statement scores to Z-scores to normalise these values. Finally, the Z-scores are then used to establish the ranking of the statements such that they can then be placed back onto the original response hierarchy framework to produce an "exemplar" Q-sort for each factor.[4] The top ranking statement is placed in the first column and first row of the response hierarchy

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[4] The interested reader is referred to Brown (1980, p. 239 – 244) who gives a full account and example of this procedure.

with the second highest ranking statement beneath it, and this continues to the lowest ranking statement which is in the final column, and second row.

PQMethod 2.0 (Schmolck, 2000) produces additional output over such standard statistical packages as SPSS, some of which are useful in determining the interpretability of the factor structured elicited. A so-called 'distinguishing statement analysis' output displays the statements that ranked significantly differently across the factors. Conversely, the 'consensus statement output' lists those statements that did not distinguish between any factors. Consensus and distinguishing factors are based upon the standard errors for each factor. In comparing two factor scores (normalised *Z*-scores), the two standard errors are squared, summed, and the square root is taken (i.e. $\mathrm{SQRT}(SE_1^2 + SE_2^2)$). This value is then multiplied by 1.96 to establish statistical significance at $p < 0.05$, and 2.58 to establish statistical significance at $p < 0.05$. (Appendix O shows the distinguishing statement tables for the four factor solution). Both the consensus and particularly the distinguishing statement outputs are useful in the interpretation of the accounts. The more a factor is able to be distinguished from another factor the more distinct the solution is.

Most interpretations focus on the top and bottom statements (in this case rankings 1 to 10, called high rankings, and 31 to 40, called low rankings) as they represent the strongest views of the participants. This is generally when the structure of the response hierarchy is bipolar - such that the top end represents most agree and the bottom end most disagree. The participant is said to hold equal strength views about the statements at each end. However, in this study, the scale used ranged from most important to least important. Notwithstanding this difference, the two ends of the continuum offer the most interpretative value as they represent those statements (and practically, "things") that were most and least important in facilitating a good death. A crucial point to recognise about this continuum is that those statements placed at the least important end mean they were the least important, not necessarily that they were not desired, just that they were less important than the other statements available.

The interpretation and development of these exemplar Q-sorts into the different accounts is facilitated by the verbalisations of the participants that occurred during the interview process. R. Stainton-Rogers (1995a) notes: "recourse is also made to the open-ended comments made by participants in explication of the position allotted to items" (p. 189). Brown (1996, listserv) suggests that the researcher "can add verbal material which serves to flesh-out the factor and give it fuller meaning and comprehensibility". However, the verbalisations must fit in with the arrangement of factor scores as well as with the "gestalt of the overall interpretation".

It is notable that in many Q-factor analysis studies the interpreted "exemplar" structure is often presented to the original participants who exemplified (i.e. loaded highly on) the factor, and they are invited to comment on its accuracy in reflecting their views (R. Stainton-Rogers, 1995a; Kitzinger & R. Stainton-Rogers, 1985; W. Stainton-Rogers, 1991). In the present research this was not carried out for two reasons. In a practical sense, it was not possible to return to the participants as many had died by the time the analysis was available for comment. Furthermore, returning to a participant to check the interpretation of their Q-sort suggests that their opinion of, or attitude to, the construct is stable. It seems possible that within the ever-changing environment of terminal illness, understandings of dying well may not remain stable over time. Although it may have been possible for them to reflect back upon what they had done earlier, an element of cognitive decline may have also been apparent which would complicate this matter. This has some implications for the findings, and these will be discussed in due course.

Most people die as they have lived; some with metaphysical and religious concerns on their minds, others, with the everyday preoccupations they have always had.

Sir William Osler
eminent physician and medical educator

Chapter 7:

Results

The results chapters focus on a four factor PCA solution using varimax rotation. This introductory chapter outlines the processes involved in arriving at this solution since several different solutions were explored using various extraction techniques, rotation methods, and numbers of factors. A synopsis of each of the four factors, which represent different understandings of dying well, is then introduced. The four chapters following this one describe each of the factors in detail, aided by comments made by the participants during the sorting process. These four chapters are in the form of both conventional results and discussion, in that the descriptions of the elaborated accounts draw upon established literature to help interpret the factors.

Choosing the Final Factor Structure

The data analysis section in the method chapter outlined the issues surrounding the use of Q-factor analysis. As noted then, most Q-methodologists use PCA with a varimax rotation, and this was also used here. However, a number of different solutions were explored, thus FA extraction and oblimin rotations were also used, each with various numbers of factors. This section presents the results that emerged as these options were explored.

Forty Q-sorts were completed which produces a correlation matrix (the matrix of correlations of each Q-sort with every other Q-sort) of 780 unique correlations. Of these correlations, 31% were greater than ±.30, and ranged from -.35 (Q-sorts 5 and 29) to +.69 (Q-sorts 31 and 40). There appeared to be clusters of correlations rather than 40 individual constructions, which suggests the matrix was indeed factorable. The full correlation matrix is presented in Appendix P.

As outlined in the method section, the recommended approach to carrying out the factor analysis suggests performing a PCA as the extraction technique, followed by a varimax rotation. The initial statistics, displayed in Table 1, indicated 12 factors with eigenvalues greater than one, which explained 79.9% of the variance.

Table 1

Initial statistics following a PCA

Factor	Eigenvalue	% of Variance	Cumulative %
1	9.38	23.4	23.4
2	5.14	12.8	36.3
3	2.59	6.5	42.8
4	2.40	6.0	48.8
5	2.24	5.6	54.4
6	1.99	5.0	59.3
7	1.75	4.4	63.7
8	1.62	4.1	67.8
9	1.43	3.6	71.3
10	1.21	3.0	74.4
11	1.17	2.9	77.3
12	1.05	2.6	79.9
13	0.96	2.4	82.3
14	0.88	2.2	84.5
15	0.79	2.0	86.5
16	0.72	1.8	88.3
17	0.60	1.5	89.8
18	0.54	1.3	91.1
19	0.51	1.3	92.4
20	0.44	1.1	93.5
21	0.41	1.0	94.5
22	0.34	0.9	95.4
23	0.32	0.8	96.2
24	0.30	0.8	96.9
25	0.26	0.7	97.6
26	0.22	0.5	98.1
27	0.16	0.4	98.5
28	0.14	0.4	98.9
29	0.12	0.3	99.2
30	0.10	0.2	99.4
31	0.07	0.2	99.6
32	0.05	0.1	99.7
33	0.04	0.1	99.8
34	0.03	0.1	99.9
35	0.02	0.0	99.9
36	0.02	0.0	100.0
37	0.01	0.0	100.0
38	0.00	0.0	100.0
39	0.00	0.0	100.0
40	0.00	0.0	100.0

As discussed earlier however, because the sample size used in the present research is not large, Brown (1980) suggests that the number of factors can be excessive when using eigenvalues as a guide. He recommends using less than seven factors, and aiming for around four. These recommendations should encourage a parsimonious, and interpretable, factor solution. This advice seemed applicable in the present research as the structure created by the 12 factor solution had many mixed loadings (i.e. loadings that did not meet PQMethod's criteria for purity) and did not appear to form a coherent pattern.

In Q-analysis, two judgements are made on the basis of the loadings. First, the criterion of 0.30 is used, as this is the standard minimum criterion for factor loadings that has achieved customary status in all factor analysis (Gorsuch, 1993). Second, PQMethod uses two criteria (outlined on page 136) which identify 'pure' loadings, that is, loadings that rate significantly on only one factor. The second PQMethod criterion produced a value of .31, which means that the off-diagonal loadings are compared with this value to test for significance. However, as this was close to the standard minimum criterion outlined above, the .30 value was used to avoid confusion.

Any type of factor analysis, be it Q or R, recommends the trial and error of a number of factor solutions. Following Brown's (1980) recommendation, a seven factor solution was therefore initially explored. The varimax rotated component matrix, with communalities and explained variance, is presented in Table 2.

Table 2

Rotated Component Matrix for Seven Factor PCA Varimax Rotated Solution Showing All Loadings Greater Than .30, Communalities, and Percentage Explained Variance

				Factors				
Q-sort	1	2	3	4	5	6	7	Commun.[5]
08	**0.802** *							0.75
27	**0.678** *							0.47
35	**0.637** *		0.361					0.59
25	**0.617** *	0.371						0.67
15	**0.587** *					0.362		0.59
21	**0.571** *				0.478			0.60
37	**0.517**						0.446	0.57
28	**0.446**				0.400			0.49
13	**0.441**			0.364		0.312		0.64
03		**0.902** *						0.85
14		**0.666** *						0.48
39		**0.639** *				0.364		0.61
40		**0.624**	0.543					0.84
31		**0.616** *	0.448					0.62
23		**0.611** *				-0.337		0.60
17		**0.575**	0.372			0.383		0.73
20		**0.557**		0.452			-0.331	0.68
07		**0.552** *	0.389					0.47
11		**0.381**		0.311		0.358		0.48
19			**0.783** *				-0.350	0.80
05			**0.646** *					0.62
06	0.345		**0.470**	0.446				0.60
29				**-0.728** *				0.71
36				**0.634** *				0.46
30		0.310		**0.538** *				0.52
16					**0.746** *			0.62
26	0.405				**0.680** *			0.73
02					**0.663** *		-0.313	0.70
04	0.469				**0.642** *			0.76
24		0.380			**0.615** *			0.64
34			0.308		**0.535**	0.511		0.69
32			0.419		**0.519**		0.370	0.69
09	0.440				**0.465**		0.435	0.78
22				0.374	**0.413**		0.314	0.51
38					0.360	**0.691** *		0.70
12	0.479					**0.549**		0.67
18	0.345				0.483	**0.484**		0.66
33			0.375			**-0.404**		0.56
01							**0.824** *	0.74
10				0.337			**0.512**	0.57
% exp. var.[6]	13	12	8	7	11	7	6	**64**

---

[5] commun. = communalities.

* Factor loadings identified by an asterix indicate those which are "pure", such that the Q-sort loads on one factor and no other. Loadings in a shaded box indicate the highest loading for each Q-sort.

[6] exp. var. = explained variance.

Although this solution explained a moderate amount of variance (64%), there are 41 off-diagonal loadings (14.6%) greater than 0.30. It is notable that only nine Q-sorts (22.5%) loaded on one factor and no other (i.e. loaded on only one factor at greater than 0.30 level). When using the formula for "pure factor" representativeness, (see page 136) 16 Q-sorts would be excluded from further analysis. The remaining "pure" Q-sorts are marked with an * in Table 2. The exclusion of so many participants seemed to suggest the solution was not entirely appropriate. This was supported by looking at the distinguishing statements (those statements ranked significantly differently on pairings of factors). The number of distinguishing statements was particularly small, with five each for factors one to three, and two, three, four, and two, for factors four through seven, respectively. This tends to suggest that the seven factor solution was not producing distinct factors.

With seven factors appearing to be too many, the next solution explored was Brown's (1980) recommended four factor approach. The rotated component matrix for this analysis is presented in Table 3.

Table 3

Rotated Component Matrix for Four Factor PCA Varimax Rotated Solution Showing All Loadings Greater Than .30, Communalities, and Percentage Explained Variance

	Factor				
Q-sort	**1**	**2**	**3**	**4**	**Communalities**
04	**0.798** *				0.72
26	**0.756** *				0.65
08	**0.751** *				0.57
09	**0.704** *				0.60
21	**0.692** *				0.57
02	**0.646** *				0.47
18	**0.638** *		0.365		0.56
16	**0.611** *				0.41
15	**0.588** *				0.44
28	**0.558** *			0.337	0.44
34	**0.546** *		0.488		0.56
27	**0.532** *				0.29
35	**0.512** *				0.40
37	**0.461** *			0.412	0.40
03		**0.840** *			0.75
40		**0.679** *	0.384		0.66
14		**0.661** *			0.44
23		**0.651** *			0.53
20		**0.649** *			0.43
31		**0.634** *	0.412		0.60
39		**0.580** *			0.35
07		**0.530** *	0.359		0.41
25	0.383	**0.475**		0.351	0.56
24		**0.329** *			0.16
33		**0.325** *			0.21
19			**0.834** *		0.76
05			**0.615** *	0.386	0.53
17		0.484	**0.500**	0.322	0.61
06			**0.494** *	0.376	0.46
12	0.402		**0.449** *		0.36
11		0.373	**0.390**		0.41
38		-0.326	**0.355**		0.41
01				**0.698** *	0.51
10				**0.643** *	0.49
30		0.332		**0.562** *	0.45
36				**0.533** *	0.31
22	0.434			**0.526** *	0.48
13	0.469	0.308		**0.501**	0.60
32	0.411		0.316	**0.477**	0.50
29	0.414			**-0.486** *	0.44
% Explained Variance	18	13	9	9	**49**

The four factor solution contrived to explain a moderate amount of variance (49%), and had approximately the same proportion of mixed loading Q-sorts (14.4%) as the seven factor solution. However, Q-sorts that loaded on one factor and no other (at the 0.30 level) amounted to 21 (52.5%), which was a substantial improvement over the seven factor solution. In addition, only six Q-sorts would need to be excluded on the basis of the purity test. The distinguishing statements analysis was also considerably more satisfactory than the seven factor solution. Factors one and two had 15 distinguishing statements, with 12 and 14 for factors three and four respectively. Furthermore, in looking at the normalised factor scores, and the exemplar Q-sorts they created, the arrangement of the statements seemed interpretable, thus meeting Brown's (1980) most important guideline.

Removing the six "least pure" Q-sorts had minimal impact upon the normalised factor scores and the overall factor hierarchy structure. As the structure was predominantly unchanged (nine of 80 statements did not make it to the top or bottom ten statements) the decision was made to include all Q-sorts. Importantly, this also meant that the understandings of all participants were present in the solution to be interpreted.

Although this four factor solution seemed appropriate, in keeping with the exploratory objective of this research, several other analyses were run, including FA extraction, Oblimin rotations, a five factor solution, and removing Q-sorts. Two indicators of the acceptability of each analysis were employed: percentage of factor loadings greater than .30, and the number of iterations the solutions took to converge. These are shown in Table 4 and Table 5. The analyses included running both the factor analysis and the weighted average procedure, as this procedure is predominantly the basis on which interpretability is decided.

Table 4

Summary of Percentage of Factor Loadings Greater Than .30 for the Various Solutions Explored

	PCA				FA			
	Varimax		Oblimin		Varimax		Oblimin	
Factors	All	Less	All	Less	All	Less	All	Less
12	×	11.0	×	×	n/a	-	n/a	-
7	14.6	14.3	×	×	n/a	11.7	n/a	7.9
5	15.0	13.2	11.5	11.6	n/a	14.7	n/a	7.4
4	14.4	13.8	12.5	11.2	n/a	13.2	n/a	9.9

All = all 40 Q-sorts in
Less = less Q-sorts 1 and 19
n/a = unable to be extracted
× = would not converge, so no rotated component matrix to interpret
- = analysis not carried out

Table 5

Summary of Number of Iterations Involved in the Various Factor Solutions Explored

	PCA				FA			
	Varimax		Oblimin		Varimax		Oblimin	
Factors	All	Less	All	Less	All	Less	All	Less
12	×	✓	×	×	n/a	-	n/a	-
7	✓	28	×	×	n/a	29	n/a	×
5	✓	✓	36	39	n/a	✓	n/a	35
4	✓	✓	✓	29	n/a	✓	n/a	38

All = all 40 Q-sorts in
Less = less Q-sorts 1 and 19
✓ = converged in under 25 iterations
× = would not converge in under 40 iterations
n/a = unable to be extracted
- = analysis not carried out

Initially a five factor solution, maintaining the PCA extraction with varimax rotation, was explored. This was followed by an oblimin rotation of the four, five and seven factor PCA solutions. The oblique solutions produced similar factor loading structures to the orthogonal rotations, although they tended to have fewer mixed loading Q-sorts (see Table 4). With the exception of one however, these solutions took more than 25 iterations to converge (see Table 5) suggesting a less stable structure. The differences between the oblique and orthogonal rotations in terms of the exemplar Q-sorts generated, were also minimal (i.e. the statements stayed, predominantly, in the same ranked order).

PAF was also explored as an extraction technique. However, because the correlation matrix was not positive definite (resulting from having the same number of Q-sorts as statements), certain factor extraction algorithms could not be applied (Schmolck, 1996, listserv). One way around this was to remove Q-sorts. Q-sorts 1 and 19 did not correlate with any other Q-sort above 0.41 (the cut-off point that represents a correlation that is two standard deviations outside the mean) (see Appendix P), thus they were removed in order to trial the PAF extraction. PAF solutions explored with both Q-sorts 1 and 19 excluded, did not differ greater from the respective solutions generated by PCA (see Table 4 and Table 5).

As the four factor PCA with varimax rotation seemed to provide the most appropriate and interpretable solution, it was selected and further interpreted using a weighted average procedure. This procedure weights the factor loadings for the Q-sorts, such that those Q-sorts that load higher on the factor are given more weight. The factor weight is then multiplied by the raw scores (i.e. item placement on hierarchy) and then summed across items. The summed scores are then converted to *Z*-scores to normalise these values. Finally, the *Z*-scores are used to establish the ranking of the statements such that they can be re-placed on the hierarchy. This procedure generates an exemplar Q-sort hierarchy for each factor, which is then interpreted. Each exemplar Q-sort is an amalgamation of the perspectives of the participants who loaded on that factor. Thus it does not represent one individual's view, but an understanding of dying well that was common to each group. The exemplars are shown at the beginning of the next four chapters, and are also available in envelopes in Appendix Q.

The result of this final factor solution was four factors that represent four distinct accounts of dying well. An examination of the placement of the statements in the exemplar accounts indicated that each account had a different focus. These accounts were therefore labelled in accordance with their focus: religious-oriented, independent-oriented, idealised, and family-oriented. In the following section, a brief synopsis of each account or factor is given as an orientation to the more detailed analysis of each account that follows.

Comparisons across factors are made on the basis of additional tables produced by PQMethod that help elaborate the relationships between the accounts. These include a descending array of differences table (see Appendix R), and tables of consensus and distinguishing statements (see Appendix S). Consensus statements are those that do not distinguish between accounts, and distinguishing statements are those that do. Only one statement, *that hospice staff are supportive*, did not distinguish between accounts. It was rated 5, 6, 5, 6 in accounts one to four respectively. This suggests that participants uniformly agreed that the hospice staff are moderately important in their various understandings of dying well.

Several distinguishing statements were apparent for each of the accounts. There were 56 distinguishing statements in total. A full table in Appendix S shows the distinguishing statements of each factor in terms of both placement on the hierarchy and Z-scores. The distinguishing statements will be discussed in detail with the individual accounts they relate to.

Account Synopses

A brief synopsis of the four different accounts is outlined below.

Factor 1 - Religious-oriented account of dying well

The pattern of the statements in this account reflects a religious orientation to dying well. The high ratings of three items explicitly related to religious components of dying, convey the core religious focus. Comments from participants further enhanced this understanding, in particular, participants verbalising the importance of religion in their life and their dying.

Other statements, that did not have an obvious religious focus, could be interpreted in a way that tied in with participants' religious beliefs. This religious interpretation related particularly to statements regarding achievement, love, meaning in life, and being ready to die. Faith in the fact that God will provide was also evident in the placement of statements reflecting personal control at the least important end of the hierarchy. The pattern of statements also follows a broadly religious view that God comes before family, who come before the individual.

Factor 2 - Independent-oriented account of dying well

This account represents an understanding that focuses on independence, control, and normality. Humour and making the most of every day were highly rated and reflect a need to maintain a sense of normality in what can be a turbulent situation. In much the same way that the religious account placed God before all else, humour was seen to be the "starting point for everything else". Furthermore there was evidence of a strong desire to avoid dependence on others, and to establish continued control in the face of change.

Control had a variety of manifestations in this account. Personal control reflected a sense of being in control of one's self in an inner sense, but was also sought through treatment decisions. Control also had a social component and was invoked by the participants when they felt the need to protect others. Whilst personal control, decisional control, and social control all refer to the present, control was also sought over the future via the funeral arrangements and financial planning. In addition, those statements that were regarded as representing ideas beyond an individual's control were rated as least important. These three foci, normality, independence, and control, provide a pattern of understanding of dying well for the participants in this group.

Factor 3 - Idealised account of dying well

The pattern of statements in this account creates an idealised and sanitised account of dying well. In combination, the highly rated statements present a somewhat unrealistic notion of dying that perhaps reflect the modern media's portrayals of death. Passivity underlies the idealism present in this account.

At the least important end of the hierarchy the statements support a death denying position. The placement endorses the position that the illness is not life threatening. In addition, *maintaining hope*, which was rated highly, further supports the idea that death is not considered imminent. Not accepting impending death allows for the fostering of a more idealised notion of what is to come. Despite denial, there is a passive acceptance of one's lot and a futility about trying to change things, that gives this account a compliant quality.

Factor 4 - Family-oriented account of dying well

The final statement configuration emphasises the importance of family to the dying patient. Several family-related statements were rated in the most important category. Together these statements form a comprehensive picture of the extent to which family is paramount, and of their role in not only the support of the individual but also their active role in the participant's dying process.

In this account, several other statements were reinterpreted in light of the family focus. Consideration was given to planning for funerals and finances as these had potential repercussions on family if not adequately managed. Similarly, dying at home took on a specific focus in terms of its potential impact on family.

The assortment of statements at the least important end also supported the notion of family importance. Family is given preference over the individual's needs, and there was a desire to share circumstances with the family rather than suppress things. However, participants constantly sought to minimise any negative impact or burden that might be placed on family.

I am ready to meet my Maker. Whether my maker is prepared for the great ordeal of meeting me is another matter.

Winston Churchill

Chapter 8:

Religious-oriented Account of Dying Well

Most Important				Quite Important				Least Important
that I have a strong faith in God 32	that I have the support of my family 12	that my death is peaceful 11	that I receive physical contact from my family 13	that I have my financial affairs in order 26	that I maintain hope 36	that I receive support from people other than family and friends 6	that my family sometimes keep their feelings to themselves 40	that I don't look ill 5
that I know where I am going after this life 8	that I have been loved 30	that my physical pain is managed 17	that at the time of my death I have my family around me 25	that hospice staff are supportive 21	that I have my funeral organised 14	that I have a say in what the hospice tells my family 15	that I die at home 22	that I try unconventional treatments 27
	that I have people praying for me 39	that at the time of my death I am ready to die 29	that I maintain my dignity 9	that I maintain my sense of humour 37	that my physical symptoms (besides pain) are controlled 34	that I have time just for me 35	that I keep some things to myself 24	
		that I feel like I have achieved something in life 18	that I feel like my life has meaning 33	that during my illness my family get on with their own lives 31	that conflict within my family is resolved 23	that I will not be forgotten 16		
		that my family will be okay emotionally after my death 7	that I have discussed what I want for my death with my family 19	that I have good friends around 28	that I feel in control 10	that I am given a timeframe 20		
			that I make the most of every day 4	that my level of medication allows me to still communicate 38	that I make my own decisions about whether or not to have treatment 3			
				that I have time to come to terms with my illness 1				
				that I avoid becoming totally dependent on others 2				

Figure 6: Q-sort Exemplar for the Religious-oriented Account

The arrangement of statements in this account (shown in Figure 6) reflects a religious orientation to the experience of dying well. Three top rating statements in this account were: *that I have a strong faith in God, that I know where I am going after this life,* and *that I have people praying for me* (hereafter collectively referred to as the religious items). The high ratings of these three items reflect a core religious focus. One participant stated "that I have a strong faith in God, that's got to go here [top position], otherwise the rest falls to pieces" [66][7] and this belief was strongly echoed throughout this group. Another stated, "[what you] experience, that's based on your faith position, you've got to have that because that's the basis on which you can have an outlook" [51], and, "if I toss him [God] away, I toss the rest of my spiritual side away [77].

