CHAPTER ONE

INTRODUCTION

As Kleinman emphasised in his "Illness Narratives" (1988, p.xii), "nothing so concentrates experience and clarifies the central conditions of living as serious illness" and further that "the study of the experience of illness has something fundamental to teach each of us about the human condition, with its universal suffering and death".

However, while Western society appeared to embrace sexuality as part of life during the twentieth century, it turned death and dying into a great social taboo (Ariès, 1974). As with any taboo, the result was an ambivalent fascination with, and concomitant horrified avoidance of, death (Berridge, 2001). In contemporary westernised South African society this ambivalence may be seen in a discomfort at speaking about, or avoidance of personal contact with, dying or bereaved people. At the same time there may be an attraction to death at a distance in violent films and popular television programmes about forensic pathologists like the CSI series.

One of the effects of the refusal to acknowledge death as part of life was that the lessons about the human condition referred to by Kleinman (1988) have not been not learnt. Furthermore, the art of dying well which was the subject of late medieval treatises like the "Ars Moriendi" (as cited in Keeley, 2001) and Eastern philosophy like "The Tibetan Book of Living and Dying" (Rinpoche, 1992) seems to have been lost:

> How should one die? We live in a world which dreads the question and which turns away from it. Earlier generations looked death straight in the face … Never perhaps has our relationship with death been so poor as in these times of spiritual bareness, where human beings, in their haste to exist, seem to sidestep the mystery. They do not realise that in so doing they rob the love of life of an essential source.
> (F. Mitterand, 1995, quoted in Corr, Nabe & Corr, 2003, p.v)

It is the art of dying, possibly described as achieving a "good" death, which is the subject of this research report. Its potential significance seems well described by Dame Cecily Saunders, often described as the founder of the modern hospice and palliative care movement: "The last part of a person's life may have an importance out of all proportion to its length." (Saunders as interviewed by Olivière, 2000, p.102).

1.1 Rationale

> Research into dying – for reasons not unconnected to social repression – is still at an early stage. Much remains to be done in gaining a better understanding of the experience and needs of dying people and the connection between such experience and needs and their way of life and self-image. (Elias,1985, p.52)

In the two decades since Elias made this comment, interest in the field of thanatology has undoubtedly grown (Corr, et al., 1994; Leming & Dickenson, 1998). However, writers on the topic continue to describe dying as "ubiquitous yet largely unexamined" (Yedida & MacGregor, 2001). In a recent review of qualitative research in palliative care covering the period 1990 to 1999 (Froggart, Field, Bailey & Krishnasamy, 2003) the authors observed that patients were respondents in only one quarter of the 0.5% of articles utilising qualitative methods. Thus there appears to be relatively little attention paid to what dying people think, feel and experience.

The paucity of work in this area, it is often argued, may be related to concerns about the ethics of research with dying patients who are understandably seen as particularly vulnerable (Aranda, 1995; Barnett, 2001; Beaver, Luker & Woods, 1999). Not surprisingly, psychological distress in terminally ill patients (61 to 79 per cent registered high distress) is notably higher than in a general cancer population (18 to 34 per cent) researched in a Canadian study of 1319 people living with cancer (as cited in Vachon, 1998).

Several recent studies have researched the accuracy of proxy reports and the related question of whether caregivers can provide reliable information about dying patients' experiences. These concluded that the more subjective the patient's experience, including his or her feelings, pain, anxiety or depression, the less accurate the information provided by others seems (Lobchuk & Vorauer, 2003; McPherson & Addington-Hall, 2002). This suggests a "need to hear the voice of the vulnerable" (Aranda, 1995, p.42). More emphatically, some authors have advocated a "moral imperative" to conduct research with dying patients to improve the ability to meet their needs (Mount et al., 1995, as cited in Froggart et al., 2003). Froggart et al. (2003) argue that even primarily descriptive articles on the experience of dying have the potential to be illuminating.

Steinhauser, Christakis et al., (2000) observed that despite increased attention paid to end-of-life care, the understanding of a good death was still scanty. This may be because the focus had been on problem avoidance rather than on "a positive ideal of a good death" (Emanuel & Emanuel, 1998, p.21).

Most research into death and dying has been conducted on the elderly for obvious reasons, or on terminally ill patients with no restriction on age. Unexpectedly, there seems to be comparatively little literature investigating the relationship between life stage and dying; in other words, most death and dying theory seems to be presented as if dying at one stage of life was much the same as dying at another. This seems unlikely, particularly in the Western world with its increased life expectancy and well-documented 'denial of death' (Ariès, 1974, 1977). Both these factors combine to create a distance from the every day experience of dying for most young and middle-aged people, who may be considered the "death-free generation" as they are likely to have reached their age without a personal experience of bereavement (Fulton, 1976, as cited in Corr, 1998).

The decision to explore the "positive ideal of a good death" (Emanuel & Emanuel, 1998, p.21) among adults in mid-life was taken on the assumption that this group experiences their own death as a critical and non-normative life event thus highlighting its features (Röcke & Cherry, 2002). Corr et al. (1994, p.298) described adulthood as the "sandwich generation" as adults feel the pressure of caring for both elderly parents and young children. Thus encounters with death and dying at this time are most likely to be the result of bereavement following the death of a parent or, more rarely, the unthinkable and appalling death of a child.

While observing that development in adulthood has been studied less than development in other life stages, Corr et al. (1994) commented that the developmental tasks of this time, achieving intimacy versus isolation and generativity versus stagnation (citing Erikson, 1963) influence attitudes to death as these tasks involve full engagement with life. Given the apparent lack of research in this area, helping to identify what may contribute to a good death in mid-life seems a positive contribution to the field. However, several authors have cautioned that the unintended result might be that notions of a good death could become prescriptive rather than helpful. Bradbury (2000) warned that those who work with the dying may have personal ideas of "good" and "bad" deaths which influence the way they treat the dying, the dead and the next of kin, while Davy and

Ellis (2000) suggested that ideas of a good death may be romanticised. These cautionary remarks have been kept in mind in both the research aims and questions.

In the light of the relative dearth of research that gives voice to those who are dying, it was hypothesised that dying at a time of life that may be considered non-normative presents particular challenges. Furthermore, it was thought that an exploration of experience through interviewing terminally ill patients who are in mid-life may shed light on what they believe a good death might be and how it might be achieved.

1.2 Research aims

The aim of this study is to explore the idea of a "good" death with patients who are terminally ill with cancer. The focus is on patients in mid-life, for whom the challenge of dying may be considered particularly acute: until they developed cancer, these people had a productive working life, were raising a family and had a network of interests and plans for the future. They might be considered in the prime of life. Thus a fundamental concern of this study is to examine whether it is possible to have even the idea of a "good" death having lived "an abbreviated life" (Paget, 1993, as cited in Grbich, 1999, p.238).

Qualitative research methods, specifically in-depth interviews followed by thematic content analysis, were used to explore what it is like to be dying before the age of fifty leaving one's parents, spouse and children, one's work, interests and unfulfilled dreams. These losses may be particularly acute in a society where life expectancy may run to three-score years-and-ten and dying significantly younger is non-normative (Röcke & Cherry, 2002). A specific concern of the research is what participants think might make this painful truncating of existence more tolerable.

A secondary aim includes establishing whether patients experience either internal or external pressure to die in a certain way be it emotionally, behaviourally or spiritually. If so, the potential sources of this possible pressure, including the patients themselves, their families, professional caregivers and religious beliefs, were investigated.

1.3 Research questions

In exploring this subject, the following research questions were addressed:

1. In the opinion of the patient who is dying prematurely, what is a 'good' death? Is there an expectation that certain preparatory work, which may be practical, emotional or spiritual, needs to be done in order to achieve a good death?

2. Does the dying person experience any internal or external pressure to die in a certain way?

If so, where does this pressure appear to come from? Does it appear to stem from the expectations of patients themselves, or others such as Hospice staff members?

CHAPTER TWO
LITERATURE REVIEW

Some authors, for example DeSpelder and Strickland (2002, p. xv), have commented that the study of death is "unavoidably multi-disciplinary", bridging the fields of medicine, the humanities and social science. As a result current literature applicable to an understanding of a good death ranges across a number of subjects and will be discussed in five main sections. Firstly, the process of becoming terminally ill and how this is defined, including issues around illness, cancer and the role of the medical profession will be discussed. Secondly contemporary and historical conceptions of death in Western society will be briefly considered. The rise of interest in this field has resulted in extensive writing in this area, particularly from a sociological point of view. The key consideration here will be the most recent shifts in social attitudes towards death and how these may affect the idea of a "good" death.

In the third section, psychological understandings of dying and its challenges, including key theorists of death and dying, like Elisabeth Kübler-Ross and her critics, will be discussed. In addition, the relationship of a terminal diagnosis to trauma theory and an existential perspective will be considered. The fourth section will consider a good death, the different ways in which this has been conceptualised and previous research that has explored this construct.

Finally, additional matters that might impact on a good death, including practical concerns around symptom control and pain will be investigated, as well as questions surrounding euthanasia and the implications of these. In addition, issues of quality of life, dignity and control, as well as the role of spirituality, religion and hope will be explored.

1. The process of becoming terminally ill

1.1 Illness

In her powerful work "Illness as Metaphor" Susan Sontag (1977, p.3), who was ill with recurring cancer over a number of years, wrote:

> Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good

> passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

One of the notable aspects of this quotation is the sense that being well and being ill are not just diametrically opposed experiences but alienated from each other, so that it is hard for someone in one of these "kingdoms" to understand what it is like to be in the other. Feigenburg and Schneidman (1985) proposed adding a third kingdom to this description, the kingdom of the dying. Although they agreed there was a world of difference between feeling ill and feeling well, they also believed there is a vast difference between being ill and dying: "The psychological distance between knowing that one has an illness (and expects or hopes to recover) and understanding that one has a mortal enemy is enormous" (Feigenburg & Schneidman, 1985, p.242). In an example of this process, Bertman (1991) quoted from Solzenitsyn's "The Cancer Ward" (1968) after Rusanoff receives his cancer diagnosis:

> But in a few days the whole close-knit, ideal Rusanoff Family – with two older and two younger children, with their completely well-ordered life and their spotless apartment, unstintingly furnished – had receded until it had vanished *on the other side of the tumour.* No matter what happened to the father, they were alive and would go on living. No matter how they might worry, exhibit concern, or weep now, the tumor had divided him from them like a wall, and he remained alive on this side of it. (as quoted in Bertman, 1991, p.40; original italics)

In a slightly different perception of this state, Benzein, Norberg and Saveman (2001, p.123) described terminally ill cancer patients as belonging to "two worlds simultaneously", "to both life and death" and that this is "a disunion and a puzzling situation". It is possible that one feature of a good death is becoming accustomed to this state of otherness, with the knowledge of no longer belonging among the well but not yet dead and gone from the world.

Further potential alienation for the patient is described in Kleinman's (1988) seminal "The Illness Narratives" and occurs in the difference between the illness as experienced by the patient and the disease the doctor attends to. This difference in perception may be the result of medical training, during which doctors are taught to focus on the course of the disease itself, leaving untreated the individual's life trajectory that is irrevocably marked by the illness (Kleinman, 1988). As Cassel (1982) noted, major illness is a threat to the integrity of our sense of self and suffering results from "challenges that threaten the intactness of the person as a complex social and psychological entity" (in Vachon, 1998, p.903). Major illness is

associated with change in appearance, physical strength, social roles and relationships with others, and disturbs trust in the health of one's body.

1.2 Cancer

> O Rose thou art sick!
> The invisible worm
> That flies in the night,
> In the howling storm,
>
> Has found out thy bed
> Of crimson joy:
> And his dark secret love
> Does thy life destroy.
> (William Blake, 'The Sick Rose': cited in Welsh, 2002)

As defined by Barraclough (1999, p.vi) "the term "cancer" covers well over one hundred different medical conditions, all involving the abnormal and excessive division of cells". Unlike this emotionless medical description, Blake's poem evokes one of the key characteristics of cancer, its "invisible' and "secret" destruction of the human body. It has been described as a burglar or an "intruder in the night" (Parkinson, 2003, p.417), "the disease that doesn't knock before it enters" and a "ruthless, secret invasion (Sontag, 1977, p.5). Both Kleinman (1988, p.20) and Sontag (1977) emphasised the way cancer challenges humanity's lack of control over death and symbolises an ongoing difficulty in making sense of the unanswerable question "Why me?"

While cancer is less stigmatised than it was when Sontag wrote in 1977, and the disease that has principally taken over this role is AIDS, there is still significant difficulty around the diagnosis. She noted that while someone who has had a coronary is as likely to die of another one within a few years as someone diagnosed with cancer is likely to become terminally ill, these patients are treated differently. Sontag attributed the difference to the ominous associations of cancer, which is "felt to be obscene – in the original meaning of that word: ill-omened, abominable, repugnant to the senses", with tumour growth that is a kind of "demonic pregnancy" (Sontag, 1977, p.14). She emphasised that this horror justifies extremely aggressive treatment, which is frequently given military overtones as in the phrase "the war against cancer" or the words in an obituary "died after a long battle with cancer". Similarly, Parkinson (2003, p.418) stressed that the sense of the cancer as "alien" and a "cloying, clasping thing inside" can evoke feelings of shame and fear, and the threat to the integrity of the body may

also threaten the ego and shake self-cohesion: “So what about *me?* I’ve gone, I’ve disappeared. I’m not normal any longer. I’m a ‘cancer victim’ and it’s taken me over” (patient quoted in Parkinson, 2003, p.421, original italics).

Kleinman (1988, p.22) agreed that a diagnosis of cancer carries meaning “with a vengeance”, including “the fear of a lingering and untimely death, the threat of disfiguring treatment with the concomitant loss of body- and self-image, the stigma of self-earned illness”. In Studs Terkel’s series of interviews with people who confront death in their everyday lives, “Will the circle be unbroken” (2001, p.318), Nancy Lanoue said:

> Cancer came into my life like a bomb. I was in no way prepared for it. Both my parents died of heart disease. I was young, athletic, strong. The thought that I would get cancer was the furthest thing from my mind ...
> A lot of people feel very isolated with cancer. They don’t dare tell anyone. In particular breast cancer, because it’s so altering to the body. At least in the old days it was. Cancer is a very hidden subject, still. People don’t talk about it. When you get cancer, the first question people ask you is: Do you smoke? What do you eat? All these questions that you think: *Ah, I did something wrong to cause me to get cancer.* Guilty. Blame the victim. I found this very irritating.

The meanings associated with cancer are of particular concern in Western society with its focus on physical beauty and perfect, healthy bodies. In her study “The dying process” Julia Lawton (2000, p.83) cited Bordo (1993) on the importance of the appearance of the physical body and Crawford (1994, p.1354) who suggested the healthy body “is the mark of distinction that differentiates those who succeed from those who will fail”. She argued that physical deterioration has a significant impact on selfhood: “having the *bodily* ability to negotiate and alter one’s environment is a crucial aspect of person / self” in Western contexts and that this is only apparent after this aspect of embodiment has been lost (Lawton, 2000, p.84, original italics).

1.3 The terminal diagnosis

While there are many different understandings of the designation “dying” or “terminal”, a useful perspective is given by Feigenberg and Shneidman (1985, p.242) who noted that “dying” is not so much an injury or an illness but an “emotional state of mind” involving the sense that one is “in an imminently life-threatening situation” and the chances of surviving are very remote. In palliative care the definition of “dying” “is based upon the presence of [a life-threatening]

disease that is not responsive to curative treatment" (Currer, 2001, p.35-36). As Cecily Saunders (1996) founder of the Hospice movement explained:

> Palliative care has its origin in the modern Hospice movement and is concerned with the physical, psychosocial and spiritual care of patients with life-threatening disease and their families, focusing on both the quality of the remaining life of the patient and on the support of the family and those close to the patient. (quoted in Field & Addington-Hall, 2000, p.93)

Muller (2000, p.29) noted that being given a terminal prognosis means that the patient realises "for the first time that their life and "aliveness" are acutely threatened"; this may trigger a sense of "sheer horror at the thought of being extinguished" (Muller, 2000, p.30) and may be the start of an intense and painful grief. In their study of patients with inoperable cancer, Benzein et al. (2001) described the shift from a life of health to a life of waiting for premature death as a bewildering and painful experience.

Dying patients may have a sense of living "on borrowed time", with the passing of time a cause of anxiety in itself (Feigenburg & Schneidman, 1985). There may be experiences of sudden accelerations or slowing of time that add to the dying person's feelings of insecurity:

> The perception of time alters and disintegrates in the process of dying… The subjective experience of time … becomes increasingly disconnected with the chronological time of those around the dying person." (Feigenburg & Schneidman,1985, p.245).

While Cecily Saunders stated: "Time, is not a question of length, it's a question of depth, isn't it?" (quoted in Buckingham, 1985, p.151), an ability to achieve this sense of the importance of quality of life rather than its quantity may be hard to achieve.

However, for some patients the knowledge that they are dying is too appalling to keep in conscious awareness and denial may be necessary to prevent a complete breakdown in the face of an intolerable threat. Denial is an unconscious defence mechanism that "revises or reinterprets a portion of painful reality avoiding what it threatens to be and holding fast to the image of what it has been" (Wool, 1988, quoted in Vachon, 1998, p.893). Denial has been described as common in a life-threatening illness, with severe denial occurring in 10% of hospitalised patients with advanced cancer and more moderate levels in an additional 18% (Block, 2001). Before intervening, it is important to consider whether the denial is helping

the patient deal with the illness; moreover, denial is at times associated with a longer life expectancy than anticipated (Adelbratt & Strang, 2000; Vachon, 1998).

Caroline Garland (2004, p.37) observed that trauma, a word usually associated with a threat to life, is an event in which:

> … the impact on mental functioning is immense. There is an immediate period of shock and denial – the event is too large and too horrible to be taken in all at once, and the mind protects itself by trying to shut down. … This shut-down may alternate with times when the event succeeds in breaking through the mental barriers, creating an overwhelming sense of intrusion.

It has been observed that "breaking bad news abruptly can precipitate patients into a major state of crisis or disequilibrium" and this therefore qualifies as a trauma (Vachon, 1998, p.901). In the study conducted by McCormick and Conley (1995, p.238) the diagnosis of a life-threatening illness was described as a "crisis of the knowledge of death". The acute crisis with anxiety at its peak was followed by a chronic living-dying phase before the patient entered the terminal phase (Pattison, cited in McCormick & Conley, 1995). A small qualitative study suggested that patients shifted from an awareness of their cancer as "incurable" to a sense of being "terminal" with death imminent; for patients, the meanings of these terms were different to those held by health professionals:

> Being incurable meant that I would have to live with it. I knew that I was going to die, but I regarded that as something in the future… Terminal meant that I had less time. It meant that dying was now countable. It was now time to prepare myself to die. (McCormick & Conley, 1995, p.242).

Despite the considerable shock of receiving either the diagnosis of cancer or a terminal prognosis, there has been a shift in attitude towards disclosure and most authors advocate telling patients the truth as "deceit hurts more" (Fallowfield, Jenkins & Beveridge, 2002, p.297; Dein & Thomas, 2002). Some authors criticised the tendency to deceive patients as disrespectful of the patient (Buckman, 1998; Costello, 2000). Moreover, Fallowfield et al. (2002) noted that avoidance of communication about prognosis does not avoid distress, as the patient is a moment-by-moment witness to his or her deteriorating body:

> Hollow cheerfulness and feigned optimism about quite unrealistic future goals are excruciating to witness, as are the anxious and stressed expressions on the faces of people trying to maintain a lie. (Fallowfield et al., 2002, p.302)

In addition, most patients believed it was important to be informed of being incurable or terminal (Edwards, 2005) as “Death is a practical business as well as an emotional one” (McCormick & Conley, 1995, p.242).

Although honest communication is important, the *way* a diagnosis or prognosis is given is argued to be critical to the future of the doctor-patient relationship. In a large Swedish study, Salander (2002) noted that if patients are given their diagnosis abruptly this may result in the loss of a sense of trust in medical practitioners. Vachon (1998, p.885) also focused on the importance of communication between doctor and patient as a process of “shared learning” in which the patient learns about his/her illness and the doctor learns about the patient; he also emphasised the need to maintain hope when breaking bad news. While this may not be the hope of recovery, it may include the hope of good management of symptoms and the assurance that the patient will not be abandoned. This author also pointed out that there is both a “right to know” and a “right not to know” and that this is a choice made by the patient (Vachon, 1998).

Instead of seeing the giving of bad news, (defined as unwelcome information), as a single event in the way doctors tend to do, Arber and Gallagher (2003) recommended a negotiated disclosure involving preparation and an awareness of how much the patient wants to know, along with the offering of support so that bad news is balanced with reassurance that the patient will not be abandoned and that symptoms can be treated. It was important not to leave the patient to cope with the devastating information alone; in addition, there was a clear sense that an empathic relationship between the medical practitioner and the patient made it easier to tolerate hearing bad news (Arora, 2003; Salander, 2002).

1.4 The medical profession

> To the typical physician my illness is a routine incident in his rounds, while for me it’s the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity. (Broyard, 1992, quoted in Bowman, 1997, p.77)

In the last two decades, a number of researchers have turned the spotlight on medicine and there has been a shift from uncritical approval of the technical achievements of modern medicine to examination of its shortcomings, in particular the loss of the human touch and the art of healing (Kleinman, 1988; MacLeod,

2000). Elias (1985, p.90) commented dryly: “It is perhaps not yet quite superfluous to say that care for people sometimes lags behind the care of their organs”. Paul Scott (1966, p.127) noted that “the world has a vested interest in those capable of being made well” and that once people can no longer be healed they seem out of place. Most medical training focuses on cure rather than care so the sense of personal failure with a terminally ill patient may be very uncomfortable. A further reason for doctors’ discomfort with dying patients was found in two studies that suggested that “one of the major reasons certain physicians enter medicine is to govern their above average fears concerning death” (Feifel, 1963 & 1967, as quoted in Kamerman, 1988). Thus the choice of a medical career may be an unconscious attempt to neutralise the fear of death (Kamerman, 1988). Together with training that emphasises a philosophy of detachment, this fear may lead to a doctor withdrawing emotionally from a terminally ill patient just when the patient’s need for support is greatest. While the doctor may desire to withdraw, “the terminally ill desire their physicians to be interested in their lives as well as their illness experience” (Mak & Elwyn, 2003, p.401). These conflicting needs may result in pronounced feelings of mutual disappointment.

Elias (1985) considered that belief in the miracles of science and medicine has become a secular faith and Berridge (2001, p.256) concurred: “In the increasingly medicalised context of contemporary death, where we count on doctors to postpone the inevitable end, they have assumed an almost God-like status.” The loss of this faith in a wonder-working doctor can be very disillusioning for patients; Picardie (1998, p.82) commented bitterly on the failure of medicine to stop her rampaging cancer:

> I am as anti-conventional and complementary medicine as ever, and why not – they’ve all fucked up so far. Shopping and eating is the only therapy that works.

However it seems likely that at times medical professionals may be the scapegoat for terminally ill patients who are struggling with their inability to change their future and are confronted with their:

> … helplessness in the face of the terrible, impersonal, biological imperative that is death. If only someone could be held responsible – the incompetent medical staff, the irresponsible relatives, anyone – then perhaps the illusion of human power and control could be maintained. (Starker & Starker, 1981, p.127)

1.5 Fighting death

Increasingly extreme ways of keeping people alive using organ transplants and artificial implants like pacemakers as well as life support equipment like artificial ventilators and intravenous feeding have resulted in debates about the right to die and the difference between medical treatments that save lives and those that postpone death (Veatch, 1989):

> The real terror of institutionalised dying is not death but the mechanical maintenance without medical purpose and the ultimate indignity of having one's final days controlled by strangers. (Buckingham, 1985, p.150)

Much of this effort seems devoted to attempting to get more and more people to reach the age of seventy or eighty, now considered a "normal life span" in Western societies (Veatch, 1989, p.8). However, one consequence is that during the twentieth century the declaration of death shifted from being aware that breathing has stopped, to checking whether the heart has stopped beating, and to assessing whether the brain is dead or alive. Recent controversial court cases like the one involving Terri Schiavo (Eisenberg, 2005; Schwartz, 2005) have complicated this still further by differentiating between lower and higher brain functions with complex philosophical debates on which functions are necessary to consider a person alive. Veatch concluded: "Yet, if in this confusing time we cannot agree on a definition of death, we have hardly begun to ask what it means to be dying" (1989, p.3).