Some other statements were also interpreted by the participant in light of their religious beliefs. Another highly rated statement was *that I have been loved.* Those within this group commonly stated that this meant to them being loved by God, as well as by family. For example, "it is most important that I have been loved by God, and I know I am continually, but though all my friends desert me, it doesn't matter because I am loved by God, you see" [51]. In addition, *feeling like I have achieved something* was seen as achieving what God had intended you to achieve. One participant stated:

> *I didn't want to die with just business consultant after my name. . . . I didn't want to go to the pearly gates and say, well, I've been a business consultant God. Oh yeah, big deal. I wanted my life in this world to mean things for the kingdom of God . . . For me, God-centred life, it's most important that I do things that are focused on what God's purpose for us in this life is.* [51]

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[7] The numbers in square brackets denote the interviewee's identification number.

Later, he continued by saying, "to have achieved something is for God to say, well done, good faithful servant" [51]. Similarly, in relation to the statement regarding meaning in life, the same participant said: "to me, outside of God, life doesn't really have meaning" [51]. Thus although many statements did not refer directly to religion, they were interpreted by the participants in this group in a way that reflected their core underlying beliefs about religion and its role in influencing the dying process.

Faith is a core value fundamental to a religious system. It is obviously apparent in the placement of the statement *that I have a strong faith in God* at the most important end but is also apparent in the position of other statements. Faith in God, that God will provide, that God has a plan for one's life, etc, seems to encourage a somewhat obedient acceptance of the situation, or yielding to God's will. This is demonstrated through the only modest amount of importance placed upon statements that reflect control, such as *I feel in control, I am given a timeframe, I have my funeral organised, I make my own decisions about treatment,* and *I try unconventional treatments.* Being given a timeframe was unimportant because, in this account, only God knows what timeframe an individual has. For example,

> *if I have a timeframe, all I am trying to do is beat the odds . . . my time frame says three score and ten. Anything less than that is less than what we've been apportioned in this world [51].*

Faith implies an externalisation of control, such that the individual yields control to a source outside of themselves, God. Whilst there may have previously been a desire for some control (thus the *I feel in control* statement is at the low end of quite important), it has been ultimately yielded to God, and no further action is taken towards control of the circumstances of the dying. This also allows the individual not to worry about the future. Matthew 6:25

states “therefore I tell you, do not worry about your life, what you will eat or drink; or about your body, . . . who of you by worrying can add a single hour to his life . . . Therefore do not worry about tomorrow, for tomorrow will worry about itself. Each day has enough trouble of its own” (New International Version).

One participant, in talking about his placement of unconventional treatments at the least important end, stated that “unless God gives us any other direction, to put our confidence in what the medical staff do, on that side, and on the other side, fully have our confidence in the promises of God” [51]. This faith or yielding to God’s will is a core value that is deeply embedded in the Christian religious value structure. For example, “now fear the Lord and serve him with all faithfulness. Throw away the gods your forefathers worshiped beyond the River and in Egypt, and serve the Lord” (Joshua 24:14, New International Version). Thus the placement of the statements that reflect control at the least important end of the hierarchy endorse yielding to God’s will.

Trying unconventional treatments was universally rated in the bottom third of the hierarchy, with the religious account ranking it lowest at 9, and the remaining three rating it 7, 7, and 8 respectively. Despite their similar rankings, the religious account’s placement of this statement is still statistically significantly different from the remaining accounts. This endorses the idea that control is not sought in this account as it is in the others.

In this account, *knowing where you are going after this life* was rated as very important, as already mentioned. Also rated as important was *that I am ready to die*. There is a recognition in Christian beliefs of the importance of death as an integral part of life. For example, "Furthermore, tell the people, 'This is what the Lord says: See, I am setting before you the way of life and the way of death” (Jeremiah 21:8, New International Version).

However, the knowledge that one is dying and moving on to somewhere "better" provides reassurance to these participants about their future. One participant stated: "doing things as God would have them done, so when you come to the end you can look forward" [57]. Such reassurance may encourage a readiness to die because it does not mean an end to life as much as a new beginning in a better life. In addition, there is some reassurance to be found in the idea that one's death and one's life are in God's hands, "what will be, will be" [84]. Another participant stated "I have got my religion which means a lot to me and therefore I have certainly not been afraid of dying" [58]. Readiness to die and fear of dying, however are slightly different ideas. Perhaps unsurprisingly, the religious items received quite different rankings in the remaining three accounts, as shown in Table 6[8].

Table 6

Rankings for Three Distinguishing Statements for the Religious Account

		Account[9]			
No.	Statement	1	2	3	4
8	that I know where I am going after this life	**1**	9	7	9
32	that I have a strong faith in God	**1**	8	6	5
39	that I have people praying for me	**2**	8	5	7

Accounts two, three and four all rate these items as less important, and the independent account most strongly so. This generally reflects the different emphases of the accounts. In particular for the independent account, the relative importance of control resulted in a lack of endorsement of the religious (i.e. unable to be controlled) items. These lower rankings in the other three accounts do not necessarily indicate a lack of religious beliefs, however they do relate to a *relative* lack of importance placed upon religious items. Within those endorsing the religious account, there was a sympathy, and sometimes condescension, towards those

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[8] The numbers in the table represent the column in which the statement was placed. Thus, columns 1 - 3 were rated most important, 4 - 6 quite important, and 7 to 9 least important.

[9] Account 1 = Religious-oriented, Account 2 = Independent-oriented, Account 3 = Idealised, Account 4 = Family-oriented.

who did not have a faith. As one woman eloquently put it, "well, if anyone doesn't believe in anything it will be just like going to bury a cow or something else" [68].

The pattern of the religious-oriented account was not simply a support of the religious items. Endorsing religious beliefs carries with it a number of other core values. A traditional Christian value system emphasises the relative importance of God, family and self. God comes first, followed by family, followed by the self. The way in which the Ten Commandments are written indicates this focus with the first commandments addressing the importance of God, followed by commandments related to family, and finally commandments reflecting the role of the individual. This value system was apparent in this account in a number of ways. Once the religious items were accounted for, the focus was the importance of family (*support of the family, family emotionally okay after death, having family around at the time of the death, physical contact from their family, discussing death with their family*). This was followed by more individualistic statements (*my pain is managed, I die with dignity, I make most of every day*). Thus it could be argued that the ordering of the statements in terms of religion, family and self, reflected a traditional Christian value system.

This differential valuing of God, family and the individual was also apparent in those statements that were rated as least important. The lack of importance placed on the individual *keeping some things to themselves*, and *having a say in what the hospice tells family*, and the family *keeping emotions to themselves*, gives a sense that the individual wants to have the family involved and doesn't want anything to be hidden from them.

Occasionally there was also a sense in these accounts that if the "correct" order was not followed, such that the individual put themselves before others, that this was breaking some moral code, and the participant felt some guilt, and with that, shame. One participant stated:

"this is a selfish one, that my physical pain is managed" [84]. Another offered an interesting, and more elaborate, discussion of the same statement:

> *that my pain is managed, I am afraid that's, that shows you how selfish I am . . . personal or physical pain, I am the only one who is going to benefit from that. That, in effect, might not be true because I behave better, which can save embarrassment.* [66]

It is likely that *I don't look ill*, under the religious pattern of responding, ties in with the pride - an individualistic idea. Being concerned with one's appearance is considered vain, and a sin in many religious systems, and it also places undue importance on the self. For example, the Bible states "when pride comes, then comes disgrace, but with humility comes wisdom" (Psalms, 11:2, New International Version).

Individualistic statements such as *having time just for me,* and *keeping some things to myself* were also rated relatively low reflecting the lack of importance placed on these more solitary aspects of a good death. Thus, this pattern of placement of the statements suggests not simply a focus on God, but also a belief in the core values of the individual's religious system.

The account created by these participants seems to reflect an understanding of dying well that has, at its core, a focus on religious values. This is reflected both in the placement of religious-oriented statements at the most important end, and in the interpretation of other statements in a way that supported the underlying religious beliefs. In addition, the ordering of statements in terms of God, family and self, endorses a particular religious value belief. Self statements, particularly those about control, were rated as less important, and when spoken about included guilt and shame about feeling selfish. Furthermore, there appeared to be a yielding acceptance or lack of desire for control over the circumstances of dying well, this was however, in the context of God having a plan for them. Finally, reassurance is to be found in faith, in faith in God's plans, and faith in the idea that one is moving on to a better place.

When I prepare for a journey I prepare as though for death. Should I never return, all is in order. This is what life has taught me.

Katherine Mansfield

Chapter 9:

Independent-oriented Account of Dying Well

Most Important				Quite Important				Least Important
that I maintain my sense of humour 37	that I avoid becoming totally dependent on others 2	that I feel in control 10	that I have my financial affairs in order 26	that I have discussed what I want for my death with my family 19	that I have time just for me 35	that I don't look ill 5	that I have been loved 30	that I know where I am going after this life 8
that I maintain my dignity 9	that my physical pain is managed 17	that my level of medication allows me to still communicate 38	that my physical symptoms (besides pain) are controlled 34	that I maintain hope 36	that I am given a timeframe 20	that at the time of my death I have my family around me 25	that I have people praying for me 39	that I will not be forgotten 16
	that I make my own decisions about whether or not to have treatment 3	that my death is peaceful 11	that I have my funeral organised 14	that I receive physical contact from my family 13	that conflict within my family is resolved 23	that I die at home 22	that I have a strong faith in God 32	
		that I make the most of every day 4	that I have the support of my family 12	that at the time of my death I am ready to die 29	that I feel like I have achieved something in life 18	that I try unconventional treatments 27		
		that during my illness my family get on with their own lives 31	that I have time to come to terms with my illness 1	that my family will be okay emotionally after my death 7	that I feel like my life has meaning 33	that my family sometimes keep their feelings to themselves 40		
			that hospice staff are supportive 21	that I keep some things to myself 24	that I receive support from people other than family and friends 6			
				that I have a say in what the hospice tells my family 15				
				that I have good friends around 28				

Figure 7: Q-sort Exemplar for the Independent-oriented Account

This account (as shown in Figure 7) represents an understanding of dying well that combines emphases on independence, control, and normality. Participants who produced this account desire to maintain control over the circumstances of their dying, maintain their independence and self-reliance, all within the context of establishing, and maintaining, a sense or normality and predictability. These three foci seem closely linked.

Maintaining a sense of humour was the most highly rated statement in this account. In much the same way as in the religious account, one participant stated that humour was the "starting point for everything else" [64]. Another, somewhat more emphatically, stated, "if you haven't got that then you might as well be bloody dead . . . [humour] is the most important thing in life" [73]. Maintaining humour seemed to allow participants to retain a sense of normality, which may relate to issues of control. Maintaining normality where things still vary but in a predictable way, allows for the feeling of control in that all is predictable. Humour begets normality, normality begets predictability, and predictability begets perceived control. Control and normality can seem unachievable in the context of the unpredictability of terminal illness and death.

Despite the obvious context of terminal illness, in the top ten statements (including humour) only one explicitly refers to death - *that my death is peaceful.* There is a sense in the remaining statements, not that there is a denial of death, but that things should continue just as they always have. For example, one woman stated: "you just get on with doing what has to be done" [52]. This sense of maintaining normality permeates this account and seems to contextualise independence and control.

Statements relating to maintaining independence (*avoid becoming dependent on others, maintain my dignity*) and continued control (*I feel in control, I make my own decisions about* *treatment,* and *my level of medication still allows me to communicate*) were rated as most important in this account. Maintaining independence was frequently mentioned by the participants during the sorting exercise. One participant stated, "that I avoid [becoming dependent on others] that's my dread, of relying on others" [73]. Another explains the relationship between dignity and independence by suggesting that "people that can see to themselves will die with dignity" [73].

Control was manifested in a number of ways. First, personal control, through the statement *I feel in control*, was rated highly and commonly mentioned during the meeting. For example, one man said, "yes, I feel in control. If I don't want a bloody thing, I just don't have it" [73]. The strength of this belief in control is particularly well demonstrated when considering the responses on the other accounts (see Table 7).

Table 7

Rankings for Several Distinguishing Statements for the Idealised Account

		Account[10]			
No.	Statement	1	2	3	4
17	that my physical pain is managed	3	**2**	3	4
2	that I avoid becoming totally dependent on others	5	**2**	5	6
3	that I make my own decisions about whether or not to have treatment	6	**2**	5	6
4	that I make the most of every day	4	**3**	1	5
10	that I feel in control	6	**3**	5	5
24	that I keep some things to myself	8	**5**	8	9
12	that I have the support of my family	2	**4**	2	1

Higher ratings on the first six statements show the core focus on control that distinguishes the independent account from other accounts. Despite the moderate rating of keeping things to oneself, it is still significantly higher than the scores on the remaining three accounts. The seventh statement relates to family and is noticeably lower than the other three, again suggesting a core independent focus.

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[10] Account 1 = Religious-oriented, Account 2 = Independent-oriented, Account 3 = Idealised, Account 4 = Family-oriented.

Having control over treatment decisions was also placed at the most important end of the hierarchy. One participant said, "that I make my own decision about whether or not to have treatment, I have already told them they are not electrifying me" [56], where "electrifying" (one assumes) refers to receiving radiation therapy. Another stated, "these pills are just to ease the pain, so I take them and I make my own decisions about whether I take them" [73]. Yet another stated that she didn't want anyone "rushing off and making decisions on my behalf" [90]. Personal control and control over decision-making were most important to members of this group.

Control is not, however, limited in its effect to personal control and decision making. Many participants actively chose control in order to prevent suffering in others. One participant, in reference to *keeping some things to myself* which was rated as quite important, said "I didn't tell her [about the doctor's appointment], well, I didn't want her worrying" [56]. In this way he felt he was protecting his wife from potential bad news. However, this also means he is able to control the situation, and, almost by default, her reactions to it. In a similar way, the placement of the statement *that during my illness my family get on with their own lives* in the top ten most important, suggests both independence and control. This statement was often followed by comments such as "I don't want them making a fuss over me, I want them to treat me as I am" [73] here, the participant wants to maintain his independence, and sense of normality, but also to encourage his family to continue their lives as normal.

Issues of control also extended beyond the here and now. *That I have my funeral organised* and *that I have my financial affairs in order* were rated relatively high in this account. This reflected not only the desire to have control over the current circumstances, but also to protect the family from financial problems in the future, from the family having to deal with organising the funeral, and also to have some control over what happened after their death. In terms of controlling after-death events, one participant stated:

> *I was doing all the technical, you know, writing down all the bits and pieces, making arrangements like pre-paid funerals, and all that sort of thing. Who was to be there, who wasn't to be there, who was to get cups of tea, and who was to get a glass of whiskey [52].*

Controlling circumstances was also reflected in "I live by myself so there is no point hoping that someone else will organise it for me the way I want it done, if I haven't left them any running instructions" [52]. Another participant, realising the financial burden of his funeral, suggested to his wife that she "borrow one of me mates [to help "cart him off" to the crematorium], and when you're having the after do, say, this is what Bob[11] wants, put it on the tab, have a pint" [56]. Having everything in order was important to another participant who stated, "I am a very independent person, so it means I have left no hassles behind" [89].

Making the most of every day seems to imply a situational control. The individual attempts to maintain control over the situation by making the most of every day. In this way an individual can feel as if they are in control and not their disease, which can also allow for a sense of normality. One participant stated, "I have still got a lot to do and a lot to think about, so I really don't spend all that much time worrying about me at all" [52].

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[11] Not his real name

Participants had clear notions of what they could and could not control. The statements that were rated as least important were often statements that the individual felt unable to exert control over. For example, *that I have people praying for me*, participants acknowledged that they had limited control over other's behaviour, so they did not try and obtain control. One participant stated, "I don't really need people praying for me, but if they want to, well, that would be kind of them I guess" [81]. Also in relation to family, another participant said, "it's the family's responsibility to be emotionally okay, "they have to learn to cope with that themselves" [64]. In relation to *looking ill*, another participant said, "I've got cancer and I'm deteriorating, but there's nothing we can do about it" [70].

Many of the statements were employed to reflect different ways of feeling in control. However, a sense of fatalism was also apparent in this account.

Another statement, *that I will not be forgotten*, produced some quite strong statements from participants. These included: "who cares if you are forgotten or not, you have made the impression you want, and if people remember you they will, and if they don't, they don't" [81], and "I know bloody well on past experience that you are forgotten two days after [73]. In terms of those things that participants felt powerless to control, there is a sense of fatalism, as might be expected.

This fatalism was also reflected in broader terms by members of this group. One participant stated, "if I had a choice I wouldn't choose to die right in the near future, I would choose it in the distant future. But I haven't got that choice so you just get on with it" [81]. Another said:

> *So why worry, I mean, we know there is no cure for it, so get on with it is the best you can do, that's all you can do really. There is no cure for it, so there's no point jumping up and down about it is there. The wife had a little howlybag*

> *but I said don't worry love, I'm not ready to cark it yet. You ain't got rid of me yet.* [56]

Still another, quite succinctly, stated, "I don't give a bugger where I die, I will just die" [73]. This fatalism does not come with a sense of giving up on life, just that things will be calmly dealt with as they arise.

Other statements that were rated as least important included: *that I have been loved, that I have a strong faith in God,* and *that I know where I am going after this life*. In addition to being statements that have an uncontrollable quality, they also reflect a lack of importance of the role of religion. However, it is important to recognise that this does not necessarily mean the participants in this group had no faith. In fact, some participants acknowledged having religious beliefs, but these were less important to them in terms of their understanding of dying well. Furthermore some of these individuals had spiritual and other-religious beliefs. One woman stated: "I am a bit in the Buddhist line, you take each day and you do the very best you can and then you take tomorrow because there might not be tomorrow" [81].

The ideas of independence, control, and normality seem highly linked. If one is able to maintain control over the situation then independence can also be managed, which can encourage a feeling of normality. The issue of control manifested in a variety of ways, including personal control, control over treatment, control over others, relinquishing control, and control beyond the time of death. Control appeared to be the core feature that allowed the individual to maintain their independence and their sense of normality. This account provides a strong contrast to the religious account identified earlier.

It's not that I'm afraid to die. I just don't want to be there when it happens.

Woody Allen
Without Feathers, "Death (A Play)"

Chapter 10:

Idealised Account of Dying Well

Most Important				Quite Important				Least Important
that I make the most of every day 4	that at the time of my death I have my family around me 25	that my level of medication allows me to still communicate 38	that I have good friends around 28	that hospice staff are supportive 21	that I receive physical contact from my family 13	that I try unconventional treatments 27	that I keep some things to myself 24	that I have my funeral organised 14
that I have been loved 30	that I maintain my sense of humour 37	that I maintain hope 36	that I receive support from people other than family and friends 6	that I have people praying for me 39	that I have discussed what I want for my death with my family 19	that I am given a timeframe 20	that I have time just for me 35	that I don't look ill 5
	that I have the support of my family 12	that my physical pain is managed 17	that my physical symptoms (besides pain) are controlled 34	that I feel in control 10	that my family sometimes keep their feelings to themselves 40	that I die at home 22	that I have my financial affairs in order 26	
		that I will not be forgotten 16	that I feel like my life has meaning 33	that I avoid becoming totally dependent on others 2	that I have a say in what the hospice tells my family 15	that I know where I am going after this life 8		
		that my death is peaceful 11	that I feel like I have achieved something in life 18	that my family will be okay emotionally after my death 7	that I have a strong faith in God 32	that I have time to come to terms with my illness 1		
			that during my illness my family get on with their own lives 31	that at the time of my death I am ready to die 29	that I maintain my dignity 9			
				that I make my own decisions about whether or not to have treatment 3				
				that conflict within my family is resolved 23				

Figure 8: Q-sort Exemplar for the Idealised Account

The arrangement of statements in this account (as shown in Figure 8) seem to reflect an idealised account of dying well. There is a sense of passivity that underlies the idealistic nature of what is sought within the dying experience. Add to this combination a sense of denial, apparent in the least important statements, and the understanding of this account becomes more complex.

One of the difficulties with this account is the lack of available additional information from the interviews themselves. Three reasons might explain this. Firstly, as a group, I felt I established the least rapport with these individuals, which therefore did not facilitate a great deal of discussion around the statements. Secondly, this group seemed to be denying the life-threatening nature of their illnesses, and thus, a researcher, asking them about something they are denying may not encourage lengthy discussion. Thirdly, at least three of the seven participants made comments that suggested they were doing this task for the Medical Director, because he had asked, and another one had been involved in research in her career, and seemed to feel it was her "duty". This context, too, did not facilitate discussion. Notwithstanding the lack of additional comments available, there was still an interpretable pattern in the placement of the statements that deserved elucidation.

The overall impression of this account is one of an idealistic dying experience. The top ten statements include *making the most of every day, having been loved, family around at time of death, sense of humour, family support, maintain hope, pain managed, peaceful,* and *not forgotten.* In combination, these statements promote a picture of dying that reflects modem media portrayals. There is a romantic quality to this account, romantic in the sense that it seems to be based on mistaken notions of the dying process.

In some ways, this account presents a blending of two of the other accounts - independence and family, as both control-related ideas and family feature strongly. Mutually highly rated statements are shown in Table 8.

Table 8

Rankings for Top Ten Statements for the Idealised Account Compared with the Independent and Family Accounts

		Account[12]		
No.	Statement	2	3	4
4	that I make the most of every day	3	1	
30	that I have been loved		1	3
25	that at the time of my death I have my family around me		2	2
37	that I maintain my sense of humour	1	2	
12	that I have the support of my family		2	1
38	that my level of medication allows me to still communicate	3	3	
36	that I maintain hope		3	
17	that my physical pain is managed	2	3	
16	that I will not be forgotten		3	
11	that my death is peaceful	3	3	1

This table clearly shows the combination of the high-ranking statements on the independent and family accounts that the idealised account also endorses. In addition, the pattern of differences between the family and independent accounts is also evident. Where the independent account has highly endorsed a statement (i.e. items 4, 37, 38, and 17) the family account has not, and vice versa for the family account (i.e. items 30, 25 and 12).