One response to this has been a movement in bioethics that argues that patient choices around both treatment and outcomes (for example choosing to die) are valid *because* they are subjective (Sullivan, 2002). "Facts known only by physicians need to be supplemented by values known only by patients" (Sullivan, 2002, p.1595).

1.6 Summary

The sense of alienation felt by a seriously ill patient from those who are healthy, and the difficulty many doctors seem to have in treating the person rather than the disease, suggests that an aspect of a good death may involve bridging these barriers. One possible way of bringing a terminally ill patient in from the cold is through open communication in the form of open talking and listening between doctor and patient, and between those who are ill and those who are well. This may help the doctor see the person in the patient, and prevent the patient from

over-idealising the doctor and expecting miracles. In addition, friends and family will be helped to see the person they know still present within the patient.

2. The twentieth century attitude towards death.

> In a world of mass death where man's sense of himself as his own destroyer has added a new dimension to self-awareness, death has become for the majority an unmanageable and unimaginable prospect. Instead of contemplating death, man has done everything in his power to forget it. There has never been an era comparable to the 20th century for giving man such a demoralised and reductive view of himself – blasted to oblivion in no man's land, a shadow on scorched earth at Hiroshima, a canister of ashes scattered to the wind or poured down a grating. (Berridge, 2001, p.182)

2.1 Denial of death.

Numerous authors have commented on the way death became the great unmentionable, in poor taste and a taboo subject in Western society in the twentieth century (Ariès, 1974, 1977; Berridge, 2001; Corr, 1998; Elias, 1985; Kübler-Ross, 1969; Veatch, 1989; Welman, 1995):

> Thus death is both an enemy to be conquered by our activist faith in human ability to solve problems and an unknown of infinite proportions. There is in our culture a simultaneous obsession with the phenomenon of death and a compulsion to conceal it. (Veatch, 1989, p.12)

In her recent book, "Vigor Mortis", Berridge likened the way twentieth century death is distanced by silence and denial to the group pretence in the story of the "Emperor's New Clothes" (2001, p.5). She described the pretence that death does not exist as "the first big lie parents tell children; a close second to Father Christmas" (Berridge, 2001, p.4).

Berridge (2001) observed that the history of death parallels the history of medicine. During the last century there was a shift away from death after acute illnesses particularly in children and young adults, to death from chronic conditions, which are frequently associated with "a lingering death" (Veatch, 1989, p.3). This change was the result of technical advances in medicine, particularly in antibiotics and infection control and resulted in death no longer being perceived as a natural event but as a failure of medicine (Berridge, 2001). At the same time, increased knowledge of the way the body works changed the way life-threatening illness was conceptualised:

> The human being is no longer shadowed by a single skeleton personifying death but by any number of germs and diseases which attack medically identifiable organs of the body. (Walter, 1994, cited in Berridge, 2001, p.20)

Elias (1985) commented extensively on one profound consequence of a longer life expectancy and the disappearance of death from everyday life and its relocation in hospitals: “Never before have people died as noiselessly and hygienically as today in these societies, and never in social conditions so much fostering solitude” (Elias, 1985, p.85).

However, it is noted that Elias wrote the above twenty years ago. In contrast, Berridge (2001) observed some shifts in social behaviour, including “click and buy” coffins available on the Internet, and the publication of a book called “The Dead Good Funerals Guide”. She observed that some of these recent changes appeared difficult for society to accept, for example a funeral store that opened in London in 1995 closed just three years later; this same concept appeared to have continued to thrive in France, signalling differences in cultural approaches to death and dying.

For Berridge (2001) some of the change in this level of denial of death in Western society can be attributed to awareness of AIDS in the 1980’s and certain celebrity deaths, most notably that of Princess Diana in the 1990’s; these jolted people into remembering their mortality and how false any sense of security is. She noted pithily: “If sex began in 1963, then arguably death began in 1982 with AIDS” and “when sex became deadly, death became sexy” (Berridge, 2001, p.263). In this regard Berridge commented on the increase in memoirs of people’s dying process, as well as the number of courses on death and dying at colleges.

However, it is worth noting that, for some authors in the field, the current increased openness about death may minimise or devalue its power and mystery: “Is openness towards death always to be applauded? Or does it sometimes reflect a nervous effort to achieve ‘death without regrets’?” asked DeSpelder and Strickland (2002, p.549).

Despite some of these changes, the modern discomfort around death continues in the use of euphemisms that keep death at arm’s length: deceased family members are said to have “passed on”, “passed away”, “gone” and “left us”. Corr considered these a “linguistic shroud” that covers and distances death (1998,

p.36). Moreover, modern life still focuses on births and marriage, but not on the third rite of passage, death. In part, this may be the result of the "absence of a protocol for death" (Berridge, 2001, p.143) so that unlike the Victorians we do not know what to say, feel, do or even wear and thus feel awkward and would rather avoid death and bereavement.

2.1.1 Fear of death

Miriam Greenspan (2003, p.170) noted that "fear arises in any situation where there is a threat of loss or harm to body, mind and spirit". However, Berridge (2001, p.6) believed that fear of dying is increased by unfamiliarity and avoidance. She observed that someone growing up in a Western society at the end of the 20th century is more likely to have experienced divorce and family breakdown as "agents of separation" than bereavement:

> Sudden, slow, young, old, expected, unexpected: death stings … [its] terrors exacerbated by a climate of repression, denial and secrecy … death is less of a bogeyman when confronted with the lights on. … The facts of death, as important as the facts of life, warrant a more enlightened approach. Increasingly, as the 20th century progressed, it was against the rules of polite society to speak of death … [and 'dead' became] the ultimate four-letter word, one letter short of the dread it inspires. (Berridge, 2001, p.6)

"The foresight of our own dissolution is so terrible to us … the dread of death the great poison of our happiness…" (Adam Smith, 1759, cited in Berridge, 2001, p.100). As a result of this fear and suffering, Elias commented that death is "repressed" both individually and socially (1985, p.9). He used Freud's definition of repression as "a group of socially-instilled psychological experiences that are denied access to memory" while continuing to influence feelings and behaviour, for example in the fear of flying and fear of open spaces (Elias, 1985, p.9).

Kamerman (1988) discussed psychologist J.P. Brantner's (1971) "Death and the self" which investigated three bases for our fear of death: firstly, a fear that death would "overtake us with projects unfinished, with things undone and with secrets poorly concealed"; secondly that death would be painful; and thirdly that we fear death because we want to live forever (Kamerman, 1988, p.138). Both the first and third of these fears seem likely to be less significant as a person reaches old age, while the second may be a concern at any age. However, it is noted that Brantner's list did not include the fear of oblivion, which many other authors have considered to be fundamental to the fear of death.

In contrast, Kastenbaum and Aisenburg (cited in McKintrick, 1985, p.228) named three death-related fears, specifically fearing the suffering and indignity of the dying process; fearing punishment and rejection in the "afterlife"; and fearing extinction. A study by Hinton (1979) found that 26 per cent of dying patients had untroubled acceptance of death; 53 per cent felt some concern; and 21 per cent were troubled by thoughts of dying (as cited in Vachon, 1998, p.904). Interestingly, recent studies concluded that fear of death tends to be highest among middle-aged adults (Fortner & Niemeyer, 1999, cited in Röcke & Cherry, 2002). This may be because these adults have many responsibilities and leave behind numerous unfinished plans; unlike the elderly, they have not yet experienced many losses due to bereavement (Kalish, 1985).

It is noted that few of those writing on the subject have distinguished between the fear of *dying* and the fear of *death.* This distinction was only noted in two articles. Röcke and Cherry (2002, citing Baltes and Skrotzki, 1995) explained that the first of these referred to the *process* of dying, including fear of pain, suffering and dependency, while the second related more to concern about what happened *after* death, including fear of oblivion and religious concerns. Vachon (1998) advocated asking patients which aspect of death concerned them most, the process of dying or what will happen after death. It seems likely that fears of both the process and the outcome would need to be explored and alleviated for a good death.

Two further authors, Corr et al. (1994) and Lawton (2000), commented that fear of dying had become particularly prevalent in Western society. However, only the latter offered a reason for this. Lawton (2000, p.90) quoted Crossley (1995, p.143), who synthesised the work of Merleau-Ponty and Goffman and argued: "the mindedness and embodiment of human life are inseparable". In her study of Hospice patients Lawton argued further that Western individualism means that as illness affects bodily capacity, this physical disintegration has a profound effect on selfhood:

> … having the *bodily* capacity to negotiate and alter one's environment is a crucial aspect of person/self in contemporary English contexts; an aspect, furthermore, which really only becomes visible after it has been lost. (Lawton, 2000, p.84, original italics)

She further argued that social relationships are dependent on embodiment and proposed that dying patients' "apathy and withdrawal appeared to stem primarily from their declining ability to act in embodied ways rather than

from a knowledge of impending death *per* se" (Lawton, 2000, p.93, original italics). These issues will be examined further in the discussion section of this report.

2.1.2 Fear of oblivion

> About suffering they were never wrong,
> The Old Masters: how well they understood
> Its human position; how it takes place
> While someone else is eating or opening a window or just walking dully along;
> (W.H. Auden "Musee des Beaux Arts", in Simpson, 1972, p.326)

Auden's poem clearly conveys the appalling knowledge that the world is oblivious to one's suffering; this knowledge is unbearable. This point is made by Mitch Albom (1997, p.8), who described Morrie Schwartz's reaction to receiving his diagnosis of a terminal neurological disease:

> My old professor, meanwhile, was stunned by the normalcy of the day around him. *Shouldn't the world stop? Don't they know what has happened to me?*
> But the world did not stop, it took no notice at all.

Elias (1985, p.59) wrote of the fearful feeling that "with our death the little world of our own person, with its unique memories and its feelings and experiences known only to ourselves, with its own knowledge and dreams, will vanish forever". Kushner (2001) postulated that this fear of being insignificant and not having lived may drive some people to do great or terrible things to ensure they are noticed while they are alive and remembered once they are dead. Several authors have linked this fear of oblivion and the retreat from death to the great wars of the twentieth century: "Loss of identity is the crux of contemporary anxiety about death. The First World War tapped into this fear very literally, for men were annihilated" (Berridge, 2001, p.46).

2.1.3 The mystery

> Like so many others contemplating a dead person, Lewis found himself pondering so many things as he thought of Morse's mind within his skull. Thought of that wonderful memory, or that sensitivity to music and literature, above all of that capacity for thinking laterally, vertically, diagonally – whateverwhichway (sic) that extraordinary brain should decide to go. But all gone, now, for death had scattered that union of component atoms into the air, and Morse would never move or think or speak again. (Dexter, 1999, p.427)

Astutely, Elias (1985, p.3) noted that "death is a problem of the living. Dead people have no problems." He emphasised that human beings are the only creatures who *know* they will die and can anticipate their own end. Thus "it is not actually death, but the knowledge of death, that creates problems for human beings" (Elias, 1985, p.5). This knowledge is challenging:

> For those who live neither with religious consolations about death nor with a sense of death (or of anything else) as natural, death is the obscene mystery, the ultimate affront, the thing that cannot be controlled. It can only be denied. (Sontag 1977, p.55)

As Carl Jung (1964, cited in Welman, 1995) in "Man and his Symbols" pithily noted: "All the corpses in the world are chemically identical but living individuals are not." Numerous writers have noted the absence of a person's "essential spirit, vital spark, soul, call it what you will" after death (Welsh, 2002, p.244). The question of what happens to this essence cannot be answered, as William Shakespeare noted several centuries ago: "Death, The undiscover'd country from whose bourn no traveller returns …", and it is this absence of knowledge of this final unknown as well as the loss of identity and sense of being "diminished in death" that seems to be particularly frightening (Berridge, 2001, p.245).

2.2 Approaches to death in previous eras

If it were not for historical studies that revealed shifts in attitudes towards death over time, as well as cultural studies that revealed different approaches, Western denial of death may seem "logical" and "natural". Historian Philippe Ariès (1974, 1977) wrote a definitive account of man's relationship with death over the last thousand years, starting with what he called the "*tame death"*: an old "familiarity with death, with neither fear nor despair, half-way between passive resignation and mystical trust' (Ariès, 1974, p.103). At this time dying was a public ritual with its own ceremony in which an aware person accepted his or her destiny, and death simply put the personality to sleep (Ariès, 1974).

This attitude lasted until the later Middle Ages (from the thirteenth to the fifteenth century), when the individual character and achievements became thoroughly evaluated. Death was seen as more personal and there may have been longing to be more or anxiety at not being enough (Ariès, 1974). The focus was on the "*death of the self"* and whether or not the soul had been saved (Ariès, 1974, p.105). Ariès believed that from the nineteenth century onward, death stopped being familiar and became the unacceptable cause of separation from loved ones.

The focus shifted to the "*death of the other"* and death became a dramatic but more distant event (Ariès, 1974, p.105). This attitude was apparent in the Victorian age when death was very visible with funeral processions, mourning clothes and a culture of remembrance.

However, in the twentieth century, following the annihilation of the First World War, "death has become *'unnameable'*": "Technically, we admit that we might die; we take out insurance on our lives to protect our families from poverty. But really, at least we feel we are non-mortals" (Ariès, 1974, p.105).

While Elias (1985) acknowledged Ariès's work and agreed with Ariès that in the Middle Ages death was more pervasive than in the twentieth century, more public and less private, more spoken of and less concealed, which may have resulted in increased levels of support from others, this did not necessarily mean death was more peaceful. Instead, there was likely to have been greater fear of uncontrolled diseases like the plague as well as a pervasive fear of judgement and hell. He thought Ariès's tame death was romanticised:

> Dying can be full of torment and pain. In earlier times people had fewer possibilities of alleviating the torment. Not even today has the art of medicine advanced sufficiently to ensure a painless death for everyone. But it is mostly able to allow a more peaceful death for many people who would earlier have died in dreadful agony. (Elias, 1985, p.13)

2.3 Summary

The profound fear of death, including fear of oblivion, extinguishing of the self and the unknown, appears to have become more prevalent as death has been distanced from everyday life, and is a significant challenge to be overcome in achieving a good death. Several authors have suggested that talking about death will help to tame death and make it more public and less isolated.

3. Theoretical understandings of death and dying

3.1 Stage theory – Kübler-Ross

One particular theory has been overwhelmingly associated with the revived interest in death and particularly the "happy death movement" (Lofland, 1978, cited in Currer, 2001). This is the work of Elisabeth Kübler-Ross (1969), a medical doctor who worked with terminally ill patients and who was one of the first people to write

about death and dying. She observed that the universal fear of death seemed to grow as science advanced and delineated five stages that patients go through after hearing about their terminal status, namely denial, anger, bargaining, depression and acceptance (Kübler-Ross, 1969).

It is particularly the final stage of *acceptance* that has become associated with "death with dignity" (Poss, 1981), a possible synonym for a good death. Kübler-Ross (1969, p.106) described this stage not as happy, but as "an existence without fear and despair", with a diminished circle of interest as the patient starts to separate him or herself from life; this sounds somewhat like the "tamed" death of Ariès (1974). It is understandable that the peacefulness associated with this description may be encouraged, as it would make the dying process easier for patients, their families and palliative-care staff.

Considering the widespread adoption of aspects of this theory, it is surprising that there still remains relatively little clarity on what exactly is entailed in "accepting" death. This does not appear to be a single process as each new physical symptom has its own challenges and triggers new thoughts and fears (Vachon, 1998). Kalish (1985, p.19) described acceptance as stopping "fighting death and hanging on to life" although not necessarily wanting to die. Acceptance appears to include the idea of "letting go" and disengaging from most relationships, gradually reducing emotional commitment and attachments to others (Kalish 1985). However, unfinished business may make this difficult for some people. While the reward for acceptance and letting go is a peace of mind that is believed to facilitate a peaceful death, Kalish (1985, p.22) emphasised that there are no right or wrong ways to die: "an appropriated death is seldom an appropriate death".

An early critique of Kübler-Ross's five stages of denial, anger, bargaining, depression and acceptance came from McCoy (1974, cited in Kalish, 1985) who suggested adding another five possible experiences: defiance, fear, laughter, tears and a search for meaning. Fear certainly seems a large omission from Kübler-Ross's initial proposal. Although the preface to her book "On death and dying" (1969) stated that "it is not meant to be a textbook on how to manage dying patients, nor is it intended as a complete study of the psychology of dying", Kübler-Ross's work has come to be seen as both these things (Currer, 2001). Thus, until relatively recently there has both been widespread, uncritical acceptance of this

theory, as well as what some authors have described as the misuse of a model that blurs the line "between description and prescription" (Corr et al., 2003, p.139):

> Hospital staff, armed with this model, tend to interpret the events of a patient's dying as fitting into one or another of these stages. So that, having imposed some structure on the world, that structured world is now seen as prior evidence of the justice of that imposition.
> (Kamerman, 1988, p.15)

As noted above, assumptions about the universality of this theory and the chronological nature of progression through the stages have consequences both for the care of the patient and for the expectations of the dying patient and his/her family. As a result, there has been growing criticism of Kübler-Ross's work from a number of different areas (Corr et al., 2003, citing Klass, 1982, and Klass & Hutch, 1985; Currer, 2001). Some authors have criticised the assumption that the five stages apply to all dying people regardless of age, gender or type of illness (Currer, 2001).

However, it is acknowledged that the experience of a terminal illness can trigger strong emotions for all involved: "The survivors have their guilt, the dying their justifiable anger" (Seaton, in Picardie, 1998 p.114). It is believed that, while terminal patients suffer greater physical symptoms, family members witnessing the process may experience more suffering; cancer has been described "a family illness" (Ferrell, 1998, p.910).

3.2 Awareness and meaning theories

> The patient's eyes
> Ice over. He is uninterested
> In lobelias, the cat, the slate, the germ.
> Flat on his back, drip-fed, his face
> The shade of a newly dug-up Pharaoh,
> Wearing his skeleton outside his skin,
> Yet his wits as bright as a lighted candle,
> He is concerned only with the here, the now,
> And requires to speak
> Of nothing but his present predicament.
>
> It is not permitted.
>
> (C. Causley, "Ten types of hospital visitor", in Enright,1980, p.81)

Glaser and Strauss (1965, as cited in Currer, 2001) proposed that the determinant of the patient's experience was the extent of his/her knowledge of his/her dying

status; patients were classified as having closed awareness, suspicion awareness, mutual pretence awareness or open awareness. The patient quoted in the poem above seems aware of his status but his visitor wishes to pretend that he is not dying; this may be termed mutual pretence awareness. A lack of connection may result in intense loneliness for the patient, and the visitor, whether friend or family, may later regret the lost opportunity (Higginson, Wade & McCarthy, 1990).

Peberdy (2000, p.76) concurred with the importance of open awareness, in which the patient, their family and medical staff acknowledge that the patient is dying: "If the possibility of dying can't be faced, a hope that goes beyond insistence on recovery cannot emerge." However, Timmermans (1994, cited in Currer, 2001) commented that Glaser and Strauss's (1965) framework emphasised rational knowing rather than emotional processes. He suggested dividing open awareness into three categories: suspended open awareness (the patient chooses to disregard what he/she has been told); uncertain open awareness (both patient and family focus on information that bolsters hope); and active open awareness (accepting the full implications of knowledge of impending death and acting accordingly). Johnston and Abraham (2000) emphasised the need to negotiate and manage awareness over time.

Other theorists contended that the meaning the individual attaches to the dying process makes a major contribution to his/her experience of it, and that this is specific to his/her context and personal experience (Peberdy, 2000). Meaning may be defined as an "individual's perception of the potential significance of an event" (Barkwell, 1991, cited in Vachon, 1998, p.893). Meaning may be ascribed, for example, to being ill, to cancer and to dying. Examples of this given by Davy and Ellis (2000) are that patients may attribute their symptoms to failure or punishment for some real or imagined misdemeanour; attaching these meanings would increase suffering. Different patients see cancer pain as a challenge (36 per cent), punishment (23 per cent) and an enemy (20 per cent); those who saw their pain as a challenge had lower depression scores, lower pain scores and higher coping scores (Vachon, 1998, p.893). Thus the perceived meaning of cancer pain was key in determining how well patients coped with it.

3.3 Severing social bonds

Seale (1998) observed the emphasis Kübler-Ross had placed on the person's *individual* dying process, but considered the severing of the *social* bond crucial to

understanding death and dying, and noted how difficult it was to hold self-identity together while this took place. "As the body fails, self identity becomes harder to hold together and the normal expectations of human relations cannot be fulfilled" (Seale, 1998, cited in Currer, 2001, p.54). Writing about the death of his beloved wife Ruth, Matt Seaton eloquently wrote:

> … the fantasy of terminal *tendresse* fell far short of the mark. … The dying person has to break her bonds with the world, to separate herself off: it is the process of alienation I still bitterly regret, but it is also a necessary part of letting go. (Picardie, 1998, p.114; original italics)

The breaking of these bonds is painful for all concerned: "Cancer can affect a family in much the same way as it affects a body – causing deterioration if left untreated" (Colin Murray Parkes, in Tanchel, 2003, p.249). Muller (2000, p.30) noted that, while both the dying person and his/her family deal with a "passage of grief", "it would be an illusion to assume that both … are on the same journey and thus know how to support one another". Instead he had frequently observed a "mutual disillusionment" at non-simultaneous grief processes, which may result in misunderstandings, anger and accusations (Muller, 2000, p.30); Kissane et al. (2003) concurred. Sometimes, the changed perspectives that come with a terminal illness may alienate the patient from the well, in unexpected ways:

> What made him most anxious, he told me, was not the big questions – mercilessness of fate, the possibility of heaven. He was too exhausted, he said, to wrestle with those. But he'd become impatient at the way people wasted their lives, squandered their chances like paychecks. (patient quoted in Lamb, 1992, p.456)

Elias (1985, p.59) emphasised that "in dying we are left alone by all the people to whom we feel attached". This breaking of ties can be even more painful for those who are left behind than for the person who is dying. Matt Seaton (Picardie, 1998, p.115) wrote of his wife Ruth's slide into dementia as the cancer attacked her brain and concluded: "… like Eurydice she was lost to the Underworld, and … the true meaning of dying is its absolute loneliness". Seaton appeared to be describing the wasteland between living and dying that both Sontag (1977) and Benzein et al., (2001) referred to at the beginning of this chapter. Furthermore, Seaton emphasised that a sudden death may be "a clean break between being and non-being, possession and loss" (in Picardie, 1998, p.103). However:

> … with a progressive disease like cancer, dying is a relentlessly attritional process of estrangement . You want so much to do and say the right thing, but you are doomed to frustration, failure and regret. The only really 'right thing' would be to make the person you love well again, and that is the one great godlike task you cannot perform.

Elias agreed, as the title of his book "The loneliness of the dying" (1985) demonstrates. He believed the parting between those who are dying and the living begins much earlier than the last hours of life, and suggested the difficulty the living have in identifying with the dying resulted in the "social death" of the patient long before their physical death (1985, p.3). "The defining feature of social death is the cessation of the individual person as an active agent in others' lives" (Mulkay & Ernst, 1991, quoted in Currer, 2001, p.26). Elias attributed the "cooling of relationships" to the living and believed this to be the result of the need of the healthy to maintain a defence against the fear of death; together with social inhibition against expressing strong emotions, there may be:

> … a peculiar embarrassment felt by the living in the presence of dying people … Feelings of embarrassment hold words back. For the dying this can be a bitter experience. While still alive, they are already deserted. (Elias, 1985, p.23)

Peter Speck (1998) described the process of dying as a process of separation from attachments to life, family and friends and ultimately, from one's own body. He emphasised that "dying is a process rather than a single point in time" and the dying person may need to be given permission to make the transition from life to death (Speck, 1998, p.811).

3.4 Task theories

Task theories of dying have predominantly replaced stage theories, which are considered too rigid, particularly in terms of chronology. Four such tasks are: to satisfy the needs of the body and minimise physical distress; to maximise psychological security, autonomy and a rich experience of living; to sustain and enhance important relationships; and to work with sources of spiritual energy and thus encourage hope (Corr, 1992, cited in Currer, 2001, p.41). These have a broader focus than the individual and his/her emotions, but may also be so broad that they are not particularly helpful, noted Currer (2001). What is pertinent is that dying is seen as "strenuous work" that demands flexibility and adaptation to a number of challenges (Currer, 2001, p.44):

> When dying people are least adaptable they are called on to be more so. No healthy person has to make such sharp adjustments in such short order. (Young & Cullen, 1996, cited in Currer, 2001, p.44)

Currer (2001) noted that newer theories focused on three themes: managing the present (finding a balance between a failing body that threatens to overwhelm and losing control to others who seek to help); abandoning the future (predominantly

about self-identity, whether to fight or give in, and emotions, where aspects of the five stage theory may apply); and issues to do with relating to others and the tearing apart of social bonds amid the loneliness of dying.