Despite the relative similarities of these accounts in terms of endorsing similar highly rated statements, adding in *that I have been loved, that I will not be forgotten,* and *that I maintain hope*, causes the balance to shift in the idealised account to create a more unrealistic quality to this understanding. This unrealistic quality also gives this account an impractical feel.

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[12] Account 2 = Independent-oriented, Account 3 = Idealised, Account 4 = Family-oriented.

There is no desire to manage the practical matters surrounding the illness, but instead a desire for several intangible qualities. Distinguishing statements, as shown in Table 9, also serve to highlight the apparent practicalities of the independent account with the impracticality of the idealised.

Table 9

Rankings for Several Statements for the Independent and Idealised Accounts

		Account[13]	
No.	Statement	2	3
30	that I have been loved	8	1
16	that I will not be forgotten	9	3
36	that I maintain hope	5	3
9	that I maintain my dignity	1	6
26	that I have my financial affairs in order	4	8
14	that I have my funeral organised	4	9

These rankings show the disparity between the two accounts in terms of the intangible nature of the first three statements, all strongly desired by the idealised account. Conversely, lack of importance is placed upon the remaining three statements that are all more practically focussed.

In addition to the idealised notions in the statements rated most important, there is a death denial apparent in the statements rated least important. In particular, rating items such as, *that I have my funeral organised*, *that I have my finances in order*, *that I have come to terms with my illness*, and *that I am given a time frame*, as least important, implies a lack of preparation for death, and endorses the denial that the illness is life threatening. Also statements such as, *that I have time just for me*, *that I keep some things to myself*, and *that I die at home*, also support a death denying position. If the individual is denying death, there is no or minimal desire to consider where might be an appropriate place to die, or whether

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[13] Account 2 = Independent-oriented, Account 3 = Idealised.

time alone is needed. In addition, *maintaining hope*, which was rated highly, further supports the idea that death was not perceived as imminent in this account. This pattem of denial at the low end lends support to the idealised notion at the other. Being in a position of denial allows the idealised notion to be fostered.

Again, distinguishing statements are useful in considering the concept of denial, as shown in Table 10.

Table 10

Rankings for Several Distinguishing Statements for the Idealised Account

		Account[14]			
No.	Statement	1	2	3	4
1	that I have time to come to terms with my illness	5	4	7	4
36	that I maintain hope	6	5	3	7
19	that I have discussed what I want for my death with my family	4	5	6	2
26	that I have my financial affairs in order	5	4	8	3
14	that I have my funeral organised	6	4	9	2

Accounts one, two and four show a moderate amount of interest in coming to terms with one's illness, but for the idealised account this is rated in the least important category. In the remaining statements the other three accounts show a desire to manage the circumstances of their situation, a desire not shown in the placement of the statements in the idealised account. This supports the idea that this account is endorsing denial.

Despite the fact that this account appears to be death denying, there is a stoic acceptance of ill health. Accepting ill health is manageable, accepting a terminal diagnosis is not. One participant spoke of "getting on with life to what my quality of life is now" [55] whilst another spoke of "focusing on living and not anticipating dying" [69]. There is also evidence of acceptance. For example, "I haven't got any chance of not becoming [dependent]" [54] with

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[14] Account 1 = Religious-oriented, Account 2 = Independent-oriented, Account 3 = Idealised, Account 4 = Family-oriented.

respect to self, and “they haven’t got much choice have they” [54] with regard to family, and them being emotionally okay after his death. Another stated, “I can’t feel in control when I am supping medicines all day” [88].

A great deal has been written about denial in the context of terminal illness, much of it stemming from Elisabeth Kübler-Ross’ (1969) work on the stages of dying. Denial is the first stage in her account, and it often occurs immediately after a diagnosis, and is a reaction to the threat to one’s mortality. Kübler-Ross’ work has been heavily critiqued (for a summary see Samarel, 1995, and Kastenbaum, 1975), and although regarded as the cornerstone of death and dying research, its oversimplification has meant some aspects of her theory have been lost.

Other important authors have also looked at the role of denial, including Avery Weisman (1972). He has noted that the term denial “now covers almost any situation, act, or verbal expression in which anyone seeks to “avoid reality”, or to escape confrontation with something unpleasant and alarming” (1972, p. 58). He has developed a notion of denial as a social act, where its purpose “is not simply to avoid danger, but to prevent loss of a significant relationship” (p. 63). It is not possible to see denial being used in this way in the idealised account, particularly as the discussion was so scant, but Weisman’s elucidation of “orders” of denial is of use here. Denying the facts of one’s illness is called first order denial. This can often occur pre-diagnosis when illness symptoms are minimised in favour of a lesser degree of illness. Denying the potential implications of one’s illness, having now accepted the facts, is second order denial. Inappropriate plans for a particularly positive future may be made on the basis that their treatment has been “successful”, i.e. extensively life extending. Third order denial is “denial of extinction . . . [which] resembles inability to imagine personal death” (1972, p. 73).

In the idealised account it appears that the participants may well be experiencing second order denial, in that they recognise and accept the nature of their illness but they fail to assimilate this information in a meaningful way that allows them to appreciate the implications of their diagnosis, that is, that they will die. In this way they can maintain hope, and create an account that seems ungrounded in diagnostic reality. 'Denial', as a concept, has developed strong negative qualities, particularly in its association with acceptance, Kübler-Ross' ultimate stage. However, Weisman (1972), and Beilen (1981-82) argue that, due to the social role it performs, denial may be in fact a healthy response. Weisman suggests, "[d]enial helps to maintain a simplified, yet constant relationship with significant others, especially at the moment of crisis" (1972, p. 65). This assists the person in maintaining the status quo, and a sense of normality.

Renowned sociologists Glaser and Strauss (1966) carried out research in the area of awareness of dying. They established four types of awareness: closed (where everyone[15] knows the patient is dying, except the patient); suspected (everyone knows and the patient suspects); mutual pretence (everyone knows but acts as if they do not); and open (everyone knows and everyone discusses it). Of interest here is what Glaser and Strauss (1966) have called "the ritual drama of mutual pretence". There is a sense that if everyone is aware that the patient is dying, including the patient, and everyone acts as if they do not know, then normality, in terms of "normal" interactions, is maintained. This idea seems to fit more neatly here with the idealised account, where normality is somewhat apparent, than with the independent account, where normality has a much stronger focus. These accounts seem to differ in terms of the application of or approach to normality. In the independent account, normality is framed by a desire for control while change is undesirable in that participants

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[15] everyone is the staff, family and the patient

may then feel out of control. Contrast this to the idealised account where normality is essentially a by-product of denying that anything is wrong. This seems more suited to the idea of mutual pretence, denial is rarely challenged, and therefore staff and family are encouraged to support the patient's denial. Given the hospice movement's emphasis on open awareness, one might have expected that mutual pretence had become a thing of the past, however, it seems possible that it is still relevant today.

In the idealised account, there is also a desire for acceptance of the self, within the context of illness. One woman stated:

> *some days I don't feel quite so good, but it just so that people can accept, a bag of bones as I call myself, and I can still laugh and joke and things like that. You know, it's how people accept you. I haven't had ones that have shunned away from me or anything like that. It's little things like that that are important, yes. They will accept you. I am my own person, I am still here, I'm still able to talk and communicate [55].*

Within this excerpt, and this account, there is also a desire for normality. Maintaining normality, in this account, repudiates the ability to come to terms with one's illness. This maintenance of normality contrasts with the 'change' focus of the religious and family accounts.

This account presents an understanding of dying well that seems idealised. Denial of the terminal nature of the illness is apparent, and attempts made to maintain a sense of normality. There is evidence of passive acceptance of the situation of ill health, and a desire for acceptance of the self within this context. Although this account is described in terms of "idealised" and "romantic", words that often assume negative connotations, this account need not be seen as negative. Rather, it should be seen, like the other accounts, as a way of understanding dying well for someone who has received a terminal diagnosis.

When I am dead, my dearest,
Sing no sad songs for me;
Plant thou no roses at my head,
Nor shady cypress tree:
Be the green grass above me
With showers and dewdrops wet;
And if thou wilt, remember,
And if thou wilt, forget.

Christina Rossetti
(1830 - 1874)
When I am Dead

Chapter 11:

Family-oriented Account of Dying Well

Most Important				Quite Important				Least Important
that I have the support of my family 12	that I have my funeral organised 14	that my family will be okay emotionally after my death 7	that I will not be forgotten 16	that my level of medication allows me to still communicate 38	that I am given a timeframe 20	that I maintain hope 36	that I try unconventional treatments 27	that I keep some things to myself 24
that my death is peaceful 11	that at the time of my death I have my family around me 25	that I receive physical contact from my family 13	that I maintain my sense of humour 37	that at the time of my death I am ready to die 29	that I feel like I have achieved something in life 18	that I have good friends around 28	that I don't look ill 5	that I know where I am going after this life 8
	that I have discussed what I want for my death with my family 19	that I maintain my dignity 9	that my physical pain is managed 17	that I feel in control 10	that I avoid becoming totally dependent on others 2	that my family sometimes keep their feelings to themselves 40	that I feel like my life has meaning 33	
		that I have been loved 30	that hospice staff are supportive 21	that during my illness my family get on with their own lives 31	that I die at home 22	that I have people praying for me 39		
		that I have my financial affairs in order 26	that I have time to come to terms with my illness 1	that I have a say in what the hospice tells my family 15	that I make my own decisions about whether or not to have treatment 3	that conflict within my family is resolved 23		
			that I receive support from people other than family and friends 6	that I make the most of every day 4	that my physical symptoms (besides pain) are controlled 34			
				that I have a strong faith in God 32				
				that I have time just for me 35				

Figure 9: Q-sort Exemplar for the Family-oriented Account

This account (shown in Figure 9) focuses on the importance of family to the dying patient. Here, family forms the foundation upon which the rest of the structure is built. Personal statements become contextualised by, and related to, their impact on the family rather than, necessarily, viewed in terms of personal significance. Family is everything in this account.

Having the support of family was the top ranking statement in this account. Four additional statements supported this family focus: *having family around at the time of death, discussing my death with family, receiving physical contact from family,* and *family being emotionally okay after my death.* Together these statements form a comprehensive picture of the importance of the family, who not only support the individual but also play an active role in the process. One participant stated that he "would rather have family around than friends" [86, field notes]. Another noted the importance of reconnecting with family at this time. She said: "there has been a lot of reorganising [of] the family for us, it has been wonderful. *Researcher* - in what way? *Interviewee* - I found a sister that I hadn't had contact with in a long while . . . it has been a very healing time" [82].

Support from family was often displayed in very tangible ways, such as when grown up children returned from overseas in order to be with the dying person. For example, "our son [who had not been home for nearly 10 years] came out from England, he brought our grandchildren and stayed for three months" [59]. This participant's wife also noted the positive health benefits for her husband associated with their son returning home. Her husband had been particularly unwell just prior to their son's arrival, but his health had improved markedly once their son and his family arrived [59].

Several other statements were rated as important in light of the impact they had on the family. *Having my funeral organised* and *having my financial affairs in order* were rated amongst the top ten statements. Participants commented that although there were some personal gains to making these arrangements, the planning was largely undertaken for the benefit of the family. One participant talked about wanting to have things organised for her family rather than for herself [72]. Another highlighted the collaborative decision making process by saying, "yes, we have made arrangements for the funeral", and then she slipped back into personalising the decision, "they know that I want to go home. I don't want to be left in a room with a bunch of dead dudes" [82]. Another, in reference to *avoiding becoming totally dependent on others*, noted that the *others*, for him, were his family, he did not want to become a burden to his family [63].

Similarly for *dying at home* (rated middle to low) and *having a peaceful death* (rated high), family members were considered when participants were deciding on where to place the statements. For example, "for my daughter, I don't want to die at home" [63], and "for family, I would rather die in the hospice" [72]. Part of the desire in *having a peaceful death* naturally was personal, but a peaceful death also has the potential to positively impact on the family. For those who had seen traumatic deaths, this seemed more pertinent. Within a dialogue about having open communication about her death with her family, one participant retold the following story:

> *while I was [on the ward] someone died and it lasted all day, all night, through into the next day, and it was noisy, and it was horrible. I have seen both my parents die and they didn't die that way and that freaked me out totally. . . . I put my walkman on and turned it up full bore, it was absolutely appalling* [82].

There are, of course, elements of raw fear in this story, particularly about the possibility of this also happening to her. But in addition, this younger woman, who had young children, was certain she did not want her family to witness her dying in this way.

Maintaining dignity also contains a family component. Given most of the participants in this account had children there was a sense that children, in particular, no matter what age, should be protected from the indignity of death. Not only should family be protected, but they should be unburdened as well.

It is interesting that the statement *that I maintain my dignity* is one of only two statements that distinguishes across all four accounts. Both accounts two and four rated this statement in the top ten, but for different reasons. In the independent account dignity is associated with autonomy, such that losing one's dignity implied losing one's independence and sense of self. Similarly, in the family account, dignity may well have an independent component, i.e. not wanting to burden family, but this idea is more socially focused. This different interpretation of dignity is supported by recent research, which investigated terminally ill patients' understandings of dignity (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002). Three major categories of dignity emerged, which were labelled: illness-related concerns, dignity conserving repertoire, and social dignity inventory. Illness-related concerns focused on levels of independence, which included both cognitive and functional components, and both physical and psychological symptom distress, which ties in with the understanding in the independent account. Similarly, the family account seems to draw upon the social dignity category which included privacy boundaries, social support, care tenor (attitude of others), burden to others, and aftermath concerns.

Impact on family is assessed not only as the here and now, as in *I have the support of my family*, but also in consideration of the future of the family, after death. Statements related to *funeral* and *financial affairs*, as well as the importance of *family being emotionally okay after my death*, suggest a future component to the care and concern expressed by the dying individual.

The combination of statements at the least important end also supported the notion of family importance. *Keeping things to self,* and *family keeping feelings to themselves* suggest a willingness to share circumstances with the family rather than hold on to things. One woman noted that her daughter was unable to keep her feelings to herself, but that she didn't want her to, she wanted her to communicate about them [63].

The focus on family in this account is the clear feature that both defines it and differentiates it from the other accounts. Some distinguishing statements, however, are of particular interest (see Table 11).

Table 11

Rankings of Several Distinguishing Statements for the Family Account

		Account[16]			
No.	Statement	1	2	3	4
11	that my death is peaceful	3	3	3	1
2	that I avoid becoming totally dependent on others	5	2	5	6
36	that I maintain hope	6	5	3	7
28	that I have good friends around	5	5	4	7
23	that conflict within my family is resolved	6	6	5	7
33	that I feel like my life has meaning	4	6	4	8

In terms of avoiding dependency on others, it seems probable that, given the "assurance" that their family will be supportive, this is not concerning to the family account. A similar logic

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[16] Account 1 = Religious-oriented, Account 2 = Independent-oriented, Account 3 = Idealised, Account 4 = Family-oriented.

perhaps applies to conflict within family. Presumably they either have confidence in their ability to overcome conflict should it arise, or given the family cohesion, believe no such conflict will ever arise.

Certainly with maintaining hope, the family account suggests that participants have come to terms with their illness and hope for a cure has dissipated. Krieger (1982, as cited in Penson, 2000), has developed a four stage system of hope. Phase one involves hoping for a cure, or that the disease is not life-threatening. This phase is not dissimilar to Kübler-Ross' denial stage (Penson, 2000). Phase two is treatment, where hope is that the treatment will be successful. Phase three, prolongation of life, involves the realisation that nothing more can be done, but hope that their life may be extended. The final phase is where they hope for a peaceful death.

These phases outlined above have interesting implications in explaining the placement of the statement *that I maintain hope*. The family account, in its placement of hope at the least important end, is perhaps acknowledging that they can no longer expect an extended life and instead chose to focus on a peaceful death (which they rated as most important), thus reflecting Kreiger's final stage. Accounts one and two may be more inclined to be in the third phase, maintaining more hope for extending their lives, whilst account three, appears to be in the second phase, hoping treatment will be successful.

The extent to which family takes precedence over the individual is also indicated in the placement of the statement *that my physical pain is managed*. This is the first account in which this statement has not occurred in the top ten. To put family before managing physical pain highlights the considerable regard given to families in this account.

Other statements that tend to reflect personal control attracted only ratings of moderate importance, as did *faith in God.* In this account God is not unimportant, however, he is second to the family. Interestingly, although *faith in God* was rated as quite important, *that I know where I am going after this life* was rated least important. As only two individuals described themselves as religious, it is possible that they held unorthodox religious beliefs.

Having good friends around was rated at the least important end. This was reflected in the quote mentioned earlier regarding the preference of family of friends, and tends to support the adage "who needs friends when you have family". However, in the younger woman's account, she gave friends and family nearly equal footing. She stated,

> *people have been important, and they have come around. I mean, you don't live your life thinking about how many friends you have got or anything like that, but whatever I have done, I have nurtured those friendships and it has come back to me . . . and not only me, it has come back to [her partner] ... as well [82].*

It may be that friendships are more important to younger people than they are to older, and as the only younger person in this account her voice became usurped by others.

In summary, family forms the basis of this account of dying well. Support comes from the family in different shapes and forms, from reconnecting with lost family and family members returning home from overseas, to communicating with family, and the family having an active role in the participant's dying process. There is both a focus on the here and now of the illness experience, as well as concern for the family in the future, after death. Many statements were interpreted in terms of their impact upon the family. In some way, this account has become less of what the individual wants in the sense of what they want for themselves, and more about what they want for their family.

Body lying flat on a last bed,
Voices whispering a few last words,
Mind watching a final memory glide past:
When will that drama come for you?

Seventh Dalai Lama

Chapter 12:
Discussion

This chapter addresses the contribution of the results of the present research to the current literature. Attention is given to the focus on the patient's perspective, the notion of individual differences in understandings of dying well, and to comparisons with the current literature. This is followed by a discussion of the problems that arose within the present research, and the future directions that dying well research in general may take. Finally, the implications of the present research for clinical practice are discussed.

Contribution of the Present Research

This research investigated individual differences in understandings of dying well, and gained a deeper understanding of a good death from the perspective of patients receiving palliative care. Using Q-methodology, four different understandings of dying well were identified. Each understanding had a different focus, that of: religion, independence, idealisation, and family. In the religious account God and faith were the key features and personal control was of minimal importance. This contrasted with the independent account where issues of control were considered fundamental. The third account, idealised, reflected a somewhat unrealistic notion of dying that included a sense of death denial. Finally, the family account focussed predominantly on the importance of family to the dying patient. Identifying four diverse perspectives shows that there are individual differences in understandings of dying well for patients receiving palliative care. Three key factors differentiate the present research from the past research on dying well: the present research focussed on addressing the patient's perspective and individual differences in understandings, which indicated further comparisons be made with the current literature. These are now discussed.

Addressing patients' perspectives

Very little research on dying well has investigated the palliative care patient's perspective and the present research has attempted to address this apparent gap in the literature. The question of "what is a good death" infers a good death *for* the patient, but the patient has not often been consulted. In fact, the patient's understanding of a good death has often been surmised from health professionals' and family members' perspectives. There are four notable exceptions where patients' perspectives have been investigated in some manner. Steinhauser and colleagues (Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000) investigated a good death from different perspectives – nurses, physicians, non-physicians, and patients – however, their patients were seriously, rather than terminally, ill. They made some interesting observations about different emphases across the groups, but none within. Payne et al. (1996) examined palliative care patients' perspectives, and they, too, made important observations about the different understandings of the patients versus the nurses. Young & Cullen (1996) have, thus far, produced the most extensive account in their in-depth study of 14 terminally ill cancer patients. They investigated the patient's perspective, as well as that of the family. Addressing the patients' perspectives, as the present research has done, extends the small amount of research already conducted, by further developing the patients' understandings of dying well.

There are several reasons why it is important to understand the patient's perspective on dying well. Firstly, the patient is the principle character in the dying process, so their view deserves priority. Secondly, specific aims of palliative care address issues of patient autonomy and choice (Ministry of Health, 2000), which impact upon dying well. Understanding the patient's perspective helps address how autonomy and choice might be enhanced. In addition, an underlying principle of palliative care and hospice practices is the provision of a good death. Taking the patient's perspective as central would make this easier to achieve. Finally, health professionals and family members are *not* patients. Their views are at least partly based on the roles they assume in the dying process, so, as discussed in Chapter 4, their views will not necessarily map onto the patient's. Investigating the patient's perspective is an important part of continuing to advance current knowledge of dying well.

Individual differences in understandings

Although there is an open acknowledgement in the literature that patients respond differently to dying, in research the idea that there is a relatively uniform view of a good death persists. In the present research, if patients endorsed a uniform view then only one factor would have emerged. As this was not the case, this indicates that there are individual differences in understandings of dying well for patients receiving palliative care.

The absence of uniformity, however, does not imply idiosyncrasy. The accounts identified in the present research appear to be situated between *total* uniformity and *total* idiosyncrasy. To be idiosyncratic, each participant would have needed to produce a different Q-sort *and* no structure would have been able to be obtained. In fact, no two Q-sorts correlated exactly (i.e. a correlation of 1.0) suggesting no participants constructed identical Q-sorts. However, a factor structure *was* able to be obtained which indicated that there was a sufficient degree of similarity in their profiles to be able to group participants. Each group of participants is therefore not homogenous but does display similarities.

Q-methodology investigates similarities in the ways in which people view a construct. In this instance, the method uncovered four groups of patients who showed similarities and commonalities in their views of dying well. The evidence provided in this research suggests that for this group of patients there is some ambiguity across and between groups: their views were neither totally idiosyncratic nor totally uniform. But, if it were necessary to locate their pattern of responding on this idiosyncrasy-uniformity dimension, whilst there was some degree of similarity, their responses were closer to idiosyncratic. These results offer a contrast with the uniform view sometimes expressed in the literature, and provide evidence for the less frequently expressed notion that there are individual differences in understandings of dying well.

As people continue to develop stereotypic views of dying well, and the practice of a good death becomes institutionalised and governed by policy, there is a danger that the notions of dying well and a good death will become increasingly uniform. The present research findings suggest that the patients' responses are closer to idiosyncratic than uniform, which implies a necessity to consult the patients as to their wishes for dying well.

Comparisons with current literature

Not only are there comparisons with current literature in terms of identifying individual differences and addressing the patient's perspective, there are also contrasts within the detail of the Q-sorts. In the current literature there remains a relatively pervasive belief that dying at home is an important factor in a good death (Bolton, 1981; Hunt, 1992; Porta, et al., 1997). However, the present research suggests that patients receiving palliative care through a hospice do not rate the idea of dying at home as important as other features. In fact, it commonly featured in the four *least important* columns. Interview data from some participants suggested that they had a strong desire not to die at home for a number of reasons, such as the desire not to devalue the home by dying in it [24]. The results of the present research provide some support for a recent notion that health professionals may have 'romanticised' the idea of dying at home, and that often family members prefer that the patient is cared for in a skilled environment (Steinhauser, Christakis, et al., 2000).

Despite pain often being mentioned as the most important feature of a good death, these accounts did not support this. However, it was rated within the top four columns on all four accounts, suggesting overall general importance but not prime importance. It has been argued in the past that because pain is under control when participants are being interviewed, it has become less salient for them, and thus they underestimate its importance (Katz & Sidell , 1994; Payne et al., 1996). This study provides no evidence upon which to evaluate this claim.

Limitations of the Present Research and Future Directions

This section discusses the limitations of the present research as well as possible future directions to attend to these and further expand the current literature. It begins with a discussion of the strengths and weakness of Q-methodology, and goes on to address some difficulties that arose in terms of the statements and the participant sample. This is followed by comments concerning the religious/spiritual divide. Future directions for research are included within each of the discussion points, however a final section addresses a key additional area that may provide a rewarding source for future research.

Strengths and weaknesses of Q-methodology

Current literature has investigated notions of a good death from a variety of perspectives, and established a number of ways of considering the construct. Researchers have investigated a good death as a series of characteristics, categories of characteristics, qualitative accounts, and a socially situated phenomenon. Q-methodology allows an alternative understanding of a good death to be uncovered. Not only did this method identify four different understandings of a good death, it also managed to illustrate a response that is often difficult to elicit, that is, death denying. Furthermore, it proved useful in exposing individual differences in understandings of dying well.

There were also pragmatic advantages to employing Q-methodology in the present research. Virtually all participants commented on the 'novelty' of the task: not only that it used magnets and a board, but also that it involved 'building a picture' of what was important to them. Although designed for practicality, the 'novelty' aspect and the sense that at the end of the task they had a visual picture of what things were important to them, was valuable. It was not only useful in encouraging the completion of the task, but also immensely satisfying to see the patients engage and retain interest in the task throughout.

Another strength of Q-methodology may be in its value as a therapeutic tool. Steinhauser and colleagues (Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000) have investigated in a general sense the differences in understanding dying well from the perspective of those involved in the process. Clinical practice using Q-methodology could investigate such differences at a case level. That is, have different individuals involved with the care of a patient each create a Q-sort for that patient, and investigate the differences or similarities in the sorts. This could also be a useful tool within the hospice setting to identify and discuss differences in understandings, particularly if there is some conflict between parties. Furthermore, an original reason for employing this method was an attempt to maintain a degree of connectedness to the participants, and doing so without overly burdening them. Many participants stated they found the task useful, some wanted copies of the statements so they could talk about them with their family. Others had not thought about all of the things listed on the statements and were grateful for the opportunity to do so. In addition, reports back to hospice staff from participants suggested that participants had benefited from being able to discuss these things with someone not directly involved in their care. One participant found the task so enjoyable he suggested to a staff member that carrying out the task had been "the highlight of his life". All these factors indicate a potential to use the Q-sort task as a therapeutic tool in clinical practice.

Notwithstanding its relative strengths, Q-methodology does have some limitations. Using this method in the present research, and following Brown (1980), may not necessarily have offered any advantages over other techniques. For example, a well designed questionnaire, that involved rank ordering statements with space available to reply to open-ended questions, and that was Q-factor analysed, would appear to offer similar results. Brown (1980) may well argue that it is, at least in part, the focus on subjectivity that differentiates the two approaches. However, it is difficult to see how Q-methodology offers a more subjective account than, say, the example given above. Individuals are surely rating their "subjective" understanding of the relationship between the questionnaire items, in much the same way as a Q-methodological approach.

It could be argued that the Q-sort task is very constrained and structured in a number of different ways. Firstly, in terms of the response hierarchy structure, in the present research participants were forced to choose only two statements that were most important to them. Often participants commented that they wanted to place more statements in the top columns than the spaces allowed, thus they felt constrained. However, a Likert scale is somewhat similarly constrained by the number of points available on the scale. Secondly, in Q-methodology once a statement has been placed on the response hierarchy it will constrain the possible placements of the remaining statements. This is unlike a Likert scale, for example, where participants can rate each statement without reference to the rating of the others – the response to each item is free to vary. However, it is important to recognise that in the present research, which had a 40 statement Q-set, there are 8.15 x 10^{47} (i.e. 40!) possible permutations of statements, thus Q-sorts. Contrast this to a 40 statement questionnaire using a 5-point Likert scale, which has 9.09 x 10^{27} (i.e. 5^{40}) possible arrangements. Q-methodology appears to be unconstrained in terms of the available ways a Q-sort can be carried out but is constrained by the placement of statements. Some researchers are beginning to offer a less structured approach to carrying out the Q-sort that does not rely on the quasi-normal forced choice distribution (i.e. Kirkland & Bimler, 1999). However, this approach requires greater discrimination between groups of statements, which was considered too demanding for the participants in this research.

Two problems arise on the basis of the dimensional scaling. Firstly, the nature of the unidimensional importance scale (*most important* to *least important*) did not allow for any statements to be of “no importance”. By virtue of being labelled *least important*, items that participants did not want to endorse *had* to be endorsed, albeit at a minimal level. One participant, for example, felt strongly about the religious statements, and did not want them rated as in any way important.

The second issue is more conceptual, and perhaps more fundamental, but follows on from the previous limitations identified. The cognitive process of ranking 40 statements onto a hierarchy is presumed to provide an accurate representation of the way that people actually perceive dying well. This task is highly constrained – it is constrained by the one dimensional scale and the reasonably large set of statements that are ranked according to a given distribution. These features serve to highly constrain the cognitive processes involved. Given these constraints, it seems unlikely that the results identified are a true reflection of the actual way people think about a construct. Brown (1980) might argue that because the task is carried out in a self-referential way this does not apply. However, just because the task is carried out self-referentially, that does not alter the highly constrained process that the individual is engaged in. There is nothing either before the ranking task, in the selection of the statements, or after the ranking task, in the factor analysis, that alters the fact that this is a constrained and complex cognitive process. It is therefore conceivable that individual's views have become distorted by the limitations placed upon them by the process, and that the results are therefore an artefact, or a function of this method. However, the results of the present research do find some support in current literature, in terms of the content and range of views elicited. The statements reflect those already identified in the literature and presented in Chapter Three. In addition, the accounts identified have similarities with Leichtentritt and Rettig (2001), and Kristjanson and colleagues' (2001) categories.

Notwithstanding these conceptual difficulties, this research identified four accounts of dying well. It is tempting to suggest that these accounts could be interpreted as stages of dying well. For example, on the basis of the Judeo-Christian Western-world value system, the process begins with the idealised account when an individual is in 'denial'. This also fits with Kübler-Ross's (1969) first stage of dying. The individual could then progress into the independent account, focusing exclusively on the self and the individual's own needs, in order to reconcile the situation within themselves. Next, having achieved some control and understanding of their predicament, they are ready to (re-)engage with their family and share their burden. Lastly, the individual moves into the final stage where their focus is on religion, and what their after death future may hold. Although the statements may be used in a way that could be interpreted as a stage approach, Q-methodology does not have a process orientation. Therefore inferences of this nature are not appropriate.

Participants did, however, allude to the idea that they thought they would feel differently at different times during the dying process. One participant stated, "I have, I might have a strong faith in the theoretical place before the close-to-death part happens, but when you get to the close-to-death part it may be very different" [51]. It is possible that patients draw upon the different accounts at different times during their illness. There may be some core structures that remain the same, or there may be a radical reworking of the account on the basis of proximity to death. This research did not set out to establish the *process* of dying well, and thus can only hypothesise as to the nature of such a process. Further research could address this issue in a variety of ways. Following participants from diagnosis up to death would provide useful process information, as would investigating the change process retrospectively. Sampling at different times in the dying process may also be beneficial in investigating stages involved in dying well.

Like most methods Q-methodology can be open to the personal bias of the researcher (although some Q-methodologists might argue otherwise (see Brown, 1980)). Selecting the concourse is a crucial stage in the process that can involve personal bias, thus this was undertaken with considerable consultation and rigorous pilot testing. This bias has been kept to a minimum by adhering to a number of protocols in the selection of statements for the Q-set.

Personal bias can also occur in describing the accounts, and in most Q-methodological studies, an additional validation process is undertaken. Two time factors play a key part in this process. Firstly, research participants are often contacted over a short time period to carry out the Q-sort task. This means that data is collected over a relatively brief time span. Secondly, the data is then analysed over an also relatively brief time period in order to facilitate revisiting the participants to clarify that the description of the account they endorsed belong does accurately reflect their views. However, with respect to the present research, both timeframes were compromised. Firstly, given the nature and variable availability of the sample used in the present research, and the sensitivity of the research question, research participants were not easy to solicit. On average, the researcher was able to conduct only two interviews per week. Secondly, having taken approximately six months to collect the data, it took a further six months to analyse it. Given the criteria for admission to the hospice service is a terminal diagnosis (meaning up to 12 months to live) it is unsurprising that the majority of the participants had died within the time taken to complete the main body of the research. It was therefore impossible to validate the accounts.

Aside from a lack of available participants to return to, other reasons arose for not validating the accounts with participants. Firstly, it was unclear, given the relative cognitive complexity of the task, whether patients who had deteriorated would be able to recall the perspective they had outlined earlier. This may have meant participants would no longer endorse the account they had originally. Secondly, it seemed possible that during the quite lengthy time frame between the Q-sort and being recontacted, the views of the participants may have changed with their changing proximity to death. It is impossible to say, without continued retesting, whether these accounts are stable or not, and this would be an appropriate investigation for future research. Despite not being able to return to the participants to clarify their accounts, for the most part the discussions during the Q-sort process provided sufficient comments to elucidate the accounts.

One question left unanswered by the use of this method is: why do individuals express these particular accounts? What personal background issues, if any, have a part in determining the expression of one account over another? What variables might predict which patients belong to which accounts? Other research methods may be in better utilised to determine the aspects that influence the manifestation of particular accounts for specific individuals. Establishing answers to these questions may be useful for developing targeted interventions in clinical practice.

Problems with statements

Whilst the strengths and weakness outlined refer to more general aspects of Q-methodology, some specific problems arose with particular statements selected for the Q-set. However, with extensive and rigorous development and testing of the statements, these were relatively minor difficulties. Individual statements seemed to be problematic in terms of social desirability, inapplicability, the inclusion of a modifier, and not distinguishing between accounts. Each of these problems is briefly discussed below.

That I don't look ill was consistently rated in the bottom third of the hierarchy, and this may have reflected the low social desirability associated with this idea. Rating this statement any higher could reveal a type of vanity, which is not endorsed in our Western culture. Some participants seemed to find the statement *that conflict within my family is resolved* redundant. Participants responded, "there is no conflict within my family", and so they placed the statement at the least important end. However, both of these statements were still distinguishing statements, suggesting that participants in different accounts had still rated them differently.

Unfortunately, one statement, *that I avoid becoming totally dependent on others* included the modifier *totally* which can make interpretation more difficult. However, for the most part, participants appeared to focus on the word *dependent* and made their judgement based on dependence rather than total dependence.

Only three statements were placed in the bottom four columns across all four accounts. These were *dying at home*, *trying unconventional treatments*, and *family keeping things to themselves*. *That I try unconventional treatments* was, however, still able to distinguish between accounts. Given the population was all hospice based, it is possible that there might be another account available outside the hospice philosophy that more readily endorses alternative approaches to treatment.

Despite the above-mentioned relatively minor limitations of a few statements, 32 of the 40 statements managed to distinguish between the accounts. Of the eight remaining, only one was a consensus statement, with the last seven differentially placed on the hierarchy, although not to a statistically significant level. This suggests the selection of statements was sufficient to allow participants to construct their own understandings of dying well.

Sampling issues

Having addressed some limitations specific to the choice of Q-methodology as an approach, it is worth considering other limitations of the present research, particularly with regard to the characteristics of the sample. The moderately small sample size and the characteristics of the sample, limit the generalisability of the results. Most participants were over 60, New Zealand European, and married or widowed, had bowel, lung, or breast cancer, and all were part of a small provincial hospice programme. In addition, participants were selected by the Medical Director on the basis of wellness and perceived ability to complete the task: they therefore were not randomly selected. Generalising the results of this study to other groups with different characteristics may not be appropriate. However, some reassurance about the results is found in the fact that other research using different methods, samples, and in different countries, has found similar results in terms of the categories of the accounts

(Kristjanson et al., 2001; Leichtentritt & Rettig, 2000). Future research replicating the present research in similar and different populations, may be of interest.

Several potential areas may also be of interest to investigate further. Cline (1996) has noted gender differences in the dying process, and it would be of interest to extend this research and investigate gender differences in dying well. Although the present research was not designed with this type of analysis in mind, a possible site for future research may be with the idealised account which included five men and only two women.

Other comparisons across groups may also be of interest. Patients of other ages may draw upon, or create, different accounts to those identified in the present research. Also, New Zealand is becoming increasingly multi-cultural, and studies on diverse groups within this population would be of interest in establishing if understandings of dying differ across cultures. Finally, investigating the experiences of dying well across the different types of cancers may also be of interest. Issues such as the impact on bodily self-image after mastectomies are investigated with women with breast cancer (Harwood & O'Connor, 1994), however future research could be undertaken with respect to the impact of different cancers on the dying experience.

Although participants in this research had a life expectancy of less than a year many outlasted this timeframe. Thus participants were at different places in the dying process when they were interviewed. A further area of study that would extend the current literature would be an evaluation of differences in understandings at – or close to – the actual time of death and the *perceived* proximity to death. One participant died two days after he was interviewed, and he was adamant he was not close to death, despite acknowledging the doctors had told him he had less than a week to live. This perception of proximity to death may also influence an individual's understanding of dying well, and is worthy of further investigation

The absence of spirituality

Although the present research did not expressly intend to address the spirituality gap in the literature, it is perhaps worth commenting upon. This analysis did capture a religious account of dying well, however, it was unable to capture a more spiritual focus. Some participants acknowledged a belief in a being greater than ourselves, but not a belief in God, in the traditional Christian sense. Given that these spiritual ideas are not readily discussed in the empirical literature outside of orthodox religion, and that spirituality was not commonly mentioned in the initial interviews conducted, this concept did not make its way into the statements. Thus, there was no way in which a non-religious spiritual account could be constructed by the participants. Investigating the role of spirituality, as opposed to orthodox religious beliefs, could be of interest in future research and may be of increasing importance with the secularisation of society and plurality of spiritual views. The way in which individuals understand their dying experience is likely to be influenced by their spiritual beliefs, and a study investigating how these differences are manifested would add valuable knowledge to current understandings. More recently, the role of spirituality was identified as important by Steinhauser, Christakis, et al. (2000), and this deserves further research attention.

A final important direction for research

It seems that two key questions that need to be addressed within this and other research on a good death are: Who is the good death for? And, who benefits from the occurrence of a good death? My own belief is that a good death should be for the dying individual and that the dying person should benefit. The individual achieving the death they choose for themselves will obviously have an impact on both the family and the health professionals dealing with them. Yet this need not be a negative impact, as might be perceived from the literature, and may indeed be positive for all parties. If the individual achieves what appears to be the good death they desire, then this 'should' be seen as good by the family. Helping to facilitate this type of death 'should' also encourage health professionals to feel as if they have performed their duties 'properly'. In light of the common perception that a good death has a positive influence on family's bereavement processes this type of dying should be beneficial to all.

However, the nature of the relationship between a patient's death and the family's bereavement processes warrants some clarification. Indeed it would be useful to establish if *perceptions* of the death being good are all that are required, or if there are better bereavement processes if the death ties in with the family's own views. This could also be applied to evaluating nurses' own experience of bereavement within the hospice setting. But before addressing this relationship, the question of 'who is a good death for?' needs answering. Q-methodology would certainly be an appropriate technique for exploring these questions.

Clinical Implications of the Present Research

Several implications arise from the results of the present research. There are some potential overall implications, as well as specific implications for each of the accounts of dying well. Each of these is discussed in turn.

Identifying different accounts of dying well for patients is not simply a source of increasing our knowledge of dying well, but also a guide for action. Meaningfully grouping individuals into accounts helps identify subgroups of people with specific needs and for whom targeted interventions may be appropriate. Encouraging patients to subscribe to accounts that do not fit well with their life experience and understanding of a good death is unlikely to encourage a positive dying experience. These accounts provide an outline of the types of things that are important to people who are dying. The accounts that were produced focus on the items that were common to the group. No one individual is likely to fit the account exactly, but their understanding of the situation is likely to fit within the bounds of that particular account. These results cause us to reflect on our existing notions of a good death and may be usefully employed in hospice settings as a guide for providing targeted interventions to specific groups of individuals.

For the religious-oriented account

In a very pragmatic sense, the provision of religious services for individuals would seem an obvious starting point. Most hospices already provide access to religious personnel, predominantly chaplains, who the patients may draw upon when and if they choose. Despite apparent religious beliefs, some may choose not to use religious personnel at all. Ultimately the decision to use the services of religious representatives should be, and most likely is already, left up to the individual.

Religion, however, is not simply the provision of a religious representative. For those with religious beliefs, their faith pervaded the account and determined their behaviour. Respect for the many aspects of religious practices, such as prayer rituals, alternative meals, appropriate settings for prayer, needs to be upheld. The development of both institutional processes that are not contrary to religious beliefs, and of a hospice culture where the reliance on God above medicine is acknowledged, may also be appropriate.

For the independent-oriented account

The sense of normality that pervades this account may provide a useful target for interventions. Maintaining normality and predictability in terms of interactions with the patient, may be appropriate in working with this group. This, however, does not equate to pretending nothing is wrong, but continuing to engage with patients in a meaningful way, as is already regularly practised in hospice.

Issues of dependence, and lack of personal, situational, decisional, and future control, are likely to be most problematic for those who endorsed this account. Ensuring the patient is (not feels) in control of treatment decisions, and other decisions about their care, will provide an opportunity for this group to experience a good death.

Deferring to the family in decision making, as is sometimes the case, is likely to cause a great deal of stress to an individual endorsing this account. Given the account's relative lack of importance ascribed to religion, provision of allied health professional services may be appropriate. Also, for these people who are greatly concerned with maintaining their independence, practical assistance to reduce the sense of dependence would need to be addressed. This, too, is likely already practised within hospice.

For the idealised account

The focus of this account is an idealised dying experience that includes a component of death denial. It may therefore be appropriate to *not* encourage individuals with this belief to come to terms with their illness. Although acceptance is a commonly identified component of a good death (see Chapter Two), this group would be uncomfortable in being encouraged towards a position that they do not endorse.

Furthermore, *not* encouraging them to make practical arrangements ties in with their death denying belief, and should therefore be respected. These participants showed a clear lack of desire to be confronted with their illness and were not interested in taking any action towards dealing with their situation. Although the death denying position is not well endorsed within society, the patients' preference for denial should be respected. It would, however, be appropriate to provide them with comfort about issues of pain, maintaining hope, and issues of peace and calm. Focussing on the present and attending to their current needs are ideal targets for encouraging this group to achieve their own good deaths.

For the family-oriented account

With the family focus of this account it should be clear that the family should be involved in all aspects of the patient's dying process. Family-centred discussions of the various issues involving the patient may be appropriate. In addition, the family may be responsible for making decisions on behalf of the patient, including decisions about treatment and other care issues. Nurses ensuring the family is around at the time of the patient's death will also facilitate a good death for those who endorse this account. Again, this is likely already practised within hospice.

Decisions that the patient may make will likely be made in light of the impact on family. Encouraging patients to draw upon the support of the family may actually be met with resistance if the patient considers that family will be adversely affected by seeking their assistance. Nurses will need to respect patients' decisions to place their family before themselves.

Summary

One of the overriding themes that emerges from the present research is that of addressing the views of the individual. In the past, this seems to have been only hinted at, rather than extensively researched and addressed, and this may be in part due to ethical concerns and the difficulties associated with the increasingly poor health of the patient. McNamara et al.'s (1994) notion that a good death has been institutionalised also suggests that focusing on the individual is being subsumed by more generic practices. As the concept has become bureaucratised, it has begun to move away from a notion of individual variation. It is difficult to establish if this bureaucratisation and institutionalisation is happening at a practice level, or merely in a more abstract, or policy, sense. Whilst policy might dictate the importance of respecting patient autonomy and choice (Ministry of Health, 2000), the nurse must manage decisions in the face of continued decline, and where, as is sometimes the case, the patient is not longer able to make their own decisions. Ultimately, however, eliciting the individual's views will help identify what is important to them for dying well.

The notion of dying well is perhaps, still in the early stages of development. The present research has used Q-methodology to investigate understandings of dying well for patients receiving palliative care, and demonstrates that this focus on patients' perspectives is worth pursuing. In addition, identifying individual differences in dying well suggests that there is not the uniform understanding that the current literature implies. Further developing the notion of individual differences in dying well will help ensure that each individual experiences a death that is in line with their own personal beliefs and values. In this way, it may truly be possible to have *a death of one's own.*

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Appendices

Appendix A

Ancient and Pre-modern Hospice

Ancient Hospice

The history of hospice dates back more than three millennia to 1134BC in ancient Greece where healing sanctuaries existed for the care of plague victims (Seplowin & Seravalli, 1983). Most temples at this time offered some sort of healing, and where there was healing sick people would commune and find refuge (Siebold, 1992). Temples were also the destination of many pilgrimages, and the association between hospice and pilgrimages is virtually inseparable. The strength of this association is also apparent in early language. Cicero (106-43BC) used the word *hospes* to mean a host who welcomed travellers, pilgrims and wanderers (Manning, 1984). Latin *hospes* has been varyingly interpreted as: guest or host (Buckingham, 1983); hospitality, especially to strangers (Clark & Seymour, 1999); and, with some Christian influence, a stranger, someone whom the host had not met personally or previously (Manning, 1984). Thus *hospes* formed the basis on which early hospices, hospitals, and Hotel-Dieu were founded, and were the predecessors to modem hotels, hospitals, hostels, school, orphanages, monasteries, nursing homes and hospices (Koff, 1980; Siebold, 1992). "They offered shelter to any traveller, well or sick, and the hungry, the orphaned, the cold, and the needy, as well as the dying" (Koff, 1980, p. 9). Some writers appear to embellish the language to encompass the idea that dying people were welcome, this is perhaps to support their historical account. For example, Hillier (1983) writes that hospice began as a place "to provide sojourn and a rest for the earthly travellers as well as those on life's pilgrimage" (p. 391). The fact that these hospices catered for the dying seems to be more a product of the population (essentially travellers of some sort) who were passing by, rather than specifically offering care for the dying. This distinction comes more into play in the development of pre-modem hospices to be discussed shortly.