3.5 Theories of loss

> The present highlights to the patient their gradual, but daily, waning of strength. They come to acknowledge the failing skills and abilities of which they were once so proud; that freedom from bodily harm no longer exists and autonomy is not a matter of course; that their role at work or at home is drastically changing, because now they belong to the 'seriously ill and dying' who seem not to matter in society any more. (Muller, 2000, p.30)

A key conceptualisation of the dying process utilised in palliative care is a focus on loss, for example by Bowman (1997), Muller (2000) and McKitrick, (1985, p.220), who described dying as "death's greedy consumption of all that is close and familiar" to the client and his/her family. Bowman (1997) presented Mitchell and Anderson's (1983) framework of losses, which included: material loss; relationship loss; health loss; role or function loss; and systemic loss. Further losses may include loss of independence and loss of privacy as a result of needing help or being in hospital. However, Bowman (1997, p.76) added that relatively little attention has been paid to the grief resulting from less tangible losses, including the loss of the imagined future as well as the loss of assumptions, illusions, innocence and dreams,

> … the loss of the imagined pictures of the way life should be, the ways things were to have occurred. Loss of dreams is more than change or even disappointment: it describes the loss of something for which there has been, and is, a significant amount of emotional investment.

The final loss for the terminally ill patient is of course loss of life itself. This is clearly articulated by Muller (2000, p.30):

> The closer dying is, the more saddening is the notion that one's life will also wither away; that what constituted one's innermost self and was perhaps adopted with so much effort and toil will become incorporeal and abstract. This is probably the most painful of all losses because it is unfathomable: having to surrender yourself completely and absolutely, including all that made you so special in this world. Coming to terms with handing over one's future and past is certainly one of the greatest achievements a dying person can make.

It is recommended that losses are named, recognised as unique to each individual life and mourned, although this process may be resisted as Western "culture has

an aversion to grief and grieving people" (Bowman, 1997, p.79). Thus both friends and professional caregivers may erroneously believe they are helping by encouraging cheerfulness and a "positive attitude". Robert Shepherd, a Canadian psychiatrist who wrote about his own terminal cancer, described the emotional experience of coming to terms with loss:

> … everybody with life-threatening sickness is depressed. It is loss, you understand, catastrophic loss, you will never be the same again … Then … imperceptibly at first, the light starts to come back. There is less pain, less despair, longer periods of rest at night. (quoted in Vachon, 1998, p.895)

However if grief is not expressed there can be a further loss of meaning in the world, which may be followed by severe depression and hopelessness.

3.6 Psychological theories with a broader application than death and dying

3.6.1 Coping theory

It may be questioned whether dying should be viewed as a totally new process for which people in the Western world are singularly unprepared and which calls forth new behaviours, or whether dying is simply another life stage along a developmental continuum (Poss, 1981) in which case, theories of *coping* may be more applicable to the process.

Lazarus and Folkman (1991, p.190) used a psychoanalytic ego psychology model to define coping as "realistic and flexible thoughts and acts that solve problems and thereby reduce stress". For theorists focussed on coping, a key assumption is that "people die as they have lived". In other words, they use the coping skills they have always used; if denial has been a defence in the past, they will use it; this need not necessarily be unhealthy. Corr et al. (2003, p.141) emphasised that those who are extremely ill, even dying, "are actors not just re-actors" and suggested "tasks are work that can be undertaken in coping with dying".

Writing specifically on coping and mortality, Weisman (1984) suggested these tasks are the search for meaning, the maintenance of morale and negotiation with death. He differentiated between positive coping in the form of negotiating and resolving obstacles to achieving these tasks, and negative defending which tends to turn a problem into a comfortable non-problem but may only be effective in the short-term (Weisman, 1984). He noted that good copers were usually optimistic and self-confident, even in difficult situations, were aware of their dying status and pragmatic about the future. Poor copers sometimes coped well but at other times

were overwhelmed by self-pity and vacillated between excessive expectations and disappointment with no compromises (Weisman, cited in Vachon, 1998).

In an article on "Coping with death" Richard Kalish (1985) noted that this involved: coping with an unknown; making meaning of death and what might come afterwards; handling the pain of loss; making practical arrangements for those left behind; communicating with others; continuing to live as pleasurably as possible; and balancing opposing pressures to let go and to hold onto life.

A useful study on terminally ill patients, while not focusing on a good death specifically, did examine outlooks on dying and concluded that these were grounded in the patients' frames of reference for other major events in their lives (Yedida & MacGregor, 2001). Serial, in-depth, semi-structured interviews took place with thirty terminally ill patients with a range of illnesses and aged between forty and a hundred years old. After in-depth analysis, seven motifs were distilled including: struggle (both living and dying are difficult); dissonance (dying is not living); endurance (triumph of inner strength); coping (finding a new balance); incorporation (belief system incorporates death); quest (seeking meaning in death) and volatile (unresolved) (Yedida & MacGregor, 2001). The authors emphasised that they were not aiming to produce a model that could be generalised but simply to hear patients' perspectives. McCormick and Conley (1995, p.237) agreed that people "tend to die in character".

3.6.2 Trauma theory

Freud (1920, p.301), writing after the devastation of WW1, conceptualised as *traumatic* "any excitations from outside which are powerful enough to break through the (mind's) protective shield"; he believed that a "breach" of this kind may "flood" the mental apparatus with such large amounts of stimuli that these cannot be mastered. This breach is particularly likely when life is threatened and tends to be accompanied by "annihilatory anxiety" and the fear of death, which he saw as "a universal fear, present in all humans" (Freud, 1920; cited in Lemma & Levy, 2004, p.8).

A key feature of trauma is that the world as it has been known, is never the same again; Garland (2004, p.48) described this evocatively as "a life-breaking trauma":

> Traumatic experiences transform reality. There is almost always loss to be endured. Whatever the loss, be it the loss of a former identity, a

> sense of oneself as good or strong or having agency, or the loss of land, sovereignty or oil rights, there must be sadness and pain. There is also rage and hatred and associated feelings of helplessness and despair. Mourning or grieving these losses denotes having the capacity and resources to tolerate the pain. (Levy & Young, 2004, p.143)

Although no literature linking death and dying to trauma theory was found, the diagnosis of a terminal illness seems to "break" the world for the individual concerned in a similar way to the description above. Moreover, during the illness people experience a wide range of actual and symbolic losses, together with an unrelenting threat to their lives. Speaking more generally of trauma, Garland (2004, p.48) noted that a period of mourning for all that has been lost needs to take place: "Some of the mourning must be for the lost aspects of the self – for the lost world of trust, the pre-trauma life and identity". For a terminally ill person who has no possibility of "a personal future" there is not just the past to mourn but also the loss of a life to come (Garland, 2004, p.48). As Ruth Picardie (1998, p.58-59), who was 33 years old when she died leaving two year-old twins, mourned:

> What hurts most is losing the future. I won't be there to clap when my beloved babes learn to write their names, I won't see them learn to swim or go to school or play the piano … I think life will continue just fine. It's just that I'll miss it so.

Several authors including Chng and Ramsey (1985, p.283) emphasised that these losses mean that "dying can be a lonely and painful act" despite devoted care from family members and other caregivers. A patient grieved:

> When I die, my husband will lose his wife, his confidante, his lover; my children will lose their mother; my sisters will lose their sister; my friends their friend, but I will lose everybody. (cited in Chng & Ramsay, 1985, p.283)

Some people may find the pain of these losses unendurable and they are unable to engage with their traumatic experiences in a way that facilitates grieving and thus, eventually, some form of acceptance of the way their lives have changed (Levy & Young, 2004). These individuals may take refuge in denial or become stuck in a pathological melancholia (Levy & Young, 2004).

3.6.3 Existential theory

Irvin Yalom (1980) considered that human beings experience a core existential conflict in the awareness of the inevitability of death and the wish to continue to exist. Moreover, no matter how close one was to others, he suggested there was always a "final, unbridgeable gap" that resulted in a sense of existential isolation

(Yalom, 1980, p.9). He concluded that a sense of meaninglessness may arise: “If we must die, if we constitute our own world, if each is ultimately alone in an indifferent universe, then what meaning does life have?” (Yalom,1980, p.9).

Davy and Ellis (2000) noted that illness and uncertainty are powerful triggers for human existential dilemmas. Quoting Yalom (1989) they observed four key challenges during illness: firstly, isolation, which may be literal or emotional loneliness, vulnerability and a sense of alienation from the healthy; secondly, meaninglessness and lack of purpose, particularly if the illness has reduced activities that were previously important; thirdly, difficult choices that need to be made but which become increasingly loaded as time runs out, with each decision in the face of uncertainty precluding other options; and fourthly, death, a unique event that is hard to imagine let alone come to terms with.

3.7 Summary

When considering the above discussion of the different stage and task theories linked with death and dying, as well as approaches focused on awareness, meaning, breaking social ties and loss, it seems possible that, as Young and Cullen (1996, p.16; in Currer, 2001) concluded “Since individual variation is so great, it is unlikely that any one conceptual system could be applied to all”. Moreover, several broader psychological theories including coping, trauma and existential theory seem useful in understanding the death and dying process. The range of practical, emotional and existential tasks that are proposed as necessary to complete life, mourn loss and prepare for death seem complex. However, it seems likely that a good death will require open awareness and thus a chance to express feelings, mourn losses and find meaning, while utilising coping strategies that facilitate continued contact to prevent isolation.

4. A “good” death

4.1 Definitions and alternative conceptualisations

Although some literature in recent years has started to use the phrase a “good” death (Bradbury, 2000; Bertman, 1991; DeSpelder & Strickland, 2002), there have been other phrases that have attempted to describe a similar concept, for example an “appropriate” death, an “ideal” death (Bertman, 1991), a “peaceful” death (Callahan, 1993, cited in Connelly, 2003) and “death with dignity” (Poss, 1981). The idea of a “good” death does not

appear to be associated with any particular theorist, but there seem to be commonalities in understanding despite variations in terminology.
Bertman (1991, p.16) referred to "the ideal death scenario – that is, the death we would orchestrate for ourselves". She specified certain characteristics of such a death, namely its timeliness (neither premature nor overdue), painlessness, consciousness (with the patient in control of his/her faculties and able to communicate) and preparedness (in other words with time for both philosophical, spiritual and emotional preparation). In "The Last Dance", DeSpelder and Strickland (2002) list a slightly different set of criteria, also attributed to Bertman, namely: a pain-free death, with social and emotional needs met, protected from needless, dehumanising and demeaning procedures, and able to choose to relinquish control over life.

A less optimistic descriptor is Battin's (1994) term "the least worst death", used by Kleespies, Hughes and Gallacher (2000) to describe good symptom management including treatment of pain, anxiety and depression, supporting the patient in grieving and saying farewell, as well as bringing closure to previously unresolved issues.

In Bradbury's (2000) discussion about what comprised a good death he cited Bloch and Parry's (1982) suggestion that in non-Western societies good deaths demonstrate some control over what happens:

> … he should die with his mind still alert and should be able to speak clearly even if only softly; he should die peacefully and with dignity; without bodily discomfort or disturbance; he should die loved and respected by his family. (Middleton, 1982, p.142, quoted in Bradbury, 2000, p.59)

In a wide-ranging discussion, Bradbury (2000) proposed three ideal types of good death in Western cultures. A *sacred* good death frequently involved faith and a conscious patient who is prepared in terms of the expectations of the particular religion concerned. In contrast, the *medical* good death means the patient is unconscious and free of pain; here control has been ceded to medical staff. Finally, there are two kinds of *natural* good deaths: either the sudden, unexpected death without pain, or the situation of an aware patient who is an active agent in their illness. The latter, and the obstacles to achieving it, appears to be the goal of many of the death and dying theories:

> When the possibility of death is acknowledged a person becomes free to choose to hope for death rather than life at any price, to hope for *a certain kind of death* and for certain circumstances to prevail. Such hope may or may not be linked to established systems of belief. (Rumbold, 1986, cited in Peberdy, 2000, p.76; italics added)

It is noted that criteria for a good death change dramatically over time. For example, Ancient Greeks considered dying young, in the fullness of one's creative energies, exceptionally lucky. Today, a young death is considered at least a misfortune and more frequently a tragedy (DeSpelder & Strickland, 2002). Some writers emphasised the importance of not seeing death as "an alien intruder into the familiarity of life" (McKitrick, 1985, p.223):

> The importance of an appropriate death, is that dying is not an extraneous foreign process but rather it is a process integrated into the style, meaning and sequence of that which has gone before. (Pattison, cited in McKitrick, 1985, p.222).