Most early hospices were run by religious orders (Koff, 1980). One of the earliest accounts of a hospice exclusively for dying comes from India around 225BC. Emperor Asoka built this hospice, and some 18 others, for religious pilgrims who flocked to the Ganges River to die (Siebold, 1992). However, the most frequently reported account of an early hospice relates to Fabiola, a Roman Matron and disciple of St Jerome (347-420AD). In about 361AD, at the time of Emperor Julian the Apostate (331 - 363 AD), she converted her home into a shelter for the healthy, sick and dying on their return from Africa (Hillier, 1983; Koff, 1980; Manning, 1984; Siebold, 1992). Two further hospices are also known around this time. In 475 AD, a hospice also existed in Syria (Koff, 1980), although little more than its date of inception seems known. In Ireland a short time later, 500 AD, Saint Bridget set up a home for the lame, lost, the sick and dying (Siebold, 1992).

Some time later, in 7th and 8th century AD Rome, a *hospitium* was established to provide shelter for those visiting the tomb of St Peter. The important feature of these early religious establishments was the provision of food, shelter and spiritual care, and their lack of purveyance of medical attention (Manning, 1984). Any medical care given was relatively primitive and was administered by a healer - very little sophisticated medical treatment was available. Hospices were a way-station that restored the weary traveller sufficiently so that he could continue on his journey (Samarel, 1991; Siebold, 1992). Goldin (1981) suggests that although religiously run, "helping [the traveller] towards the shrine had nothing to do with helping them towards heaven" (p. 389). Caring and "unconditional acceptance and concem for one's fellow man regardless of wealth, religion and age" (Manning, 1984, p. 35) were the foundation upon which early hospices were built.

In the UK between 925 and 1170 AD, religious fervour was growing, and offering hospitality to strangers became a serious religious and moral duty (Manning, 1984; Siebold, 1992) and a sign of one's dedication to God (Munley, 1983). For those who offered religious healing, their motivation was not simply aiding the sick, but also saving their own soul (Siebold, 1992). Christianity was dominant in the hospice movement, although other religious groups were also active. Moslems also emphasised caring for the dying as a sacred duty and thus built hospices wherever Mohammed was worshipped (Siebold, 1992). With this religious ardency came the development of hospices in Yorkshire and Worcester in 925 AD by Saxon Bishops Oswald and Wulfstan. From these developments a number of variations on hospice combining monasteries, friaries, and charitable hospitals were established throughout the UK (Manning, 1984). Possibly the most famous order to establish a hospice was the Knights Hospitallers of the Order of St John. In 1100 AD, in Jerusalem, Brother Gerard and fellow Monks established hospices that extended through Europe (Hillier, 1983; Koff, 1980; Manning, 1984). By 1306, the Knights Hospitallers became a military order fighting in the crusades in Rhodes, but continuing to maintain their existing hospices and establish new ones. In Rhodes, the division between curable and incurable began, with the fatally ill being cared for in different rooms to those with non-life threatening illnesses (Buckingham, 1993). Although not typically catered for, the nuns of the Order of St John around this time established a hospice exclusively for women called the St Mary Magdalene (Seplowin & Seravalli, 1983; Siebold, 1992).

As hospices arose around the sites of crusades, so too did they around the sites of shrines. In 1170AD a shrine to St Thomas of Canterbury was built and with this came the establishment of hospices that combined guesthouses and infirmaries. These were built in Canterbury and Southwark, which was on the highway to this shrine and was seen to facilitate the pilgrim's successful journey (Manning, 1984). For those of the Christian faith, dying was a sacred time that offered time to reflect on life, but more importantly the opportunity to repent and attain a place in heaven (Manning, 1984). Thus, the institutions of this time were still primarily focused on spiritual care to the exclusion of scientific-oriented medical care, and conversion to Christianity for the dying was encouraged. In addition, the dying were revered as they were seen to be on the pathway to a "true" life with God (Siebold, 1992). These features led to the dying being well cared for, at least in the spiritual sense (Manning, 1984).

The provision of spiritual only care continued well into the 12th and 13th centuries. However, the concept of hospice as a place to die developed largely in response to the plagues (Seplowin & Seravalli, 1983). Leprosy was rife in Europe during this time leading to the establishment of *larazettos*, named after Lazarus, a biblical leper. These were shelters that were built on the outskirts of town, segregating the fatally ill lepers from the non-infected community. With no cure for leprosy, these ill individuals, who were suffering much physical pain, were provided only with spiritual care. In France and Germany some 4000 lazarettos existed, with another 200 in England and Scotland (Seplowin & Seravalli, 1983). This appears to be an early example of a structure exclusively established for the care of the dying. The apparent primary reason however, for these establishments being sequestered from others was to avoid contamination from this highly infectious disease. It is perhaps unsurprising then that the modern community perception of hospice is still rooted in the idea of hospice being a place to die.

By the 13th century some 750 hospices in England (Clark & Seymour, 1999), 40 in Paris and 30 in Florence alone (Manning, 1984), had been established, problems however, began to arise. From 1270 to 1470 the popularity of pilgrimages and travelling began to dwindle, and wanderers and vagrants became the mainstay hospice guest. Hospice owners began to distinguish between "chronic invalids", the desired guests, and "casual comers", the particularly unwanted guests (Manning, 1984). By the 16th century the problem of faking illness, false claims of poverty, and religious upheavals, combined with King Henry VIII's (1491 - 1547) withdrawal of support for monasteries, friaries, charities and hospitals (all major operators of hospice) lead to the demise of early hospices (Clark & Seymour, 1999; Hillier, 1983; Manning, 1984). Not only did King Henry VIII outlaw monasteries and religious institutes, he also reduced the powerful influence of the church on medical practices (Seplowin & Seravalli, 1983). These reforms, although causing the dis-establishment of hospice and directly influencing the care and treatment of the dying, revolutionised the hospital movement. "Modern hospitals [were] primarily designed to keep the machinery of expendable labour working efficiently" (Manning, 1984, p. 39-40) and thus the dying, who were "unfixable", were excluded from care and abandoned. In addition, with the changing religious values, physical suffering such as illness, came to be viewed as a punishment for sin, and thus deserved (Manning, 1984). Hospices were replaced by workhouses in which inhabitants were given just sufficient care to allow them to recommence work.

The move into the 18th century and the Victorian Age, saw the rise in medicine as a positivist science (Clark & Seymour, 1999) which further marginalised the dying. With fierce competition for funding, beds being occupied by the dying was an impediment to an application for funding so the incurably ill were denied admittance, and thus the workhouses became the unhappy exile of the dying (Manning, 1984). With medical technologies advancing rapidly and the onset of reductionist techniques, identifying the disease and finding a cure were the primary focus, and death (and the dying) were a threat to the medical profession's development (Siebold, 1992).

Despite earlier reforms, some religious order hospices continued, such as those of Benedictines and Augustines. In addition, at this time many charities that cared for the poor were founded (Du Bois, 1980; Manning, 1984). However, these charity-based hospices were for the deserving poor, not for the destitute poor (Seplowin & Seravalli, 1983). They catered only for those who had toiled hard for most of their life but by some misfortune had to spend their retirement in abject poverty (Manning, 1984).

Pre-Modern Hospice

At the end of this era a new period of hospice development began. In France, a somewhat fairy tale story emerged. A young French Roman Catholic priest, St Vincent de Paul (1581 - 1660), was captured by pirates in 1602. During his captivity, however, he converted the pirates to Christianity and secured his release. On return to France, he then established what was to become an early pre-modern hospice for the galley slaves (Manning, 1984).

During the 18th century, St Vincent de Paul hospices were established all over France for the poor, orphans, the sick and the dying (Hillier, 1983). These hospices were run by Sisters of Charity nuns and their methods revived earlier beliefs that fostered care and compassion for the sick and dying (Manning, 1984). These compassionate methods became the model for many future establishments. Several important figures feature in the proliferation of these methods to far afield. Sister Mary Aikenhead, an Irish Sister of Charity, visited the St Vincent de Paul hospice and eventually took the method back to Ireland (Seplowin & Seravalli, 1983). Baron Von Stein of Prussia witnessed the workings of the Sisters of Charity hospices and convinced a Protestant pastor, Fliedner, to found a hospice under the direction of the Sisters of Charity (Hillier, 1983). The hospice, called Kaiserworth, was run by nuns who became known as the Sisters of Kaiserworth (Manning, 1984). In the meantime, an English Quaker, Elizabeth Fry, was also influenced by the caring methods of the Sisters of Charity and set about reforming hospitals and prisons based on these teachings (Manning, 1984).

Another key figure, Florence Nightingale, was also working with the Sisters of Charity in France at this time. Although the Sisters of Charity's methods were spreading widely, the advent of the Crimean War (1854-1856) drew together the key figures of Aikenhead, the Sisters of Kaiserworth, Fry, and Nightingale, which further solidified the use of these methods, particularly on their return to their respective homelands (Manning, 1984).

The late 1800s were a productive time in the development of pre-modern hospices. Sister Mary Aikenhead initiated the development of Our Lady's Hospice for the Dying in Dublin in 1879 (Koff, 1980; Manning, 1984; Seplowin & Seravalli, 1983), although the conception of it occurred some years earlier (Siebold, 1992). This hospice is generally recognised as the beginning of the pre-modern hospice movement (Clark & Seymour, 1999). It is notable that other authors (i.e. Goldin (1981)) suggest the earliest hospice was one that was attached in the 1830s to St Vincent's Hospital in Sydney, Australia, although the St Vincent's Hospital website makes no mention of this on its history page. However, Saunders (1993) suggests that Mme Jeanne Garnier, in France, was establishing *hospices*, or *calvaries*, in 1874, and this was the first time the word hospice was used as an institute for the dying. Between 1890 and 1906 a number of now well-known hospices were founded. In 1890, the Irish Sisters of Charity, reaching further afield, established the Sacred Heart Hospice, in Sydney, Australia (Clark & Seymour, 1999). One year later in 1891, the Free Home for the Dying (or Hostel of God) was established by the Anglican Servants of the Poor and a philanthropic brewer and benefactor, William Hoare (Clark & Seymour, 1999; Koff, 1980). In 1894, other religious groups were becoming involved, and St Luke's, a Methodist hospice, was established near Regents Park in London by Mr Howard Barrett (Clark & Seymour, 1999; Manning, 1984; Siebold, 1992). In 1900 a Jesuit Priest, Father Peter Gallwey established, with the assistance of five of the original Irish Sisters of Charity, St Joseph's Convent in the East End of London (Hillier, 1983; Manning, 1984). By 1905-1906, St Joseph's Hospice was opened and began admitted patients (Koff, 1980; Manning, 1984). Most of these pre-modem hospices were run by a range of religious orders but in common was their primary focus on spiritual care, and religious conversion was still a feature. Because many of the illnesses of this time were incurable, i.e. tuberculosis, cancer and heart disease, this seemed to legitimise the minimal medical attention, and the focus on spiritual treatment (Manning, 1984).

By the end of the 19th century there were many new hospices offering spiritual care (Seplowin & Seravalli, 1983). However, it would still be another half a century before medical care took its place in the hospice. It is also noteworthy that in 1889 the Home of Peace was established based on the German *Freidenheim*. The Freidenheim provided peaceful care for people with tuberculosis, and the Home of Peace adapted this idea for the cancer patient. However, this idea did not achieve widespread success, perhaps because at this time beliefs about aggressive medical interventions were changing due to the successful treatment of a number of conditions and "investment in homes for the hopeless seemed increasingly inappropriate" (Murphy, 1989, p. 227, as cited in Clark & Seymour, 1999).

Although much of the pre-modem hospice development took place in Europe, similar advancements were taking place in the USA, albeit half a century behind. Workhouses in the 1700s in the US, like those in Europe, offered a separate room for the sick, but the conditions in these establishments were generally squalid. Medical treatment was only available in almshouses, and this was administered by a variety of "health professionals" including clergy, "barber surgeons, midwives, and diploma physicians" (Siebold, 1992, p. 21). As in Europe, US hospices developed out of hospitals' disinterest in caring for the dying, and the late 1800s proved the most productive time in pre-modem hospice development for the

US (Siebold, 1992). In 1899, Mrs Catherine McParlan, with the assistance of some Irish Catholic laywomen, established the House of Calvary in Manhattan. In the early 1900s Rose Hawthorne Lanthrop (who later become Mother Alphonsa) and her Dominican Sisters of Hawthorne established seven homes for the terminally ill (Koff, 1980). These followed the European traditions of caring for the terminally ill, and particularly focused on care for dying cancer patients. Originally, these hospices were solely home care services until sufficient funds were raised to build in-patient units, with St Rose's Hospice in Manhattan being the first to be built (Siebold, 1992). These ancient and pre-modern hospice paved the way for the modem hospice movement to be established by Cecily Saunders through St Christopher's Hospice in London (Seplowin & Seravalli, 1983). The modem hospice movement is briefly discussed in Chapter 2.

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Appendix B

Semi-structured Interview for Health Professionals

Interview Outline

Introduction

1. explain who I am
    - primary researcher under the supervision of Associate Professor John Spicer
    - this is my PhD project
    - how I came to be doing this research

2. general aim of project and this phase of project
    - to discover different meanings/understandings of dying well from the perspective of a variety of health professionals who deal with people with terminal illnesses and later get patients' perspectives
    - develop appropriate/sensitive questions for patient interviews

3. explain the purpose/context of the interview
    - context: terminal illness (not accidental/sudden death)
    - highlight the importance of "personal" perceptions, not intended to represent whole nursing field or hospice in general
    - particularly keen to get a variety of perceptions - suspect there are many differences
    - I have read what is in the textbooks but quite often they fail to reflect the reality of the situation which is why I want the HPs' opinions – they know more than what is in the book and it is this information that I am interested in
    - based on what the HPs tell me I will be using this information in a measurement type process so I really need their individual experiences, expertise and knowledge
    - I am looking at the dying well process and not just the point of death so any experiences around this time would be useful
    - confidentiality: won't be identified by the statements at all, all that will be available is a list of statements
    - outline other rights - withdraw at any time, choose not to answer questions, recheck still want to take part
    - get HPs consent to tape

General Getting Started Question

4. details of current role
    - how does role bring them into contact with PWTI
    - what sorts of things do you do? (to help me understand your role)

Main Questions

5. Can you give me some examples of dying well that you have seen, bearing in mind the idea of the dying process not just the end point?

6. Can you think of anyone else who died well, but somehow differently from those you have described already?
    - why did you think it was a good death for that person?

7. Is there anything good that can come out of a good death either for the individual or for the family?
    - What are the consequences of a good death for the individual, family member or staff member?

8. Have you ever felt in conflict with patient's views such that they wanted something in order to die well that you felt was not ideal or that turned out to be not ideal?
    - if no experience, think in the abstract of any times when this has potential to occur

9. Have there been any occasions when you or the patient were in conflict with the family's views?
    - how were they in conflict and how did it turn out?
    - if no experience, think of any times when this has potential to occur

repeat 5 - 9 with respect to **bad** death

10. Can you give me some examples of dying **badly** that you have seen, bearing in mind the idea of the dying process not just the end point?

11. Can you think of anyone else who died **badly**, but somehow differently from those you have described already
    - why did you think it was a **bad** death for that person?

12. What **bad** things come out of a **bad** death either for the individual or for the family?
    - What are the consequences of a **bad** death for the individual, family member or staff member?

13. Have you ever felt in conflict with patient's views such that **you** wanted something **for them** in order **for them** to die well but that they did not want?
    - if no experience, think of any times when this has potential to occur

Conclusion

14. Any of these questions too "raw" to ask patients?

15. Is there anything about dying well that I have missed?

16. Do you have any questions?

17. Thanks

Appendix C

Semi-structured Interview For Patients

Interview Outline

Introduction

1. explain who I am
   - primary researcher under the supervision of Associate Professor John Spicer
   - this is my PhD project
   - explain briefly what the project is about and purpose
     - helping patients live well up until their death
     - to ensure that everyone understands each other, people have different ideas about what dying well means
     - so I want to discover different meanings/understandings of dying well from the perspective of a variety of patients
     - it is an important time of life
     - it is hoped that the process of being interviewed may prove cathartic
     - this research should help ensure other's care is as good as possible

2. give information sheet to read
   - answer any questions
   - make sure they understand that what they say won't affect their care
   - also highlight that there are no right or wrong answers but that I am interested in their own perceptions
   - as I am the researcher the information they give me will be held in confidence and thus won't be passed on to anybody. It is hoped that talking to me about it might help facilitate their talk with carers or others

3. get to sign consent form

Main Questions

4. Tell me a bit about how you came to be here
   - what sort of effect does it have?
   - how have you been feeling?
   - hopefully this might get at the good and bad things that have happened

5. What would make things easier for you now?
   - what things could have been dealt with better?
   - as you look ahead what will make things easier in the future?

6. How might your family make the dying experience better?
    - how are your family coping?

7. How might the health professionals make your dying better?

8. Who else might assist in making the dying experience better?

9. Has there been any conflict between your views and your family's views?

10. Has there been any conflict between your views and the staff's views?

11. What things would get in the way of dying well?

12. It seems odd to think that anything good can happen but has anything positive come out of your illness?

13. Acknowledgement of their important contribution and ask them if there is anything that they would like to talk about.
    - any questions?

Appendix D

Information Sheet for Hospice Patients Involved in Developing the Concourse

Meanings of Dying Well

Principal Investigator:

Ms Angela McNaught
PhD Candidate
School of Psychology
Massey University
Private Bag 11-222
Palmerston North

Phone: (06) 350-5799 extn 2032

You are invited to take part in a study of differences in people's views of dying well. You can choose whether or not to take part, and can take as long as you wish to decide.

What is the study about?
The aim of the study is to develop an understanding of the variety of meanings of dying well from your perspective.

Who is being approached?
As a first step in the study we are seeking the participation of 10 patients who are diverse in terms of their age, gender, ethnic group and medical condition. This will enable us to find out what kind of issues are important to understanding dying well. We are approaching inpatients and outpatients who have been identified by Dr Allan, the Medical Director of Arohanui Hospice, as being well enough to cope with one 30 to 60 minute interview.

All participants will be interviewed by the principal researcher, Angela McNaught. Inpatients will be visited by Angela at the Hospice, and outpatients will be visited at their homes or anywhere else that they choose. During the interview you will be asked to talk about your own opinion on issues surrounding the idea of dying well. The information you provide will be used in the next part of the study which will include a larger group of patients.

What will happen to the information?
The interviews will be tape recorded so that the interviewer can concentrate on what you are saying and not on taking notes. Once the tapes have been transcribed by the principal researcher, they will be destroyed, unless you request the tape be returned to you. The transcriptions will be kept securely for five years and then destroyed. No material which could personally identify you will be used in any reports on this study.

The information you provide will not be passed on to any medical or nursing staff involved in your care, since it is being collected only for research purposes. We assume that you will communicate your needs and concems as usual with those who are caring for you.

What can participants expect?
Participation is entirely voluntary; it is your choice. If you choose not to take part, this will not affect your current or future care or treatment. If you do participate, you are free to withdraw at any time without giving a reason. Withdrawal will also not have any effect on your care or treatment. During the interview you do not have to answer all the questions and you may stop the interview at any time. Please also feel free to being along a friend, relative, whanau or support person to the interview.

We hope that participants will benefit from discussing their understandings of dying well in more detail than usual. Discussing some issues may prove upsetting, but if this happens you can pause or stop the interview. If there is any continuing distress, counselling help is available. In broader terms, participants may benefit from the knowledge that they are helping to develop an understanding of dying well that may enhance the care provided for future patients.

Once the study is complete, you can receive a summary of the results if you wish.

Where can I get further information?
This study has received ethical approval from the Manawatu-Whanganui Ethics Committee. If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate, phone 0800 112 233. If you have any questions about the study in general, please feel free to contact Ms McNaught, whose address and phone number are provided at the beginning of this information sheet, or you may contact Ms McNaught's supervisor, Dr John Spicer on 350-5799 extn 2070.

Appendix E

Consent Form Used for All Interviews

CONSENT FORM

Meanings of Dying Well

I have read and I understand the information sheet for volunteers taking part in a study of differences in people's views of a dying well. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time, and this will in no way affect my continuing health care.

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

I understand that the discussion will be audiotaped and that at the completion of the study the audiotape can be returned to me if I choose, otherwise it will be destroyed.

I have had time to consider whether to take part.

I know who to contact if I have any questions about the study.

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

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

This project has been approved by the Manawatu-Whanganui Ethics Committee. This means that the Ethics Committee may check that this study is running smoothly, and has followed appropriate ethical procedures. Complete confidentiality is assured. If you have any ethical concerns about the study, you may contact the Manawatu-Whanganui Ethics Committee on 06 356 7773.

Signature .... Date ....

Full names and phone numbers of researcher:
At Massey: Angela McNaught – 350-5799 xtn 2032, Dr John Spicer – 350-5799 xtn 2070.
At Arohanui Hospice: Dr Simon Allan – 356-6606.

Appendix F

Letter and Summary Information Sent to Interview Participants

28 June 2000

Dear

Meanings of Dying Well

During April and May of this year you may recall being interviewed for a study which aimed to understand individual meanings of dying well. The following is a summary of the results of these interviews as requested.

Most importantly, please accept my thanks for allowing me into your homes and lives, and for sharing with me your thoughts and feelings around a very sensitive topic. Your honesty in the interviews was very much appreciated and it is hoped that the information that you have given me will be able to help others who are in a similar situation.

What should become clear as you read through this summary is the diversity of themes that were produced by those who were interviewed. Different people talked about different things in different ways. The varied themes that emerged will provide the foundation for ongoing research, which will explain the themes in more detail.

Thank you for your valuable contribution to this research.

Kind regards

Angela McNaught
PhD Student

Meanings Of Dying Well

Summary of Participant Interviews

Participants and Setting

For this part of the study a total of 10 participants who were receiving palliative care from Arohanui Hospice were interviewed. Six women and four men, aged from early 40s to late 70s, agreed to be interviewed. All participants had cancer, although the sites of the cancers were variable, e.g. bowel, colon, and included some rare forms of cancer. The interviews lasted between 20 minutes and 3 hours (not in one sitting) and were carried out in the participant's home, my home or at the hospice.

Themes

During the interviews a wide range of themes arose that were important to the participants. In the following section each of the key themes will be identified, discussed briefly, and some examples given which characterise the particular theme. The examples that are given tend to paint a positive picture of the dying process. However, some of the themes listed were identified by the participants as being *absent* rather than *present* in their experience. For example, some participants felt that having family members visit was important even though their own family could not visit.

Family

For the majority of participants immediate and extended family played an important role. The importance of family was divided into three categories:

Family supportive
- I have the support of my own family
- my family visit me

Family get on with own life
- I respect that my family have their own lives to lead

Family characteristics
- I have wonderful children
- my family don't fuss
- my family are able to cope

Friends

Participants referred to their friends as having an important part in their lives, which differed from the roles their family fulfil.

- it is good to have friends around who understand my situation and who are accommodating
- I like to have good friends around me

Other Supportive People

Support outside of family and friends came from a number of different areas.

General
- I get support from my work colleagues
- I find my cancer support group good
- I have good neighbours
- I have a Christian family (i.e. experience fellow Christians as family)

In addition, participants identified particular characteristics of supporters that were beneficial in terms of fulfilling their role.

Characteristics
- you need people around who are not embarrassed to talk to you
- you need people who are able to cope with the situation

Work

Not all participants were still working, either because they had reached retirement or because of their ill health. For those who were employed (or would return to work), work provided a welcome diversion from their illness.

- work is challenging and therefore diverting
- work is part of my life, outside of my family
- work is therapeutic

Physical Symptoms

Physical symptoms were regularly mentioned. However, two distinct areas emerged: pain-related and non-pain related symptoms.

Pain
- I am not worried about pain because I know it will be kept under control
- I am comfortable to the point of being able to do things
- there is a balance between pain, nausea and still being coherent

Non-pain
- I still have energy to do things
- I am still able to eat what I want
- my physical problems are dealt with

Hospice

The hospice provided some general and specific services that were important to meeting the needs of participants. In terms of the hospice itself, three subcategories emerged:

The Hospice
Services
- the community nurse visits when the need arises
- I enjoyed my time at the day centre
- there is someone to help me with any spiritual concerns I may have

Education/Advice
- appropriate information is available if I need it
- I was informed of the potential side effects of the treatment
- I know what my disease entails

General
- I can contact the hospice day and night
- I know who the health professional is that I am going to see, it is not someone new each time

As well as the hospice and its services, the hospice staff were identified as a core feature. In particular, the personal characteristics of the staff were highlighted by most participants. However, different combinations of characteristics were apparent and clearly depended on individual participants' needs and preferences.

Hospice Staff
Characteristics
- the staff are friendly
- I like that the staff seem laid back
- I appreciate their honesty

General
- I like the hands-on approach
- I appreciated being introduced to everyone and shown around the hospice
- the staff seem to have good working relationships with each other

Time

Having time to deal with their illness was a frequent theme for participants.

- it is good for the family to have time to deal with the illness together
- I am glad that I have been told the timeframe
- I feel good about reaching my time limit and surviving

Location

Where the participant lived had the potential to influence their experience.

- I live in a community-spirited environment which is great
- it is good to live close to the hospital

Personal Competence

Personal competence is a category that seems to include a number of different personal characteristics that were important to individuals, particularly in maintaining their sense of self. Several different subcategories emerged:

Communication
- it is good to talk about my illness with my family
- I can talk to my family about death
- openness and honesty are particularly important to me

Feeling that they are able to continue to do things that they had done in the past, and that they were still capable of performing everyday tasks seemed to give the participants a feeling of competence.

Feeling Competent/Capable
- I am still active and able to do things that I enjoy
- I can still care for myself

Humour
- I enjoy a good laugh with friends
- there are still things I can laugh about

The idea of having control over our lives is a particularly powerful one, and it was a common feature here. However, the participants saw the ability to have control as targeted at certain areas.

Control
Of Treatment
- I realised that the treatment would be worse than the symptoms so I decided against treatment
- I have resisted traditional treatment and sought alternative treatments
- the doctors and I mutually agreed on what treatment was best for me

Of Life
- I feel in control of the little things at least
- I have actively decided not to worry

Wishes Granted
- I believe that my dying wishes will be respected

At times participants found control hard to achieve and on these occasions they drew on the themes of fatalism and luck.

Fatalism
- I realise that I can't do anything about the situation
- death is just a part of life
- fairness doesn't come into it

Luck
- I've been lucky

Comparison to Others

Participants frequently made comparisons to others who were worse off than they were and this seemed to provide a source of comfort. Having made the comparison they felt reassured because "things could be worse".

- I look at her and she is much worse off than I am
- I feel a bit guilty going into the hospice because I am the only one walking around

Live For Now

The idea of living for the moment came through in a number of interviews and seemed to fit into four subcategories. In the first category, live normally, there is a real emphasis on maintaining a normal lifestyle despite the circumstances.

Live Normally
- I want to lead a normal life as long as I can
- I don't think too much about death
- I am putting the disease aside

In the second category, being able to reconcile past issues that may have been troubling the individual allows them to live more fully in the present.

Reconciling the Past
- I am content with the way that I have lived my life
- there is nothing left for me to do
- I have no regrets

Living in the present, the third category, allows the individual to live as normally as possible in the moment as it arrives.

Living in the Present
- I just live day-to-day
- I am realistic about the situation

Finally, the fourth category, future, seemed to focus on having specific goals.

Future
- there are things that I look forward to
- you have got to have aims

Acceptance/Contentment

Accepting the situation and being content within themselves was important to some participants.

- I have accepted that I am dying
- I am at peace
- I am not afraid of dying

Spirituality

Spirituality did not play a role for all participants. However, when it did, it seemed to occur in two ways: either the individual had their own faith, or they had no faith of their own but allowed others with faith to help them

A Faith of One's Own
- I can enlist the help of a higher power
- I am peaceful because I know where I am going
- I have made peace with God
- my faith makes me feel supported

Accepting the Faith of Others Despite Own Beliefs
- people are praying for me
- I am hoping for a miracle

Moment of Death

Some participants spoke of aspects of their death that were important to them.

- I am sure it will be very quiet
- I will be well medicated so I won't know anything
- it will be quick

After Death

This was not so much spiritually, what would happen to the individual after death, but more what would be occurring for others (particularly family) after they had died.

- I know my family will be financially stable after I have gone
- I have talked about my future hopes for our children to my partner
- God will help my family after my death

Positive Things About Having Cancer

The final category, and probably the most extensive, was that of positive things that had come out of having a cancer diagnosis. This was a particularly diverse theme, but three broad sub-categories arose:

Family/Relationships
- I have become more family oriented
- my relationship with my children has changed
- I have been able to share some very precious moments with my children

Reflecting on Life
- you begin to re-evaluate your life
- I love life
- you leam to live for the moment
- I have reflected on my life and made some changes now

Personal Growth
- I am less controlling that I was before
- I have learned to compromise and become more adaptable
- I have got rid of the baggage and now have a stress free run
- I now realise that some things are just not my problem

Appendix G

48 Statements for Pilot Testing

No.	Statement Contents	Group
1	that I can access emotional advice through the hospice	other
2	that I am accepting of death	psych.
3	that I make my own decisions about whether or not to have treatment	body
4	that I make the most of every day	psych.
5	that I continue to do the things I enjoy	psych.
6	that I receive support from people other than my family and friends	social
7	that I feel my family will be okay after my death	other
8	that I know where I am going after this life	other
9	that I maintain my dignity	psych.
10	that I feel in control	psych.
11	that the hospice staff are understanding	social
12	that I have the support of my family	social
13	that I receive physical contact from my family	social
14	that my death is respectful	body
15	that hospice educates my family about my disease	other
16	that I will not be forgotten	psych.
17	that my physical symptoms are controlled	body
18	that I have no regrets	psych.
19	that I have discussed what I want for my death with my family	social
20	that I have my will organised	other
21	that hospice staff talk to me honestly	social
22	that at the time of my death I am at home	body
23	that conflict within my family is resolved	social
24	that I keep some thins to myself	psych.
25	that at the time of my death I have my family around me	body
26	that I have my finances in order	other
27	that I try alternative treatments	body
28	that hospice treats me like a well person	other
29	that at the time of my death I am ready to die	body
30	that I have been loved	psych.
31	that my family et on with their own lives	social
32	that I have a strong faith in God	other
33	that I realise the value of life	psych.
34	that at the time of my death I hear the spoken word	body
35	that I have time just for me	psych.
36	that I maintain hope	psych.
37	that people are sensitive to the needs of my new situation	social
38	that my level of medication allows me to still communicate	body
39	that I have people praying for me	other
40	that my family feel able to freely express their feelings	social
41	that hospice helps me to understand what is happening to me	other
42	that my pain is managed	body

No.	Statement Contents	Group
43	that I am given a timeframe	other
44	that the hospice staff are laid back	social
45	that my death is peaceful	body
46	that I have good friends around	social
47	that I don't look ill	body
48	that I have my funeral organised	other[17]

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[17] These represent very broad categories, and where psych. = psychological, and body, refers to physical aspects of dying as well as actual time of death details.

Appendix H

Pilot Study Information Sheet for Patients

Meanings of Dying Well

Principal Investigator:

Ms Angela McNaught
PhD Candidate
School of Psychology
Massey University
Private Bag 11-222
Palmerston North

Phone: (06) 350-5799 extn 2032

You are invited to take part in a study of differences in people's views of dying well. You can choose whether or not to take part, and can take as long as you wish to decide.

What is the study about?
The aim of the study is to develop an understanding of the variety of meanings of dying well from your perspective.

Who is being approached?
As a first step in the study we are seeking the participation of 25 patients who are diverse in terms of their age, gender, ethnic group and medical condition. This will enable us to find out what kinds of issues are important to understanding dying well. We are approaching inpatients and outpatients who have been identified by Dr Allan, the Medical Director of Arohanui Hospice, as being well enough to cope with one 30 to 60 minute interview.

All participants will be interviewed by the principal researcher, Angela McNaught. Inpatients will be visited by Angela at the Hospice, and outpatients will be visited at their homes or anywhere else that they choose. During the interview you will be asked to talk about your own opinion on issues surrounding the idea of dying well. The information you provide will be used in the next part of the study which will include a larger group of patients.

What will happen to the information?
The interviews will be tape recorded so that the interviewer can concentrate on what you are saying and not on taking notes. Once the tapes have been transcribed by the principal researcher, they will be destroyed, unless you request the tape be returned to you. The transcriptions will be kept securely for five years and then destroyed. No material which could personally identify you will be used in any reports on this study.

The information you provide will not be passed on to any medical or nursing staff involved in your care, since it is being collected only for research purposes. We assume that you will communicate your needs and concerns as usual with those who are caring for you.

What can participants expect?
Participation is entirely voluntary; it is your choice. If you choose not to take part, this will not affect your current or future care or treatment. If you do participate, you are free to withdraw at any time without giving a reason. Withdrawal will also not have any effect on your care or treatment. During the interview you do not have to answer all the questions and you may stop the interview at any time. Please also feel free to being along a friend, relative, whanau or support person to the interview.

We hope that participants will benefit from discussing their understandings of dying well in more detail than usual. Discussing some issues may prove upsetting, but if this happens you can pause or stop the interview. If there is any continuing distress, counselling help is available. In broader terms, participants may benefit from the knowledge that they are helping to develop an understanding of dying well that may enhance the care provided for future patients.

Once the study is complete, you can receive a summary of the results if you wish.

Where can I get further information?
This study has received ethical approval from the Manawatu-Whanganui Ethics Committee. If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate, phone 0800 112 233. If you have any questions about the study in general, please feel free to contact Ms McNaught, whose address and phone number are provided at the beginning of this information form, or you may contact Ms McNaught's supervisor, Dr John Spicer on 350-5799 extn 2070.

Appendix I

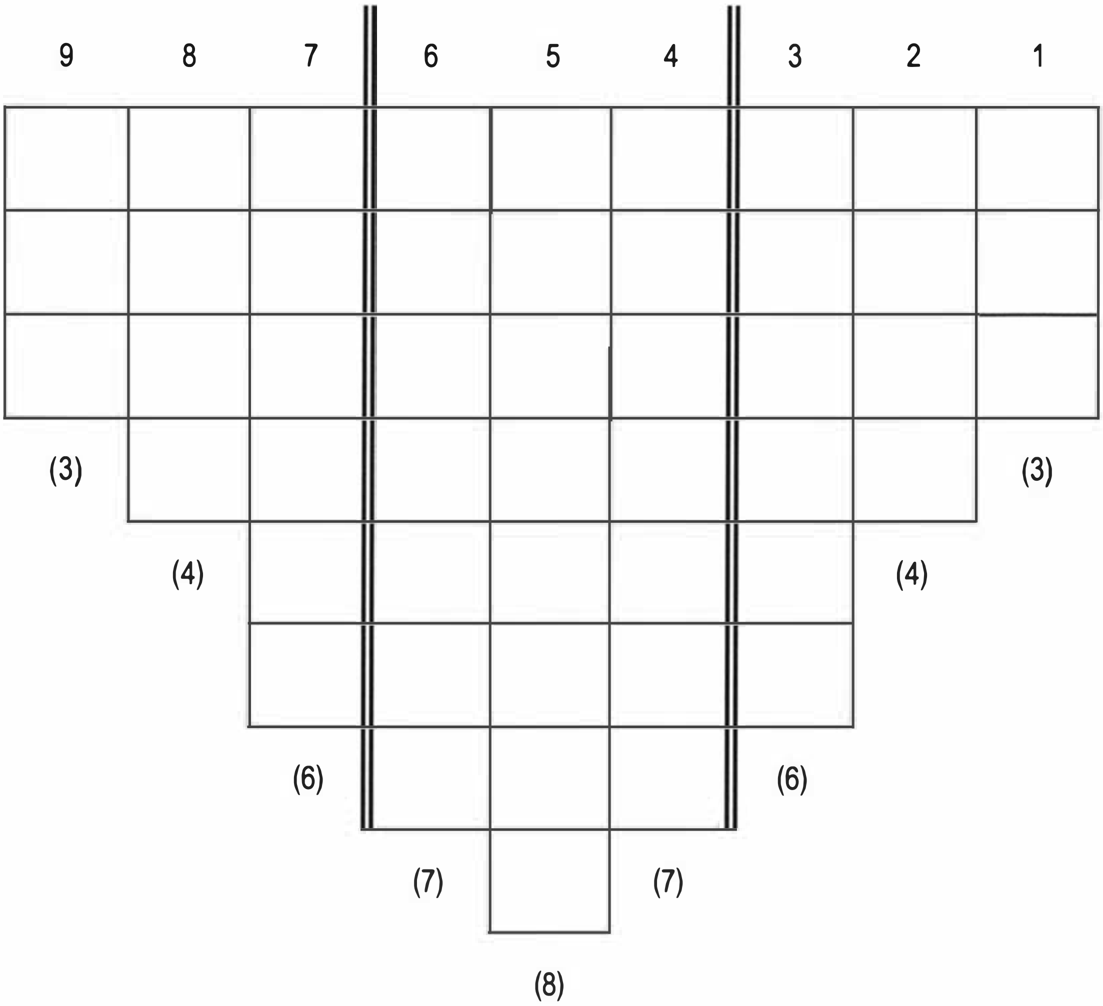
Scoring Sheet for 48 Statement Q-set

Scoring Sheet for 48 Statement Q-set

Participant Number: ______________

Date: ______________

Very important to me-----------------Somewhat important to me --------Not at all important to me



Comments:

Appendix J

Table of Main Study Participant Characteristics

Main Study Participant Characteristics

	n	%
Age		
30 - 39	1	2.5%
40 - 49	5	12.5%
50 - 59	3	7.5%
60 - 69	12	30.0%
70 - 79	11	27.5%
80+	8	20.0%
Ethnicity		
NZ European	34	85.0%
Maori	3	7.5%
Other	3	7.5%
Marital Status		
Married	19	48.5%
Widowed	9	22.5%
Single	4	10.0%
Divorced	3	10.0%
Other	4	7.5%
Gender		
Male	23	57.0%
Female	17	43.0%
Primary Disease Site		
Bowel/Colon	11	27.5%
Lung	6	15.0%
Breast	5	12.5%
Stomach	3	7.5%
Prostate	3	7.5%
Head/Neck	2	5.0%
Leiomyosarcoma	1	2.5%
Lymphoma	1	2.5%
Myeloma	1	2.5%
Oesophagus	1	2.5%
Pancreas	1	2.5%
Renal	1	2.5%
Thyroid	1	2.5%
Unknown	1	2.5%
Motor Neurone Disease	1	2.5%

Appendix K

Information Sheet for Main Study Participants

Meanings of Dying Well

Principal Investigator:

Ms Angela McNaught
PhD Candidate
School of Psychology
Massey University
Private Bag 11-222
Palmerston North

Phone: (06) 350-5799 xtn 2045

You are invited to take part in a study of differences in people's views of dying well. You can choose whether or not to take part, and can take as long as you wish to decide.

What is the study about?
The aim of the study is to develop an understanding of the variety of meanings of dying well from your perspective.

Who is being approached?
We are seeking the participation of 60 patients who are diverse in terms of their age, gender, ethnic group and medical condition. This will enable us to find out how people understand dying well. We are approaching inpatients and outpatients who have been identified by Dr Allan, the Medical Director of Arohanui Hospice, as being well enough to cope with up to two 30 to 60 minute interviews.

All participants will be interviewed by the principal researcher, Angela McNaught. Inpatients will be visited by Angela at the Hospice, and outpatients will be visited at their homes or anywhere else that they choose. During the first interview you will be asked to carry out a task which involves rank ordering statements about dying well and talking about any issues surrounding the idea of dying well that you feel are important. You may be asked to do a second interview during which you will be asked to reflect on the task from the first interview.

What will happen to the information?
The session will be tape recorded so that conversations can be easily recorded and not interrupted by either frequent questioning or excessive writing. Once the tapes have been transcribed by the principal researcher, they will be destroyed. All transcriptions and completed forms (ranking statements) will be identified by a code number and will only be available to the research team. The transcriptions and forms will be kept securely for five years and then destroyed. No material which could personally identify you will be used in any reports on this study.

The information you provide will not be passed on to any medical or nursing staff involved in your care, since it is being collected only for research purposes. We assume that you will communicate your needs and concerns as usual with those who are caring for you.

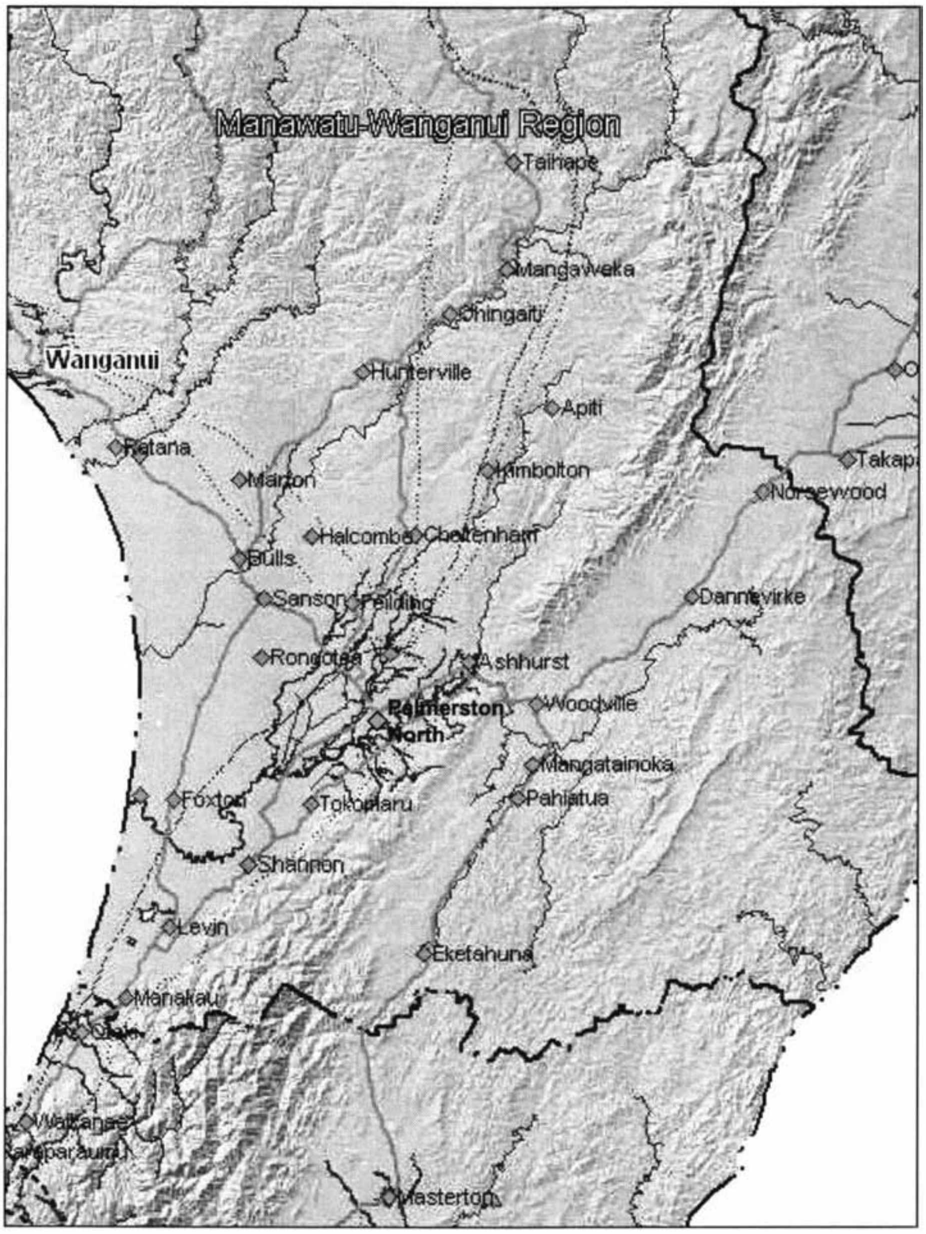
What can participants expect?
Participation is entirely voluntary; it is your choice. If you choose not to take part, this will not affect your current or future care or treatment. If you do participate, you are free to withdraw at any time without giving a reason. Withdrawal will also not have any effect on your care or treatment. During the interview you do not have to answer all the questions and you may stop the interview at any time.

We hope that participants will benefit from discussing their understandings of dying well in more detail than usual. Discussing some issues may prove upsetting, but if this happens you can pause or stop the interview. If there is any continuing distress, counselling help is available. In broader terms, participants may benefit from the knowledge that they are helping to develop an understanding of dying well that may enhance the care provided for future patients.

Where can I get further information?
This study has received ethical approval from the Manawatu-Whanganui Ethics Committee. If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate, phone 0800 112 233. If you have any questions about the study in general, please feel free to contact Ms McNaught, whose address and phone number are provided at the beginning of this information sheet, or you may contact Ms McNaught's supervisor, Dr John Spicer on 350-5799 extn 2070.