Elias (1988, p.87) articulated the need for the presence of family and friends for a good death:

> … it can be one of the last great joys for dying people to be cared for by family members and friends – a last proof of love, a last sign that they mean something to other people.

However, Davy and Ellis (2000) warned that palliative care professionals may have romantic notions of the idea of a good death. They observed that an apparently peaceful death which takes place over several days may be "easy" for staff while being "emotionally difficult" for relatives (Davy & Ellis, 2000, p.118). DeSpelder and Strickland (2002, p.550) were also concerned that "death is not necessarily fully described or contained by rosy-coloured projections and fantasies about a good death."

Emanuel and Emanuel (1998, p.21) commented that despite significantly increased attention to death and dying over the last few decades, a "good" death is still more of a hope than it is standard medical practice. Moreover, the focus has tended to be on avoiding problems and bad interventions rather than on creating the "positive ideal of a good death". These authors quoted the (American) Institute of Medicine's definition, which several commentators have declared vague, over-simplistic and difficult to implement (Emanuel & Emanuel,1998):

> [A] *decent or good* death is one that is: free from avoidable distress and suffering for patients, families and caregivers; in general in accord with

> patients' and families' wishes; and reasonably consistent with clinical, cultural and ethical standards. (Institute of Medicine, 1997; original italics)

However, Kalish (1985) questioned whether there was a "best" style of dying or a "best" way to cope with death. He asked, *best for whom* - for health professionals, for society at large, or for family members? He warned that professionals working in the field might find it easy to persuade themselves that what was best for the patient was what was best for *them*, the doctors, nurses, priest or psychologist:

> We need to keep in mind that cancer patients are aware of the needs and wants of other important individuals, and many patients, made vulnerable through their illness, will seem to agree with the implicit or explicit message they are receiving as to how they should cope with death, rather than risk the premature loss or abandonment of such significant persons. (Kalish, 1985, p.11)

However, Karl Rahner's description of death's "darkness" as a destructive rather than a neutral force may be closer to the experience of many dying patients, but a hard reality for caregivers and families to accept (quoted in Bregman, 2001). In her study of patients' experiences of palliative care, Julia Lawton expressed dismay at the practical reality of dying, despite the warmth and excellent care provided in hospices:

> What I was unprepared for was somewhat different: it was the visible signs of bodily decay; the stench of incontinence; the lethargy and despondency of patients, many of whom had struggled with their illness for months or years; and the burnout and exhaustion experienced by their families and friends. (Lawton, 2000, p.vii)

Other first-hand observers have agreed:

> If I learnt one thing over Ruth's last weeks, it was that the illusions one holds about a peaceful, dignified death and the family's perfect bedside farewell will almost certainly be tugged away. If one is left with any shreds of comfort, then they must be unlooked-for blessings. Dying is nasty, ugly and painful; it's so obvious, isn't it? (Seaton, in Picardie, 1998, p.100)

It seems likely from the above comments that there is tremendous pain and suffering for the observers of a lingering death and that, as has been frequently noted, cancer is an illness experienced by the family rather than just the individual. Furthermore, the idea of a good death may simply be what we wish for our loved ones and ourselves but may be difficult to

achieve, despite the best intentions and considerable hard work (Lawton, 2000).

4.2 A 'bad' death

It is worth noting that the Greek origin of the word euthanasia has been described as "eu" meaning good, and "thanatos" meaning death (Collins Concise Dictionary, 1989). Bertman (1991, p.18) contrasted the ideal death with its possibilities of "closure and the quiet dignity of fading away peacefully" with a painful, un-reconciled, agonised death with no sense of composure or control, and no ability to communicate. She termed this "the indignity that can befall a person whose dying is prolonged" (Bertman, 1991, p.20). The need to avoid this kind of death is the basis of the "Living Will" prepared by Euthanasia Education Council New York (1974):

> Death is as much a reality as birth, growth, maturity and old age – it is the one certainty. I do not fear death as much as I fear the indignity of deterioration, dependence and hopeless pain. (cited in Bertman, 1991, p.21)

4.3 The responsibility to die well

> The art of dying consists in having cultivated throughout life a sense of acceptance and the will, the intuition, and the prudence necessary to know when to fully commit to this duty at the end of life. (Connelly, 2003, p.60)

As the quotation above indicates, American philosopher Robert Connelly (2003, p.59) wrote of "the distinct obligation to accept death". He believed that to arrive reluctantly at this position only at the end of life was a "moral failing" (Connelly, 2003, p.59). Connelly considered the art of dying to be composed of numerous factors including: the ability to comprehend relevant medical information; the ability to listen to one's own body and its needs and failings; "a developed character" that was able to be flexible about life's ups and downs; a sense of style and humour (citing Allport, 1961); shared decision-making as a result of satisfying relationships; and "a sense of individual closure in the lifelong pursuit of spiritual meaningfulness".

Connelly (2003) believed this approach challenged the commitment of Western medicine to extending the length of life at all costs, and brought the possibility of Ariès's tamed death closer. He advocated a deliberate shift away from the "presumption in favor of life toward a more radical presumption in favor of good

dying" that would include "experiencing well the last stages of living" (Connelly, 2003, p.59):

> Paradoxically, an active, responsible, and skilful approach to letting go is more life affirming than the self-deluding strategy of denying the imminence of death. Dying well is living fully up to the last moment.

This suggestion of choosing to co-operate with death rather than fighting it is positioned as a unique human responsibility that is linked to the unique human foreknowledge of death (Connelly, 2003). Co-operation would include a readiness to die, knowing when it is time to die, and the will to die. To prepare for, and participate actively in one's death are suggested as ways to make death meaningful (Connelly, 2003). Part of this preparation may include reflecting on the ideal death. It is suggested that numerous benefits flow from this acceptance in contrast to the costs of the denial of death: "Once you learn how to die, you learn how to live" (Morrie Schwartz: in Albom, 1997, p.82)

In "Grace and Grit" (1991, p.360), Ken Wilber's book about the death of his wife from breast cancer, he quoted her saying: "Because I can no longer ignore death, I pay more attention to life". Similar thoughts have been proposed by Norman Cousins (1989; in Bowman, 1997, p.78) who wrote that "healing is possible even when curing is not", and Stephen Levine, one of whose many books is titled "Healing into life and death" (1987).

4.3 Previous studies of a good death

One informative study involved twelve focus groups of six participants each, ranging from patients and recently bereaved family members to physicians, nurses, social workers and chaplains discussing a good death (Steinhauser, Clipp, et al., 2000). The greatest fears reported were of dying in pain and/or struggling to breathe. These fears were reduced by clear communication and decision-making between patient, medical staff and family; these were seen as empowering and respectful. There was a need for greater preparation for the end of life, including practical issues like a will and the funeral, and more information about the dying process.

In a further study on factors considered important at end of life, it was noted that there were a number of attributes highly valued by patients that were not valued by physicians (Steinhauser, Christakis et al., 2000). These included being mentally

aware, being at peace with God, not being a burden to family, being able to help others, having a funeral planned and feeling one's life is complete:

> Whereas physicians tend to focus on physical aspects, patients and families tend to view the end of life with broader psychosocial and spiritual meaning, shaped by a lifetime of experiences. (Steinhauser, Christakis et al., 2000, p.2482).

A number of authors concluded their studies with the emphasis that shared decision-making and communication of the patient's personal values was important in facilitating the kind of death he or she wanted (Baum & Gallagher, 1987; Singer, Martin & Kelner, 1999; Thompson & McClement, 2002).

In their exploration of a good death Emanuel and Emanuel (1998, p.22) emphasised that "death is not just a medical experience and the patient's full social network can significantly influence their experience". They saw dying as a multidimensional experience with four critical components: the fixed characteristics of the patient including demographics like their age and level of education, as well as their disease; the modifiable aspects of the patient's experience including their physical symptoms, social support, hopes and expectations, psychological and cognitive symptoms, economic demands and care-giving needs, and spiritual and existential beliefs; the potential interventions available to family, social and spiritual supporters and health-care providers; and the overall outcome (Emanuel & Emanuel, 1998). The encouraging part of this approach is how much of the experience is seen as modifiable and thus an area of potential intervention if desired by the patient; however, it seems overly complex.

Block (2001) described the goals central to a good death as follows: optimising physical comfort; maintaining a sense of continuity with one's self; maintaining and enhancing relationships; making meaning of one's life and death; achieving a sense of control; and confronting and preparing for death. These findings, with one exception, were replicated in a study by Singer et al., (1999) who investigated quality end-of-life care with AIDS, dialysis and long term care patients; it is noted that there were no cancer patients, however both the AIDS and dialysis patients were in their thirties and forties. The exception to the previous findings was the addition of the avoidance of inappropriate prolongation of dying as a significant concern (Singer et al., 1999).

While several other studies of a good death were sourced, two of these specifically related to individuals dying in old age (Leichtentritt & Rettig 2001; Vig, Davenport & Pearlman, 2002) and one to patients with AIDS (Pierson, Curtis & Patrick, 2002).

4.5 Summary

The Steinhauser, Clipp et al., (2000) study stated that a good death was facilitated by pain and symptom management, clear decision making and preparation for death, completion, contributing to others and affirmation of the whole person. Completion involved issues of faith but also included a life review, resolving conflicts, spending time with loved ones and saying farewell; significant growth may take place. These four themes had been expected from the literature. However, it was unexpectedly important for patients to value being able to contribute to the well-being of others and to want to be known and affirmed as unique and whole people (Steinhauser, Clipp et al., 2000). It was emphasised that there "is no single formula for a good death" (Steinhauser, Clipp et al., 2000, p.830).

5. <u>What else might contribute to a good death?</u>

In other words, what might help someone bear the unbearable and reach a sense of completion in life? This section will explore symptom control, aspects of quality of life including adaptation, and self-concept, and the role that might be played by religion, spirituality and hope.

5.1 Symptom control

> My God, if you can't get depressed about death, what the hell can you? (Picardie, 1998, p.11)

The symptom most cancer patients worry about is pain, with good reason – one study showed that hospital doctors underestimate the severity of pain in up to 90% of patients (Rogers & Todd, 2000). It is noted that patients who are depressed or experiencing existential despair can have a lower pain threshold (Emanuel & Emanuel, 1998). It has also been found that patients with pain and physical disability have higher rates of depression (Smith, Gomm & Dickens, 2003). In addition, both fatigue (Potter, 2004; Richardson & Ream, 1998) and physical weakness (Brown, 1999) are highly prevalent toward end of life. Patients report

significant distress as a result of impaired role performance and this is most likely to be affected by pain, fatigue and weakness (Vachon, 1998).

Numerous reports emphasised significant levels of psychiatric disorders including anxiety and depression among terminally ill patients; these may be present in up to 47% of cancer patients (Block, 2001) and incidence of depression increases in younger patients (Vachon, 1998). Dying may trigger depression or anxiety if there are previously unresolved separations or losses, a lack of social support, or an inappropriate delivery of prognosis that does not allow natural adjustment to take place (Vachon, 1998). The under-diagnosis of psychiatric disorders among terminally ill patients seems to be the result of seeing depression as "appropriate" in a severe medical condition (Kleespies et al., 2000; Pillay, 2001). The erroneous nature of this perception is revealed in studies in which patients regained a sense of optimism once their psychiatric condition was treated (Lloyd-Williams, 2002).