Appendix L

Map of Manawatu and Horowhenua Regions



Source: http://www.treenote.co.nz/Maps/mapni_manawaturegion.htm

Appendix M

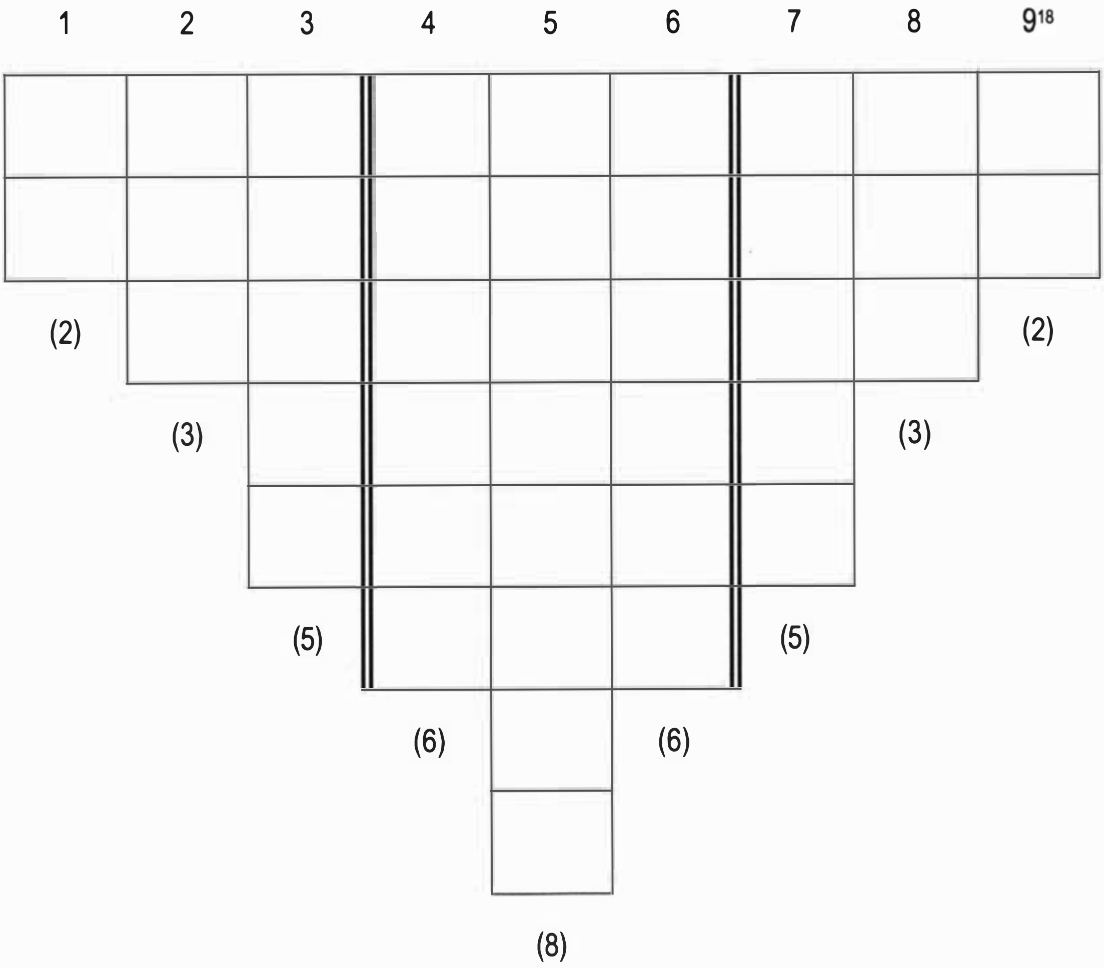
Scoring Sheet for 40 Statement Q-set

Scoring Sheet for 40 Statement Q-set

Participant Number: ______________

Date: ______________

Most important------------------------------- Quite important----------------------------- Least important



Comments:

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[18] These numbers represent the numbers entered into PQ-Method and SPSS

Appendix N

Demographic Information Form

Demographic Information

Participant No. ______________

Date ______________

Gender	Male	☐	0
	Female	☐	1
Date of Birth	____ / ____ / 20____		
Age	<20	☐	1
	20 - 29	☐	2
	30 - 39	☐	3
	40 - 49	☐	4
	50 - 59	☐	5
	60 - 69	☐	6
	70 - 79	☐	7
	>80	☐	8
Type of Illness	Breast Cancer	☐	1
	Colon and Rectum Cancer	☐	2
	Female Genital Organ Cancer	☐	3
	Lung Cancer	☐	4
	Male Genital Organ Cancer	☐	5
	Oesophagus and Stomach Cancer	☐	6
	Skin Cancer	☐	7
	Other Cancer ____________________	☐	8
	Non-Cancer ____________________	☐	9
Marital Status	Divorced	☐	1
	Married	☐	2
	Single	☐	3
	Widowed	☐	4
	Other ________________________	☐	5
Religion[19]	Yes	☐	0
	No	☐	1
Ethnicity	Asian	☐	1
	NZ European	☐	2
	NZ Maori	☐	3
	Pacific Island	☐	4
	Other ________________________	☐	5

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[19] The following question was asked: Do you describe yourself as religious?

Appendix O

Table of Distinguishing Statements Across All Four Accounts

Rankings of Distinguishing Statements Across All Four Accounts

		Account			
No.	**Statement**	**1**	**2**	**3**	**4**
8	that I know where I am going after this life	**1**[20]	9	**7**	9
32	that I have a strong faith in God	**1**	**8**	6	5
39	that I have people praying for me	**2**	8	**5**	7
7	that my family will be okay emotionally after my death	**3**	5	5	**3**
29	that at the time of my death I am ready to die	**3**	5	5	5
9	that I maintain my dignity	**4**	**1**	**6**	**3**
13	that I receive physical contact from my family	**4**	5	6	**3**
25	that at the time of my death I have my family around me	**4**	**7**	2	2
37	that I maintain my sense of humour	**5**	1	2	**4**
14	that I have my funeral organised	**6**	**4**	**9**	**2**
34	that my physical symptoms (besides pain) are controlled	**6**	4	4	**6**
16	that I will not be forgotten	**7**	**9**	3	4
35	that I have time just for me	**7**	6	**8**	5
22	that I die at home	**8**	7	7	6
27	that I try unconventional treatments	**9**	7	7	8
17	that my physical pain is managed	3	**2**	3	4
2	that I avoid becoming totally dependent on others	5	**2**	5	**6**
3	that I make my own decisions about whether or not to have treatment	6	**2**	5	6
4	that I make the most of every day	4	**3**	**1**	5
10	that I feel in control	6	**3**	5	5
12	that I have the support of my family	2	**4**	2	**1**
24	that I keep some things to myself	8	**5**	8	9
33	that I feel like my life has meaning	4	**6**	4	**8**
5	that I don't look ill	9	**7**	9	8
30	that I have been loved	2	**8**	**1**	3
36	that I maintain hope	6	5	**3**	**7**
28	that I have good friends around	5	5	**4**	**7**
19	that I have discussed what I want for my death with my family	4	5	**6**	**2**
1	that I have time to come to terms with my illness	5	4	**7**	4
26	that I have my financial affairs in order	5	4	**8**	3
11	that my death is peaceful	3	3	3	**1**
23	that conflict within my family is resolved	6	6	5	**7**
	Total Number of Distinguishing Statements Per Account	**15**	**15**	**12**	**14**

---

[20] Bold text denotes for which factor the statement is distinguishing.

Appendix P

Correlation Matrix

	P01	P02	P03	P04	P05	P06	P07	P08	P09	P10	P11	P12	P13	P14
P01	-													
P02	-0.28	-												
P03	0.21	-0.25	-											
P04	-0.08	0.65	-0.26	-										
P05	0.28	-0.05	-0.02	0.24	-									
P06	0.14	0.21	0.02	0.21	0.33	-								
P07	0.06	-0.08	0.46	-0.11	0.19	0.19	-							
P08	-0.01	0.39	-0.25	0.68	0.11	0.15	0.02	-						
P09	0.18	0.32	-0.16	0.61	0.14	0.12	-0.02	0.45	-					
P10	0.38	0.06	0.19	0.13	0.38	0.33	0.12	0.06	0.28	-				
P11	0.12	-0.01	0.32	0.27	0.19	0.40	0.39	0.24	0.22	0.30	-			
P12	0.09	0.04	-0.02	0.34	0.15	0.29	-0.01	0.38	0.36	0.00	0.15	-		
P13	0.31	0.11	0.31	0.36	0.29	0.31	0.28	0.49	0.39	0.35	0.54	0.34	-	
P14	0.04	-0.19	0.51	-0.06	0.08	0.22	0.28	0.02	-0.09	0.16	0.27	0.16	0.09	-
P15	-0.17	0.18	0.05	0.35	0.12	0.32	0.12	0.55	0.34	0.28	0.29	0.35	0.50	0.16
P16	-0.09	0.49	-0.21	0.59	0.09	-0.04	0.06	0.34	0.42	0.06	0.03	0.20	0.28	-0.06
P17	0.12	-0.04	0.46	0.16	0.35	0.49	0.36	-0.05	0.25	0.47	0.32	0.32	0.42	0.39
P18	-0.18	0.47	-0.18	0.48	0.26	0.37	0.02	0.35	0.48	0.38	0.26	0.35	0.39	-0.10
P19	-0.26	0.15	-0.16	0.38	0.39	0.37	0.24	0.19	0.04	0.02	0.36	0.34	0.06	0.04
P20	-0.16	0.08	0.52	0.00	0.12	0.14	0.15	0.09	-0.29	0.13	0.17	-0.18	0.29	0.31
P21	0.01	0.37	0.11	0.54	0.09	0.10	0.21	0.64	0.35	0.14	0.10	0.21	0.48	0.05
P22	0.10	0.31	0.01	0.27	0.05	0.15	-0.06	0.36	0.37	0.40	0.15	0.06	0.38	0.02
P23	0.04	-0.22	0.59	-0.16	0.04	0.07	0.06	-0.21	-0.25	0.12	0.11	-0.34	0.09	0.32
P24	-0.05	0.16	0.29	0.10	0.04	-0.04	0.12	-0.23	0.00	0.27	-0.01	-0.15	0.06	0.25
P25	0.12	-0.02	0.19	0.12	-0.15	0.31	0.11	0.35	0.16	0.28	0.44	0.11	0.42	0.39
P26	0.00	0.49	0.18	0.54	0.06	0.18	0.24	0.43	0.46	0.41	0.32	0.16	0.48	0.06
P27	0.09	0.19	-0.04	0.36	-0.02	0.26	-0.17	0.42	0.39	0.13	0.14	0.36	0.28	-0.04
P28	0.23	0.30	-0.22	0.56	0.23	0.14	-0.04	0.49	0.49	0.28	0.09	0.11	0.36	-0.04
P29	-0.31	0.21	-0.01	0.26	-0.35	-0.25	0.04	0.18	0.44	-0.16	-0.09	0.26	-0.09	0.14
P30	0.24	0.03	0.28	0.07	0.12	0.38	0.36	0.24	0.05	0.24	0.47	0.14	0.50	0.32
P31	0.15	-0.12	0.55	0.03	0.15	0.35	0.46	0.11	-0.02	0.19	0.38	0.25	0.31	0.25
P32	0.28	0.32	-0.06	0.46	0.44	0.41	0.08	0.28	0.49	0.25	0.19	0.21	0.36	0.05
P33	-0.01	0.14	0.19	0.26	0.16	0.13	0.22	0.24	0.28	0.20	0.14	0.04	0.17	0.13
P34	-0.04	0.22	0.03	0.48	0.36	0.16	0.15	0.25	0.49	0.37	0.30	0.44	0.43	-0.11
P35	0.00	0.42	-0.03	0.35	0.11	0.47	0.27	0.52	0.30	0.09	0.19	0.46	0.40	0.12
P36	0.09	0.08	0.08	0.11	0.12	0.41	-0.07	0.10	0.05	0.26	0.29	0.19	0.37	0.09
P37	0.25	0.06	-0.01	0.25	0.04	0.28	-0.10	0.37	0.49	0.44	0.04	0.38	0.32	0.15
P38	0.05	0.25	-0.13	0.41	0.25	0.03	-0.05	0.21	0.45	0.31	0.29	0.31	0.36	-0.22
P39	-0.04	-0.14	0.54	0.02	-0.09	0.16	0.17	-0.02	-0.07	0.07	0.29	0.19	0.26	0.38
P40	0.20	-0.04	0.49	0.15	0.34	0.44	0.51	0.17	0.14	0.24	0.32	0.22	0.32	0.43

	P15	P16	P17	P18	P19	P20	P21	P22	P23	P24	P25	P26	P27	P28
P01														
P02														
P03														
P04														
P05														
P06														
P07														
P08														
P09														
P10														
P11														
P12														
P13														
P14														
P15	-													
P16	0.14	-												
P17	0.33	0.12	-											
P18	0.58	0.40	0.34	-										
P19	0.12	0.13	0.32	0.25	-									
P20	0.12	-0.05	0.21	0.02	0.04	-								
P21	0.51	0.25	0.14	0.38	-0.09	0.09	-							
P22	0.26	0.29	0.34	0.22	-0.08	0.08	0.28	-						
P23	0.05	-0.30	0.26	-0.12	-0.16	0.62	0.15	0.05	-					
P24	-0.05	0.43	0.16	0.08	-0.12	0.22	0.16	0.12	0.23	-				
P25	0.37	0.05	0.21	0.14	-0.08	0.19	0.32	0.49	0.17	0.16	-			
P26	0.44	0.53	0.31	0.49	-0.04	0.05	0.56	0.40	-0.15	0.39	0.42	-		
P27	0.40	0.18	0.03	0.35	0.12	-0.06	0.27	0.12	-0.12	-0.06	0.39	0.42	-	
P28	0.28	0.31	0.05	0.39	0.08	-0.01	0.43	0.25	-0.06	0.11	0.26	0.35	0.36	-
P29	0.04	0.17	0.02	0.04	-0.08	-0.24	0.16	-0.04	-0.29	0.05	-0.02	0.28	-0.03	-0.07
P30	0.24	0.04	0.38	0.12	-0.04	0.25	0.25	0.39	0.13	0.05	0.37	0.28	-0.02	0.14
P31	0.08	0.03	0.52	-0.05	0.33	0.47	0.12	0.22	0.29	0.11	0.24	0.10	0.04	-0.05
P32	0.22	0.47	0.41	0.35	0.15	0.01	0.29	0.53	0.02	0.27	0.24	0.37	0.13	0.32
P33	0.12	0.03	0.20	0.09	0.16	0.16	0.38	0.14	0.18	0.08	0.24	0.26	0.20	0.12
P34	0.50	0.52	0.45	0.68	0.34	0.01	0.30	0.21	-0.07	0.23	0.06	0.54	0.29	0.33
P35	0.36	0.18	0.22	0.38	0.30	0.17	0.34	0.33	-0.12	-0.02	0.38	0.27	0.32	0.32
P36	0.06	0.10	0.18	0.12	-0.01	0.24	0.04	0.29	-0.05	0.19	0.24	0.20	0.11	0.22
P37	0.28	0.15	0.25	0.34	-0.16	0.03	0.31	0.33	-0.07	-0.02	0.36	0.32	0.35	0.32
P38	0.19	0.29	0.28	0.42	0.13	-0.12	0.08	0.35	-0.25	0.00	-0.21	0.21	-0.13	0.14
P39	0.29	0.10	0.38	0.14	0.08	0.32	0.10	-0.04	0.36	0.25	0.22	0.18	0.18	0.04
P40	0.18	0.14	0.58	0.11	0.31	0.36	0.29	0.15	0.36	0.16	0.35	0.26	0.32	0.09

	P29	P30	P31	P32	P33	P34	P35	P36	P37	P38	P39	P40
P01												
P02												
P03												
P04												
P05												
P06												
P07												
P08												
P09												
P10												
P11												
P12												
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P15												
P16												
P17												
P18												
P19												
P20												
P21												
P22												
P23												
P24												
P25												
P26												
P27												
P28												
P29	-											
P30	-0.19	-										
P31	-0.15	0.31	-									
P32	-0.16	0.35	0.24	-								
P33	0.09	-0.07	0.33	0.30	-							
P34	0.02	0.16	0.21	0.41	0.22	-						
P35	0.06	0.30	0.27	0.40	0.22	0.29	-					
P36	-0.28	0.43	0.27	0.28	0.14	0.15	0.22	-				
P37	0.15	0.25	0.10	0.20	0.11	0.26	0.29	0.16	-			
P38	0.14	0.17	0.04	0.22	-0.14	0.41	0.04	0.24	0.19	-		
P39	-0.06	0.06	0.31	-0.08	-0.15	0.24	0.02	0.10	0.24	0.02	-	
P40	-0.16	0.26	0.69	0.43	0.44	0.25	0.42	0.05	0.24	-0.16	0.29	-

Appendix Q

Exemplar Q-Sorts

Most Important				Quite Important				Least Important
that I have a strong faith in God 32	that I have the support of my family 12	that my death is peaceful 11	that I receive physical contact from my family 13	that I have my financial affairs in order 26	that I maintain hope 36	that I receive support from people other than family and friends 6	that my family sometimes keep their feelings to themselves 40	that I don't look ill 5
that I know where I am going after this life 8	that I have been loved 30	that my physical pain is managed 17	that at the time of my death I have my family around me 25	that hospice staff are supportive 21	that I have my funeral organised 14	that I have a say in what the hospice tells my family 15	that I die at home 22	that I try unconventional treatments 27
	that I have people praying for me 39	that at the time of my death I am ready to die 29	that I maintain my dignity 9	that I maintain my sense of humour 37	that my physical symptoms (besides pain) are controlled 34	that I have time just for me 35	that I keep some things to myself 24	
		that I feel like I have achieved something in life 18	that I feel like my life has meaning 33	that during my illness my family get on with their own lives 31	that conflict within my family is resolved 23	that I will not be forgotten 16		
		that my family will be okay emotionally after my death 7	that I have discussed what I want for my death with my family 19	that I have good friends around 28	that I feel in control 10	that I am given a timeframe 20		
			that I make the most of every day 4	that my level of medication allows me to still communicate 38	that I make my own decisions about whether or not to have treatment 3			
				that I have time to come to terms with my illness 1				
				that I avoid becoming totally dependent on others 2				

Figure 6: Q-sort Exemplar for the Religious-oriented Account

Most Important				Quite Important				Least Important
that I maintain my sense of humour 37	that I avoid becoming totally dependent on others 2	that I feel in control 10	that I have my financial affairs in order 26	that I have discussed what I want for my death with my family 19	that I have time just for me 35	that I don't look ill 5	that I have been loved 30	that I know where I am going after this life 8
that I maintain my dignity 9	that my physical pain is managed 17	that my level of medication allows me to still communicate 38	that my physical symptoms (besides pain) are controlled 34	that I maintain hope 36	that I am given a timeframe 20	that at the time of my death I have my family around me 25	that I have people praying for me 39	that I will not be forgotten 16
	that I make my own decisions about whether or not to have treatment 3	that my death is peaceful 11	that I have my funeral organised 14	that I receive physical contact from my family 13	that conflict within my family is resolved 23	that I die at home 22	that I have a strong faith in God 32	
		that I make the most of every day 4	that I have the support of my family 12	that at the time of my death I am ready to die 29	that I feel like I have achieved something in life 18	that I try unconventional treatments 27		
		that during my illness my family get on with their own lives 31	that I have time to come to terms with my illness 1	that my family will be okay emotionally after my death 7	that I feel like my life has meaning 33	that my family sometimes keep their feelings to themselves 40		
			that hospice staff are supportive 21	that I keep some things to myself 24	that I receive support from people other than family and friends 6			
				that I have a say in what the hospice tells my family 15				
				that I have good friends around 28				

Figure 7: Q-sort Exemplar for the Independent-oriented Account

Most Important				**Quite Important**				**Least Important**
that I make the most of every day **4**	that at the time of my death I have my family around me **25**	that my level of medication allows me to still communicate **38**	that I have good friends around **28**	that hospice staff are supportive **21**	that I receive physical contact from my family **13**	that I try unconventional treatments **27**	that I keep some things to myself **24**	that I have my funeral organised **14**
that I have been loved **30**	that I maintain my sense of humour **37**	that I maintain hope **36**	that I receive support from people other than family and friends **6**	that I have people praying for me **39**	that I have discussed what I want for my death with my family **19**	that I am given a timeframe **20**	that I have time just for me **35**	that I don't look ill **5**
	that I have the support of my family **12**	that my physical pain is managed **17**	that my physical symptoms (besides pain) are controlled **34**	that I feel in control **10**	that my family sometimes keep their feelings to themselves **40**	that I die at home **22**	that I have my financial affairs in order **26**	
		that I will not be forgotten **16**	that I feel like my life has meaning **33**	that I avoid becoming totally dependent on others **2**	that I have a say in what the hospice tells my family **15**	that I know where I am going after this life **8**		
		that my death is peaceful **11**	that I feel like I have achieved something in life **18**	that my family will be okay emotionally after my death **7**	that I have a strong faith in God **32**	that I have time to come to terms with my illness **1**		
			that during my illness my family get on with their own lives **31**	that at the time of my death I am ready to die **29**	that I maintain my dignity **9**			
				that I make my own decisions about whether or not to have treatment **3**				
				that conflict within my family is resolved **23**				

Figure 8: Q-sort Exemplar for the Idealised Account

Most Important				Quite Important				Least Important
that I have the support of my family 12	that I have my funeral organised 14	that my family will be okay emotionally after my death 7	that I will not be forgotten 16	that my level of medication allows me to still communicate 38	that I am given a timeframe 20	that I maintain hope 36	that I try unconventional treatments 27	that I keep some things to myself 24
that my death is peaceful 11	that at the time of my death I have my family around me 25	that I receive physical contact from my family 13	that I maintain my sense of humour 37	that at the time of my death I am ready to die 29	that I feel like I have achieved something in life 18	that I have good friends around 28	that I don't look ill 5	that I know where I am going after this life 8
	that I have discussed what I want for my death with my family 19	that I maintain my dignity 9	that my physical pain is managed 17	that I feel in control 10	that I avoid becoming totally dependent on others 2	that my family sometimes keep their feelings to themselves 40	that I feel like my life has meaning 33	
		that I have been loved 30	that hospice staff are supportive 21	that during my illness my family get on with their own lives 31	that I die at home 22	that I have people praying for me 39		
		that I have my financial affairs in order 26	that I have time to come to terms with my illness 1	that I have a say in what the hospice tells my family 15	that I make my own decisions about whether or not to have treatment 3	that conflict within my family is resolved 23		
			that I receive support from people other than family and friends 6	that I make the most of every day 4	that my physical symptoms (besides pain) are controlled 34			
				that I have a strong faith in God 32				
				that I have time just for me 35				

Figure 9: Q-sort Exemplar for the Family-oriented Account

Appendix R

Descending Array of Differences Tables

Descending Array of Differences Between Religious and Independent Accounts

No.	Statement	Rel[21].	Ind.	Diff.
3	that I make my own decisions about whether or not to have treatment	0.37	-1.44	1.80
37	that I maintain my sense of humour	-0.10	-1.84	1.75
2	that I avoid becoming totally dependent on others	0.06	-1.60	1.67
10	that I feel in control	0.33	-1.20	1.53
24	that I keep some things to myself	1.60	0.18	1.42
27	that I try unconventional treatments	2.35	0.97	1.39
9	that I maintain my dignity	-0.41	-1.72	1.31
38	that my level of medication allows me to still communicate	0.02	-1.18	1.20
5	that I don't look ill	1.70	0.71	0.99
20	that I am given a timeframe	1.25	0.26	0.99
4	that I make the most of every day	-0.21	-1.10	0.90
34	that my physical symptoms (besides pain) are controlled	0.17	-0.56	0.73
22	that I die at home	1.51	0.79	0.71
31	that during my illness my family get on with their own lives	0.00	-0.70	0.70
35	that I have time just for me	0.88	0.25	0.63
17	that my physical pain is managed	-0.94	-1.52	0.58
14	that I have my funeral organised	0.12	-0.44	0.55
15	that I have a say in what the hospice tells my family	0.73	0.19	0.54
40	that my family sometimes keep their feelings to themselves	1.47	0.99	0.48
26	that I have my financial affairs in order	-0.19	-0.56	0.37
1	that I have time to come to terms with my illness	0.03	-0.33	0.35
21	that hospice staff are supportive	-0.10	-0.25	0.15
11	that my death is peaceful	-1.04	-1.13	0.09
6	that I receive support from people other than family and close friends	0.67	0.65	0.02
36	that I maintain hope	0.07	0.08	-0.01
23	that conflict within my family is resolved	0.30	0.36	-0.06
28	that I have good friends around	0.01	0.24	-0.23
19	that I have discussed what I want for my death with my family	-0.25	0.01	-0.26
13	that I receive physical contact from my family	-0.57	0.11	-0.68
7	that my family will be okay emotionally after my death	-0.62	0.18	-0.80
33	that I feel like my life has meaning	-0.36	0.54	-0.90
29	that at the time of my death I am ready to die	-0.75	0.17	-0.91
12	that I have the support of my family	-1.33	-0.39	-0.95
16	that I will not be forgotten	1.04	2.12	-1.08
18	that I feel like I have achieved something in life	-0.73	0.45	-1.17
25	that at the time of my death I have my family around me	-0.43	0.78	-1.21
30	that I have been loved	-1.16	1.03	-2.18
39	that I have people praying for me	-1.12	1.44	-2.56
8	that I know where I am going after this life	-1.66	1.79	-3.45
32	that I have a strong faith in God	-2.71	1.70	-4.41

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[21] Rel. = Religious-oriented account, Ind. = Independent-oriented account, Ide. = Idealised account, Fam. = Family-oriented account, Diff. = difference.

Descending Array of Differences Between Religious and Idealised Accounts

No.	Statement	Rel.	Ide.	Diff.
16	that I will not be forgotten	1.04	-0.80	1.85
4	that I make the most of every day	-0.21	-1.99	1.78
27	that I try unconventional treatments	2.35	0.76	1.59
37	that I maintain my sense of humour	-0.10	-1.41	1.31
6	that I receive support from people other than family and close friends	0.67	-0.61	1.27
38	that my level of medication allows me to still communicate	0.02	-1.23	1.25
25	that at the time of my death I have my family around me	-0.43	-1.61	1.18
36	that I maintain hope	0.07	-0.96	1.03
40	that my family sometimes keep their feelings to themselves	1.47	0.69	0.79
28	that I have good friends around	0.01	-0.71	0.71
34	that my physical symptoms (besides pain) are controlled	0.17	-0.53	0.70
30	that I have been loved	-1.16	-1.83	0.68
22	that I die at home	1.51	0.95	0.55
10	that I feel in control	0.33	-0.20	0.53
31	that during my illness my family get on with their own lives	0.00	-0.39	0.40
24	that I keep some things to myself	1.60	1.22	0.37
20	that I am given a timeframe	1.25	0.89	0.36
21	that hospice staff are supportive	-0.10	-0.35	0.25
2	that I avoid becoming totally dependent on others	0.06	-0.12	0.18
33	that I feel like my life has meaning	-0.36	-0.51	0.15
3	that I make my own decisions about whether or not to have treatment	0.37	0.24	0.13
15	that I have a say in what the hospice tells my family	0.73	0.69	0.04
17	that my physical pain is managed	-0.94	-0.95	0.01
23	that conflict within my family is resolved	0.30	0.36	-0.07
12	that I have the support of my family	-1.33	-1.25	-0.08
5	that I don't look ill	1.70	1.90	-0.20
11	that my death is peaceful	-1.04	-0.74	-0.30
18	that I feel like I have achieved something in life	-0.73	-0.40	-0.32
35	that I have time just for me	0.88	1.35	-0.47
7	that my family will be okay emotionally after my death	-0.62	-0.08	-0.54
39	that I have people praying for me	-1.12	-0.27	-0.85
19	that I have discussed what I want for my death with my family	-0.25	0.64	-0.88
29	that at the time of my death I am ready to die	-0.75	0.19	-0.93
13	that I receive physical contact from my family	-0.57	0.42	-0.99
1	that I have time to come to terms with my illness	0.03	1.11	-1.09
9	that I maintain my dignity	-0.41	0.70	-1.11
14	that I have my funeral organised	0.12	1.69	-1.58
26	that I have my financial affairs in order	-0.19	1.39	-1.58
8	that I know where I am going after this life	-1.66	1.06	-2.72
32	that I have a strong faith in God	-2.71	0.69	-3.40

Descending Array of Differences Between Religious and Family Accounts

No.	Statement	Rel.	Fam.	Diff.
16	that I will not be forgotten	1.04	-0.71	1.76
14	that I have my funeral organised	0.12	-1.61	1.73
19	that I have discussed what I want for my death with my family	-0.25	-1.42	1.18
25	that at the time of my death I have my family around me	-0.43	-1.58	1.15
27	that I try unconventional treatments	2.35	1.24	1.11
6	that I receive support from people other than family and close friends	0.67	-0.43	1.09
22	that I die at home	1.51	0.59	0.92
20	that I am given a timeframe	1.25	0.38	0.87
15	that I have a say in what the hospice tells my family	0.73	0.06	0.67
11	that my death is peaceful	-1.04	-1.70	0.66
37	that I maintain my sense of humour	-0.10	-0.70	0.60
26	that I have my financial affairs in order	-0.19	-0.76	0.57
12	that I have the support of my family	-1.33	-1.88	0.55
1	that I have time to come to terms with my illness	0.03	-0.52	0.55
7	that my family will be okay emotionally after my death	-0.62	-1.16	0.54
35	that I have time just for me	0.88	0.36	0.52
21	that hospice staff are supportive	-0.10	-0.57	0.48
9	that I maintain my dignity	-0.41	-0.89	0.48
13	that I receive physical contact from my family	-0.57	-1.01	0.44
5	that I don't look ill	1.70	1.30	0.40
10	that I feel in control	0.33	-0.04	0.37
40	that my family sometimes keep their feelings to themselves	1.47	1.15	0.32
38	that my level of medication allows me to still communicate	0.02	-0.16	0.18
24	that I keep some things to myself	1.60	1.52	0.08
31	that during my illness my family get on with their own lives	0.00	-0.04	0.04
30	that I have been loved	-1.16	-0.88	-0.27
17	that my physical pain is managed	-0.94	-0.65	-0.29
4	that I make the most of every day	-0.21	0.13	-0.33
3	that I make my own decisions about whether or not to have treatment	0.37	0.71	-0.34
2	that I avoid becoming totally dependent on others	0.06	0.49	-0.43
34	that my physical symptoms (besides pain) are controlled	0.17	0.74	-0.57
29	that at the time of my death I am ready to die	-0.75	-0.10	-0.65
36	that I maintain hope	0.07	0.93	-0.86
28	that I have good friends around	0.01	0.94	-0.94
23	that conflict within my family is resolved	0.30	1.24	-0.95
18	that I feel like I have achieved something in life	-0.73	0.43	-1.16
33	that I feel like my life has meaning	-0.36	1.43	-1.79
39	that I have people praying for me	-1.12	1.22	-2.33
32	that I have a strong faith in God	-2.71	0.29	-3.00
8	that I know where I am going after this life	-1.66	1.68	-3.34

Descending Array of Differences Between Independent and Idealised Accounts

No.	Statement	Ind.	Ide.	Diff.
16	that I will not be forgotten	2.12	-0.80	2.92
30	that I have been loved	1.03	-1.83	2.86
25	that at the time of my death I have my family around me	0.78	-1.61	2.39
39	that I have people praying for me	1.44	-0.27	1.71
6	that I receive support from people other than family and close friends	0.65	-0.61	1.25
33	that I feel like my life has meaning	0.54	-0.51	1.05
36	that I maintain hope	0.08	-0.96	1.04
32	that I have a strong faith in God	1.70	0.69	1.01
28	that I have good friends around	0.24	-0.71	0.94
4	that I make the most of every day	-1.10	-1.99	0.89
12	that I have the support of my family	-0.39	-1.25	0.86
18	that I feel like I have achieved something in life	0.45	-0.40	0.85
8	that I know where I am going after this life	1.79	1.06	0.73
40	that my family sometimes keep their feelings to themselves	0.99	0.69	0.31
7	that my family will be okay emotionally after my death	0.18	-0.08	0.26
27	that I try unconventional treatments	0.97	0.76	0.21
21	that hospice staff are supportive	-0.25	-0.35	0.10
38	that my level of medication allows me to still communicate	-1.18	-1.23	0.05
23	that conflict within my family is resolved	0.36	0.36	-0.01
29	that at the time of my death I am ready to die	0.17	0.19	-0.02
34	that my physical symptoms (besides pain) are controlled	-0.56	-0.53	-0.03
22	that I die at home	0.79	0.95	-0.16
31	that during my illness my family get on with their own lives	-0.70	-0.39	-0.31
13	that I receive physical contact from my family	0.11	0.42	-0.31
11	that my death is peaceful	-1.13	-0.74	-0.39
37	that I maintain my sense of humour	-1.84	-1.41	-0.44
15	that I have a say in what the hospice tells my family	0.19	0.69	-0.50
17	that my physical pain is managed	-1.52	-0.95	-0.57
19	that I have discussed what I want for my death with my family	0.01	0.64	-0.63
20	that I am given a timeframe	0.26	0.89	-0.63
10	that I feel in control	-1.20	-0.20	-1.00
24	that I keep some things to myself	0.18	1.22	-1.04
35	that I have time just for me	0.25	1.35	-1.10
5	that I don't look ill	0.71	1.90	-1.19
1	that I have time to come to terms with my illness	-0.33	1.11	-1.44
2	that I avoid becoming totally dependent on others	-1.60	-0.12	-1.49
3	that I make my own decisions about whether or not to have treatment	-1.44	0.24	-1.68
26	that I have my financial affairs in order	-0.56	1.39	-1.95
14	that I have my funeral organised	-0.44	1.69	-2.13
9	that I maintain my dignity	-1.72	0.70	-2.42

Descending Array of Differences Between Independent and Family Accounts

No.	Statement	Ind.	Fam.	Diff.
16	that I will not be forgotten	2.12	-0.71	2.83
25	that at the time of my death I have my family around me	0.78	-1.58	2.35
30	that I have been loved	1.03	-0.88	1.91
12	that I have the support of my family	-0.39	-1.88	1.49
19	that I have discussed what I want for my death with my family	0.01	-1.42	1.43
32	that I have a strong faith in God	1.70	0.29	1.42
7	that my family will be okay emotionally after my death	0.18	-1.16	1.34
14	that I have my funeral organised	-0.44	-1.61	1.18
13	that I receive physical contact from my family	0.11	-1.01	1.12
6	that I receive support from people other than family and close friends	0.65	-0.43	1.07
11	that my death is peaceful	-1.13	-1.70	0.57
21	that hospice staff are supportive	-0.25	-0.57	0.33
29	that at the time of my death I am ready to die	0.17	-0.10	0.26
39	that I have people praying for me	1.44	1.22	0.22
22	that I die at home	0.79	0.59	0.21
26	that I have my financial affairs in order	-0.56	-0.76	0.20
1	that I have time to come to terms with my illness	-0.33	-0.52	0.20
15	that I have a say in what the hospice tells my family	0.19	0.06	0.13
8	that I know where I am going after this life	1.79	1.68	0.11
18	that I feel like I have achieved something in life	0.45	0.43	0.01
35	that I have time just for me	0.25	0.36	-0.11
20	that I am given a timeframe	0.26	0.38	-0.12
40	that my family sometimes keep their feelings to themselves	0.99	1.15	-0.16
27	that I try unconventional treatments	0.97	1.24	-0.28
5	that I don't look ill	0.71	1.30	-0.59
31	that during my illness my family get on with their own lives	-0.70	-0.04	-0.66
28	that I have good friends around	0.24	0.94	-0.71
9	that I maintain my dignity	-1.72	-0.89	-0.84
36	that I maintain hope	0.08	0.93	-0.85
17	that my physical pain is managed	-1.52	-0.65	-0.87
23	that conflict within my family is resolved	0.36	1.24	-0.89
33	that I feel like my life has meaning	0.54	1.43	-0.89
38	that my level of medication allows me to still communicate	-1.18	-0.16	-1.02
37	that I maintain my sense of humour	-1.84	-0.70	-1.15
10	that I feel in control	-1.20	-0.04	-1.15
4	that I make the most of every day	-1.10	0.13	-1.23
34	that my physical symptoms (besides pain) are controlled	-0.56	0.74	-1.30
24	that I keep some things to myself	0.18	1.52	-1.34
2	that I avoid becoming totally dependent on others	-1.60	0.49	-2.10
3	that I make my own decisions about whether or not to have treatment	-1.44	0.71	-2.14

Descending Array of Differences Between Idealised and Family Accounts

No.	Statement	Ide.	Fam.	Diff.
14	that I have my funeral organised	1.69	-1.61	3.30
26	that I have my financial affairs in order	1.39	-0.76	2.15
19	that I have discussed what I want for my death with my family	0.64	-1.42	2.06
1	that I have time to come to terms with my illness	1.11	-0.52	1.64
9	that I maintain my dignity	0.70	-0.89	1.59
13	that I receive physical contact from my family	0.42	-1.01	1.43
7	that my family will be okay emotionally after my death	-0.08	-1.16	1.08
35	that I have time just for me	1.35	0.36	0.99
11	that my death is peaceful	-0.74	-1.70	0.96
12	that I have the support of my family	-1.25	-1.88	0.63
15	that I have a say in what the hospice tells my family	0.69	0.06	0.63
5	that I don't look ill	1.90	1.30	0.60
20	that I am given a timeframe	0.89	0.38	0.51
32	that I have a strong faith in God	0.69	0.29	0.41
22	that I die at home	0.95	0.59	0.37
29	that at the time of my death I am ready to die	0.19	-0.10	0.28
21	that hospice staff are supportive	-0.35	-0.57	0.23
25	that at the time of my death I have my family around me	-1.61	-1.58	-0.04
16	that I will not be forgotten	-0.80	-0.71	-0.09
10	that I feel in control	-0.20	-0.04	-0.15
6	that I receive support from people other than family and close friends	-0.61	-0.43	-0.18
17	that my physical pain is managed	-0.95	-0.65	-0.29
24	that I keep some things to myself	1.22	1.52	-0.30
31	that during my illness my family get on with their own lives	-0.39	-0.04	-0.35
40	that my family sometimes keep their feelings to themselves	0.69	1.15	-0.47
3	that I make my own decisions about whether or not to have treatment	0.24	0.71	-0.47
27	that I try unconventional treatments	0.76	1.24	-0.48
2	that I avoid becoming totally dependent on others	-0.12	0.49	-0.61
8	that I know where I am going after this life	1.06	1.68	-0.62
37	that I maintain my sense of humour	-1.41	-0.70	-0.71
18	that I feel like I have achieved something in life	-0.40	0.43	-0.84
23	that conflict within my family is resolved	0.36	1.24	-0.88
30	that I have been loved	-1.83	-0.88	-0.95
38	that my level of medication allows me to still communicate	-1.23	-0.16	-1.07
34	that my physical symptoms (besides pain) are controlled	-0.53	0.74	-1.27
39	that I have people praying for me	-0.27	1.22	-1.49
28	that I have good friends around	-0.71	0.94	-1.65
36	that I maintain hope	-0.96	0.93	-1.89
33	that I feel like my life has meaning	-0.51	1.43	-1.94
4	that I make the most of every day	-1.99	0.13	-2.12

Appendix S

Distinguishing Statement Tables Showing Hierarchy Placement and *Z*-scores for Each Account

Distinguishing statements, Z-scores and corresponding place on hierarchy for religious-oriented account

		Religious		Independent		Idealised		Family	
No.	**Statement**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**
32	that I have a strong faith in God	1	-2.71*	8	1.70	6	0.69	5	0.29
8	that I know where I am going after this life	1	-1.66*	9	1.79	7	1.06	9	1.68
39	that I have people praying for me	2	-1.12*	8	1.44	5	-0.30	7	1.22
29	that at the time of my death I am ready to die	3	-0.74*	5	0.17	5	0.19	5	-0.10
7	that my family will be okay emotionally after my death	3	-0.60	5	0.18	5	-0.10	3	-1.16
13	that I receive physical contact from my family	4	-0.60	5	0.11	6	0.42	3	-1.01
25	that at the time of my death I have my family around me	4	-0.43*	7	0.78	2	-1.6	2	-1.57
9	that I maintain my dignity	4	-0.40	1	-1.70	6	0.70	3	-0.89
37	that I maintain my sense of humour	5	-0.10*	1	-1.80	2	-1.40	4	-0.70
14	that I have my funeral organised	6	0.12*	4	-0.40	9	1.69	2	-1.61
34	that my physical symptoms (besides pain) are controlled	6	0.17*	4	-0.60	4	-0.50	6	0.74
35	that I have time just for me	7	0.87	6	0.25	8	1.34	5	0.36
16	that I will not be forgotten	7	1.04*	9	2.12	3	-0.80	4	-0.71
22	that I die at home	8	1.51	7	0.79	7	0.95	6	0.59
27	that I try unconventional treatments	9	2.35*	7	0.97	7	0.76	8	1.24

[•] All statements significant at $p > 0.5$; asterisk indicates significance at $p < 0.1$

Distinguishing statements, *Z*-scores and corresponding place on hierarchy for independent-oriented account

		Religious		Independent		Idealised		Family	
No.	**Statement**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**
9	that I maintain my dignity	4	-0.40	1	-1.72*	6	0.70	3	-0.89
2	that I avoid becoming totally dependent on others	5	0.06	2	-1.60*	5	-0.10	6	0.49
17	that my physical pain is managed	3	-0.90	2	-1.50	3	-0.90	4	-0.65
3	that I make my own decisions about whether or not to have treatment	6	0.37	2	-1.44*	5	0.24	6	0.71
10	that I feel in control	6	0.33	3	-1.20*	5	-0.20	5	-0.04
4	that I make the most of every day	4	-0.20	3	-1.10*	1	-2.00	5	0.13
14	that I have my funeral organised	6	0.12	4	-0.44*	9	1.69	2	-1.61
12	that I have the support of my family	2	-1.30	4	-0.39*	2	-1.30	1	-1.88
24	that I keep some things to myself	8	1.60	5	0.18*	8	1.22	9	1.52
33	that I feel like my life has meaning	4	-0.40	6	0.54*	4	-0.50	8	1.43
5	that I don't look ill	9	1.70	7	0.71	9	1.90	8	1.30
25	that at the time of my death I have my family around me	4	-0.40	7	0.78*	2	-1.60	2	-1.57
30	that I have been loved	2	-1.20	8	1.02*	1	-1.80	3	-0.88
32	that I have a strong faith in God	1	-2.70	8	1.70*	6	0.69	5	0.29
16	that I will not be forgotten	7	1.04	9	2.12*	3	-0.80	4	-0.71

Distinguishing statements, *Z*-scores and corresponding place on hierarchy for idealised account

		Religious		Independent		Idealised		Family	
No.	**Statement**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**	**Place.**	**Z-Sc.**
4	that I make the most of every day	4	-0.20	3	-1.10	1	-1.99*	5	0.13
30	that I have been loved	2	-1.20	8	1.02	1	-1.83*	3	-0.88
36	that I maintain hope	6	0.07	5	0.08	3	-0.96*	7	0.93
28	that I have good friends around	5	0.01	5	0.24	4	-0.70*	7	0.94
39	that I have people praying for me	2	-1.10	8	1.44	5	-0.27*	7	1.22
19	that I have discussed what I want for my death with my family	4	-0.30	5	0.01	6	0.64*	2	-1.42
9	that I maintain my dignity	4	-0.40	1	-1.70	6	0.70*	3	-0.89
8	that I know where I am going after this life	1	-1.70	9	1.79	7	1.06	9	1.68
1	that I have time to come to terms with my illness	5	0.03	4	-0.30	7	1.11*	4	-0.52
35	that I have time just for me	7	0.87	6	0.25	8	1.34	5	0.36
26	that I have my financial affairs in order	5	-0.20	4	-0.60	8	1.39*	3	-0.76
14	that I have my funeral organised	6	0.12	4	-0.40	9	1.69*	2	-1.61

Distinguishing statements, *Z*-scores and corresponding place on hierarchy for family-oriented account

		Religious		Independent		Idealised		Family	
No.	Statement	Place.	Z-Sc.	Place.	Z-Sc.	Place.	Z-Sc.	Place.	Z-Sc.
12	that I have the support of my family	2	-1.30	4	-0.40	2	-1.30	1	-1.88
11	that my death is peaceful	3	-1.00	3	-1.10	3	-0.70	1	-1.70
14	that I have my funeral organised	6	0.12	4	-0.40	9	1.69	2	-1.61*
19	that I have discussed what I want for my death with my family	4	-0.30	5	0.01	6	0.64	2	-1.42*
7	that my family will be okay emotionally after my death	3	-0.60	5	0.18	5	-0.10	3	-1.16
13	that I receive physical contact from my family	4	-0.60	5	0.11	6	0.42	3	-1.01
9	that I maintain my dignity	4	-0.40	1	-1.70	6	0.70	3	-0.89
37	that I maintain my sense of humour	5	-0.10	1	-1.80	2	-1.4	4	-0.70*
2	that I avoid becoming totally dependent on others	5	0.06	2	-1.60	5	-0.1	6	0.49
34	that my physical symptoms (besides pain) are controlled	6	0.17	4	-0.60	4	-0.5	6	0.74*
36	that I maintain hope	6	0.07	5	0.08	3	-1.00	7	0.93*
28	that I have good friends around	5	0.01	5	0.24	4	-0.70	7	0.94*
23	that conflict within my family is resolved	6	0.30	6	0.36	5	0.36	7	1.24*
33	that I feel like my life has meaning	4	-0.40	6	0.54	4	-0.50	8	1.43*

Hierarchy Placement and Z-scores of Consensus Statements

		Religious		Independent		Idealised		Family	
No.	Statement	Place.	Z-Sc.	Place.	Z-Sc.	Place.	Z-Sc.	Place.	Z-Sc.
21	that hospice staff are supportive	0	-0.1	-1	-0.25	0	-0.35	-1	-0.57