There have been a number of recent studies exploring the desire for euthanasia among the terminally ill (Chochinov et al., 1995; Kelly et al., 2002; Kleespies et al., 2000; Mak & Elwyn, 2003). In fact, suicide among cancer patients is considered rare and the wish to hasten death tends to be transient (Chochinov et al., 1995; Kelly et al., 2002). In all the above studies it was concluded that end of life despair and hopelessness were usually associated with treatable symptoms including depression and pain, as well as with poor family support. Other concerns of those patients who wanted help to die sooner were fear of the future, dread of being a burden, loss of autonomy and a lack of dignity. Feeling more in control through information that reduces uncertainty and shared decision-making can be beneficial (Vachon, 1998). However, it has been noted that uncontrollable vomiting or diarrhoea, or external lesions with a strong odour, among other symptoms that are repugnant to both the patient and observers, can contribute to a desire for euthanasia (Lawton, 2000).

At the time of writing, the desire to hasten death among the terminally ill was topical as seen in newspaper articles titled "Taking control of the final act" (New York Times in the Sunday Times 3 April 2005) and a Time Magazine cover titled "The end of life, who decides?" (4 April 2005). Much of this publicity about the right to die was triggered by the controversy over the decision to disconnect Terri Schiavo from life support machines including artificial feeding.

5.2 Quality of life – a dynamic construct

> The way a person dies depends not least on whether and how far he or she has been able to set goals and to reach them, to set tasks and perform them. It depends on how far the dying person feels that life has been fulfilled and meaningful – or unfulfilled and meaningless. (Elias, 1985, p.62)

In the above quotation, Elias suggested that quality of life for the dying is intimately related to the quality of a person's life while they were healthy, specifically: "the image of one's own death is closely connected to the image of oneself, of one's own life, and the nature of this life" (Elias, 1985, p.60).

It has been said that little research has been done on quality of life in patients with advanced cancer, but that this can be defined as "the patient's perception of life satisfaction" (Spiroch, Walsh, Mazanec & Nelson, 2000, p.235). Interviews with thirty patients (average age 65 years old) with advanced cancer found more positive feelings about their quality of life than expected; family was specified as the most important component of quality of life (Spiroch et al., 2000).

Allison, Locker and Feine (1997) proposed that quality of life, whether related to life or the dying process, is not a stable construct but a within-subject dynamic construct affected by changeable attitudes towards circumstances and modified by psychological phenomena such as adaptation, coping, expectancy, optimism, self-control and self-concept (Allison et al., 1997). These researchers cited numerous studies that found life satisfaction among cancer patients exceeded that of controls among the healthy population. As these apparently paradoxical results seem to indicate, "determinants of well-being will lie within the person" (Heyink, 1993, as quoted in Allison et al., 1997, p.223).

5.2.1 Adaptation

> Death smiles at us all. All a man can do is to smile back. (Russell Crowe as General Maximus in the film "Gladiator")

Adaptation has been described by Heyink (1993, quoted in Allison et al., 1997, p.223) as "an intrapsychic process in which past, present and future situations and circumstances are given such cognitive and emotional meaning that an acceptable level of well-being is achieved". An individual's adaptation level is said to be the result of all stimuli from the past and present and how they affect the present

situation (Helson, 1964, cited in Allison, et al., 1997); thus “adaptation is an individual’s attempt to normalise stimuli” (Allison, et al., 1997, p.224).

In the context of death and dying, adaptation could be seen as another word for acceptance. As previously mentioned, few studies have researched this topic (Röcke & Cherry, 2002, citing Baltes & Skrotzkis, 1995). These authors suggested that the greater the satisfaction with life, the more an individual is able to accept death; unexpectedly, they believe it is dissatisfaction and regret that make dying so difficult. The acceptance of death can be facilitated through reminiscence that aims to see life as a continuum. The process of creating a biography integrates life events, including conflicts, and takes the opportunity to resolve pertinent issues (Röcke & Cherry, 2002).

5.2.2 Stress and coping

As Kalish (1985, p.10) proposed, “it appears logical that we cope with our own foreseeable death in much the same manner as we cope with other highly stressful situations”. Lazarus and Folkman (1991) emphasised two fundamental forms of coping with stressors: problem-focused coping aimed at managing or changing the problem, which may include seeking information and aid as well as direct action; and emotion-focused coping attempting to moderate emotional response to the problem.

It seems likely that an individual will respond initially to being diagnosed with a life-threatening illness by predominantly utilising problem-focused coping; when given a terminal prognosis there is a realisation that the problem cannot be controlled and a shift to a higher proportion of emotion-focused coping. Helpful strategies at this point may include avoidance, detachment, and trying to see humour in the situation (Lazarus & Folkman, 1991).

An example is “Before I say goodbye”, a collection of newspaper columns written by Ruth Picardie during her illness and published in The Observer (1997). After developing secondary cancer in her bones, she said: “I obviously have bionic breast cancer – I want the primary tumour to be hung, drawn and quartered after my death.” At times this was a biting humour: “At least life becomes a case of collecting your thoughts not your pension” (Picardie, 1998, p.8).

5.2.3 Self-control

Twycross and Lichter (1998) recommended that a patient who is terminally ill needs to feel safe when he or she must surrender control and independence, and emphasised the importance of doing nothing that disregards individuality or damages self-esteem. This yielding of autonomy may be extremely difficult for some patients and cause significant distress.

Furthermore, Cameron (2003) and Twycross and Lichter (1988, p.987) observed that some patients might experience "terminal anguish". They defined this as "a tormented state of mind" related to long-standing emotional problems, interpersonal difficulties or unhappy memories. While the patient is conscious he or she is able to control thoughts and denial can function. However, increasing weakness and drowsiness allow hidden material in the unconscious mind to surface. The patient may become restless and cry out, with sedation the only way to moderate the patient's and the family's distress. The authors recommended dealing with "psychological skeletons in the cupboard" while the patient is still strong enough to do so, in order to prevent this (Twycross & Lichter,1988, p.988).

5.2.4 Optimism and expectations

The Steinhauser and Clipp study (2000) reiterated that the quality of dying is likely to be related to the individual's character and needs to be seen in the context of their lifetime of experiences. Optimism is considered a stable personality construct that provides a higher level of well-being and a more active use of problem-focused coping strategies (Scheier & Carver, 1987, cited in Allison et al., 1997). Once optimists perceive a situation as being uncontrollable, they tend to be more likely to use acceptance and resignation as coping strategies, and appear to be more adaptable (Allison et al., 1997).

Calman (1984) defined an individual's quality of life as "the gap between her expectations and her reality" (cited in Allison et al., 1997, p.227). Bandura (1977, cited in Allison et al., 1997) noted that people's motivation and thus their actions were affected by their beliefs about likely results and that, when a desired outcome was apparently unattainable, people tended to disengage themselves from it. This behaviour seems to protect the self against continued disappointment and is particularly important in dealing with an unchangeable outcome like a terminal illness.

5.2.5 Self-concept

Self-concept has been defined as “the sum total of all that a person feels about himself/herself” (Schain, 1980, as quoted in Allison et al., 1997, p.225). Furthermore, Foltz (1987, cited in Allison et al., 1997) considered self-concept and quality of life interdependent. Self-concept is subdivided into four components: the body self (comprising both physical self and body image); the interpersonal self (psychosocial and sexual interaction); the achievement self (both job and role functions) and the identification self (spiritual and ethical beliefs) (Foltz, 1987, cited in Allison et al., 1997). A terminal illness impacts dramatically on all four of these components and threatens to shatter all “that a person feels about him or herself” (Schain, 1980, as quoted in Allison et al., 1997, p.225). Although McCrae and Costa (1988, cited in Allison et al., 1997) argued that people downgrade an aspect of self that they are unable to feel good about, an event that impacts on all domains may be extremely challenging to a sense of integrity and wholeness.

5.3 Death with dignity

Bertman (1991, p.215) cited Freud’s (1908) insight that the unconscious cannot face the thought of its own death, which results in “death anxiety”; this may apply to observers as much as to the dying patient. In contrast, however, Bertman (1991, p.65) quoted Hine (1977): “In a life-and-death struggle we always assume that the struggle is for life *against* death. I wonder if there is a time in each human life when life itself becomes the lesser state and the victorious must struggle for death?” (original italics).

It has been emphasised that a basic feature of human dignity is the right to choose the moment of death, specifically the right to stop any therapy that is painful or exhausting and to let the disease progress naturally (Mystakidou et al., 2002). In addition, Sylvia Poss (1981) considered that the counter-intuitive process of coming to terms with the “annihilation” of the self (Schneidman, 1973, p.66, cited in Kamerman, 1988, p.18) required mental, emotional, social and spiritual *work* in order to die with dignity.

However, in a letter to the editor of the American Journal of Hospice and Palliative Care titled “Whose dignity are we talking about?” Thomas Welk (2000) noted that

although the word dignity was frequently used in palliative care, it was hard to define. He quoted Judge Reinhardt (1996) issuing judgement in a US court case:

> A competent, terminally ill adult, having lived nearly the full measure of life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his [sic] existence to a childlike state of helplessness, diapered, sedated, incontinent. (quoted in Welk, 2000, p.279)

Welk (2000, p.279), Director of Professional Education in a Kansas Hospice, postulated that this statement "sums up the attitude of the American culture that places a high premium on external appearances" and independence. He noted that children are not less valued for being dependent and wearing "diapers", nor do they find this undignified. Welk quoted Morrie Schwartz, who said in an interview with Ted Koppel that he initially felt ashamed when his illness meant he could no longer wipe his own bottom. However, when he realised this shame was culturally imposed and let it go, he was able to enjoy the care he received as a bedridden patient, with its reminders of being a child who is utterly loved. Morrie said: "I revel in it. I close my eyes and soak it up." (as quoted in Welk, 2000, p.279). Welk emphasised: "Being dependent isn't what causes indignity. Not being cared for is what brings about indignity." (2000, p.279).

5.4 Spirituality

Speck (1998) noted that it is relatively recently that a distinction has been drawn between "religious" and "spiritual". While he described the adjective "religious" as "a particular system of faith and worship", the term "spiritual" was a broader concept including "the search for essential meaning within any given life experience" (Speck, 1998, p.806). Various studies have consistently revealed an inverse relationship between spiritual wellbeing and state-trait anxiety (Hirai, Morita & Kashiwagi, 2003; Hopper, 2000; Vachon, 1998).

Kushner (2001, p.147) suggested that people who are suffering might turn to religion "for the reassurance that the universe is not indifferent":

> Like Ruth, I have no religion, but I can more easily understand than ever the appeal of the idea of an afterlife … In truth, and she knew it, Ruth's afterlife is in her children. It was a bitter-sweet comfort, for they are the thing she could least bear to give up. (Seaton in Picardie, 1998, p.116)

This belief in death as an end to everything, is clearly held by Elias:

> Death hides no secret. It opens no door. It is the end of a person. What survives is what he or she has given to other people, what stays in their memory. (1985, p.67)

However, other authors have put forward a completely different point of view. Berridge (2001, p.268) quoted a letter from Mary Drew, Gladstone's daughter, written in 1895 in which she noted "the utter grimness of death unbrightened by faith". Berridge (2001, p.269) explained this "grimness" as being "cut adrift from opportunities for contemplation, mystery and awe." These may be described as expanding and connecting emotions that provide an ill person with a comforting sense of being part of something greater than the self.

There have been a series of recent articles examining the integration of spirituality into palliative care (Cornette, 2005; Dowling Singh, 2000; Habernecht & Prior, 1997; Kellehear, 2000; McClain, Rosenfeld & Breitbart, 2003; Walter, 2002; White, 2000; Wright, 2002). Several authors have noted that the search for meaning may intensify when illness or death disrupts a sense of purpose and that this is essentially a spiritual process (Highfel, 1992, cited in White, 2000).

A study of 160 patients with a life expectancy of less than three months indicated that spiritual well-being offered some protection against end-of-life despair through helping to create a sense of peace and meaning (McClain et al., 2003). They defined spirituality as "the way in which people understand their lives in view of their ultimate meaning and value" (McClain et al., 2003, p.1603). Interestingly they noted a significantly stronger association with meaning in this sense than with spiritual well-being rooted in religious faith.

The benefit of paying attention to spiritual needs was said to lie in providing an "essential and integrating" experience that gave a sense of connection to all things (McClain et al., 2003, p.481). This may be particularly important in countering the sense of disintegration experienced during a terminal illness.

However, it is also possible that previously devout believers may suffer a "dark night of the soul", feel their faith is shaken and they have been betrayed by God when they do not get well (St. John of the Cross, quoted by Speck, 1998, p.807). Furthermore, there may be pressure from those who insist that "if your faith is strong enough you will be healed"; Speck (1998) described this as emotional blackmail. In these situations, and those involving concerns about guilt and

punishment, spiritual counselling may be essential for the peace of mind of the patient.

5.5 Making meaning

Kalish (1985) observed that there are different meanings that can be associated with the death of the self, including seeing it as an ending, a beginning, a transition or all three. Furthermore, untimely death can be perceived as a reward or a punishment, bad luck or a release from the stress of the world (Kalish, 1985). He believed that those who most feared death were those who were least sure of what it meant for them and for whom this lack of certainty mattered.

Psychologist Miriam Greenspan emphasised:

> But each of us must make some meaning of loss or be devastated by it. The need to find meaning in loss and death is as urgent as the thirst for drink or the hunger for food. Without meaning, despair sets in and stays, a permanent, uninvited guest. (2003, p.99)

In this, she concurred with Viktor Frankl (1959) whose renowned "Man's Search for Meaning" stated that a primary motivation of man's life is the "will to meaning", and that each individual has the responsibility to find his or her "unique and specific" meaning (Frankl, 1959, p.121). Once this is found, Frankl believed the wisdom of Nietzche held true: "He who has a *why* to live for can bear with almost any *how*" (Frankl, 1959, p.126).

Frankl believed this meaning, or *why* to live given the challenging circumstances of many human lives, could come from one of three areas: firstly, creativity in a particular work or task; secondly, by experiencing something - such as goodness, beauty or truth - or someone and loving the uniqueness of him or her; and thirdly by the attitude taken towards "unavoidable suffering" (Frankl, 1959, p.131-132). In expanding on this third way to find meaning he stated:

> We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. For what then matters is to bear witness to the uniquely human potential at its best, which is to transform a personal tragedy into a triumph, to turn one's own predicament into a human achievement. When we are no longer able to change a situation – just think of an incurable disease such as inoperable cancer – we are challenged to change ourselves. (Frankl, 1959, p.135)

Were it not for Dr Frankl's own experiences in Auschwitz, this may seem like wishful thinking. However, in their consideration of the impact of the individual on

his or her experience, Twycross and Lichter (1998) concurred, stating that suffering is not directly related to the severity of symptoms and that mild symptoms can cause significant distress if the patient has not come to terms with their terminal status:

> Suffering stems from conditions or events which threaten the integrity of a person as a complex psychological and social entity. Suffering is experienced by persons not by bodies. It can occur in relation to any aspect of the person – physical, psychological, social, or spiritual. A sense of loss of meaning and purpose, helplessness, hopelessness, endlessness, and lack of control are major causes of suffering (Twycross & Lichter, 1998, p.979).

These authors emphasised that certain personality traits may make suffering more acute, for example a negative outlook on life or fierce independence and a need to maintain control. It can be a goal to put suffering and death into a larger context as part of life: “Meaning can be found in the very act of bearing witness to the events of one’s life” (Greenstein & Breitbart, 2000, p.494). It has also been noted that psychological growth can come from the process of adaptation to major loss and that making personal meaning out of painful experience contributes greatly to this (Davis, Nolen-Hoeksema & Larson, 1998; Evans, 1995; Miller & Harvey, 2001).

5.6 Hope

> To experience hope is a way of coming out of the dark.
> (Benzein et al., 2001, p.123)

In palliative care, Benzein et al. (2001, p.117) described hope as “built on the belief that better days or moments can come”, which is essential in providing a “will to live for a while longer” (Benzein et al., 2001, p.119). Their in-depth study of the meaning of the lived experience of hope from the point of view of patients with incurable cancer revealed four themes. Firstly, a hope of being cured or at least getting better; good symptom control was essential to maintain this: “it is the symptoms that decide how much you hope” (Benzein et al., p.121). A second theme was the hope of living as normally as possible. Despite this, patients “had lowered their sights concerning what could be realised” (Benzein et al., 2001, p.121) and the study quoted one patient whose hope was to be able to sit up for her afternoon visitor. A third hope involved the presence of connecting relationships (Benzein et al., 2001). Speck (1998) described this as hoping for the ability to love and be loved. Finally, they hoped for reconciliation with life and death through both practical and emotional preparation. This ranged from taking

care of legal issues and their funeral to looking back over their lives; both of these last two hopes allowed a “re-collection” of the self as a unity (Benzein, 2001, p.21). The authors concluded that living with incurable cancer does not mean living without hope, thus hope can be compatible with acceptance. As Twycross and Lichter (1998, p.977) noted, when patients are close to death, “hope becomes refocused on ‘being’, rather than ‘doing’, and emphasizes relationships – with others and with God”. There may also be the hope of “finding meaning in the mystery of death” (Speck, 1998, p.810). Benzein et al. commented on the lived experience of hope involving:

> … a tension between various dimensions of hope; to *hope for something*, that is the hope of being cured, and *living in hope*, that is reconciliation and comfort with life and death. Which dimension is prominent varies over time. (2001, p.123, italics in original)

5.7 Summary

A good death seems to be made up of a number of factors that are able to operate when good symptom management occurs. These include adaptation, which facilitates reaching acceptance of death while maintaining hope, and utilising existing coping skills that may include the creation of meaning or a reliance on faith. An ability to let go of control and be willing to be dependent and accept help is important. In addition, a good death seems likelier if the patient is able to release investment in their sense of self as conditional on achievement and their physical body and instead invest in their interpersonal and identification selves, thus maintaining a healthy self-concept.

CHAPTER THREE

METHODOLOGY

> Knowledge here means illuminating human experience: the complexity, opaqueness, and mystery of an essentially subjective species.
> (Paget, 1999, p.101)

1.1 In-depth interviews

This study aimed to explore the subjective experience of dying by using in-depth interviewing to access lived experience, and in particular what might constitute a good death to people in mid-life who are terminally ill. It used exploratory, qualitative research, based on an understanding of the world as "fine-grained, variegated, and to some extent, always resistant to comprehensive explanation" (Gubrium & Holstein, 1999, p.131).

Paget (1999, p.101) described in-depth interviewing not simply as a means to access information, but as a "search procedure" with the answers to questions continually informing the conversation as it evolves. "Knowledge thus accumulates with many turns at talk. It collects in stories, asides, hesitations, expressions of feeling and spontaneous associations" (Paget, 1999, p.91). This approach seemed appropriate as the idea of a "good" death is not part of everyday language, and it was anticipated that an understanding of it might arise both from the manifest and the latent content of the interviews.

Paget emphasised the curiosity of the individual interviewer as a powerful contributor to the "complex and multi-meaninged construction of experience" (1999, p.92) between interviewer and subject that unfolds in a dynamic and cumulative process. Holstein and Gubrium (1999, p.106) noted that interviews are a particular form of conversation and are of necessity interactive: in collaboration with interviewers, respondents are "constructors of knowledge" rather than "passive vessels of answers" (Holstein & Gubrium,1999, p.108). These authors discussed Douglas's "creative interviewing" and use of "many strategies and tactics of interaction, largely based on an understanding of friendly feelings and intimacy, to optimise *cooperative, mutual disclosure and a creative search for mutual understanding."* (1985, cited in Holstein & Gubrium, 1999, original italics).

An example of this co-creation of knowledge follows, taken from the interview with James, with “D” as the interviewer and “J” as the respondent:

D: So you’ve been healthy.
J: Absolutely.
D: A very healthy man most of your life. It must make it harder in some ways to to go from being so healthy to so unwell. Such a change.
J: Frustration!
D: It’s frustrating for you.
J: (coughs) Pull my hair out, absolutely pull my hair out.
D: What is it you find so frustrating?
J: I can’t do things. I can’t walk from here to there without huffing and puffing. While I’m sitting here I’m fine.
D: You’ve always been so active from the sound of things.
J: (describes his love of sailing in detail) But this!
D: Just having to sit around.
J: Drives me insane.
D: Maybe also accepting help is not so easy?
J: It isn’t.
D: Because it sounds like you’ve been very independent for the last however many years really.
J: Well I have. Technically I’ve lived on my own for the last ten years …
D: So to go from being very independent and strong and fit and healthy to feeling as you say …
J: Hopeless.
D: … tired and breathless and needing help. I mean that’s very hard.
J: As I say Hphphrrr!
D: You feel very frustrated.
J: Frustrated Ja. But … so be it. My philosophy says some live long, some live short, and if this means living short you got to accept the facts and go from there and make the adjustments.
D: So it sounds like that philosophy’s helping?
J: Mmm. I would say so.
D: And I’m wondering if there’s anything else that you’re finding supportive …

1.2 Sample

Purposive sampling was used and the subjects were patients with cancer who had received a terminal diagnosis at least two months prior to the request for participation. (It is noted that James was an exception to this: he had been told he was terminally ill only just over a month before the interview.) Social workers and home-care sisters from the Houghton Hospice in Johannesburg were asked to source six patients for the study; as a result permission to take part in the research project was sought by a third party. In their selection of patients who were aware of their condition and able to talk about it, the primary concern of Hospice staff was the well-being of patients. While this was ethically responsible, selection bias is

likely as only patients who had in some sense come to terms with their situation were interviewed. Thus there is no suggestion that the findings are representative.

Kleinman (1988, p.5) postulated that the illness experience "is always culturally shaped", as there are conventional expectations of illness and ways of being ill and behaving that society considers appropriate. Elias (1985, p.4) noted "the experience of death, too, can differ from society to society. It is variable and group specific". Given this socially and culturally embedded process of dying, it was considered important that a relatively homogenous sample of interviewees should be selected. As a result, the sample was limited to white, broadly middle class, English-speaking men and women.

A second sample criterion was age, specifically individuals in mid-life, defined as below fifty years old. In Western 'developed' societies, an average life expectancy of 75 years can be anticipated (Elias, 1985), thus at the age of thirty or forty, death is remote. Muller (2000, p.30) described this group as "people in their prime who have had almost no inkling of death". Although there is a high death rate among some South Africans of this age group predominantly as a result of the AIDS epidemic, life expectancy for white, middle-class South Africans is still in line with Western norms. This sample thus had in common the untimely nature of their deaths.

A third criterion was people with children and/or a spouse. This meant that respondents' deaths were untimely not only in terms of their expected life cycle, but also in terms of their responsibilities (e.g. caring for spouse and/or children). In addition, it seemed likely that these subjects had tasks and dreams left undone and were terminally ill at a time when it would be more likely that their parents would be dying; thus the family's continuity is broken, a sense of what is "natural" in terms of the life cycle may be reconsidered and a re-evaluation of death and its meanings may be likely.

Fourth, all patients selected were ill with cancer as "cancer diagnoses often have a clear-cut trajectory that is not evident in other conditions" (Beaver et al., 1999, p.14). Thus a point had been reached with these patients where curative treatment was no longer effective and they were informed that their disease would kill them in the foreseeable future.

In summary, four men and two women ranging in age from 37 to 52 years of age, all of whom had children and may be broadly categorised as English-speaking and middle-class, were interviewed for the study. All six interviewees had different types of cancer: three had been ill for a number of years and three were relatively recently diagnosed. Interviews were conducted in October/November 2004 and February/March 2005. At the time of writing, all participants had died.

It is important to note that the health of two additional patients who had agreed to participate deteriorated suddenly before interviews could take place; three other patients (all of whom, perhaps coincidentally, were in their thirties) were approached by nursing staff or social workers and were unwilling to participate. Overall, finding a group of patients who met the criteria and were willing to be part of the study was more challenging than had been anticipated by either the researcher or the Hospice staff; as a result, some flexibility, for example in terms of age, was shown.

For further details of the sample please see the three pages of participant summary information at the end of this chapter. Please note that participants' names have been changed.

1. 3 Procedure

Patients who were Houghton Hospice service-users were asked by either their home-care sister or a social worker whether they were willing to be interviewed for approximately an hour-and-a-half on their thoughts about death and dying. It was made clear that declining to participate would in no way compromise the service they received from Hospice. After patients had agreed to participate the interviewer telephoned them, explained about the research and made an appointment for an interview. This two-step referral procedure sought to prevent coercion (Beaver et al., 1999).

1.3.1 Data collection

The interviews took place in a venue that was chosen by the participant: three interviews took place in respondents' homes, two in the homes of a friend or family member where the participant was staying, and one in the In-patient Unit (IPU) at Hospice. The patient who was seen at Hospice, Sally, was seen on two occasions with a day between the interviews because the initial interview was interrupted by the arrival of visitors. It is worth noting that two interviews took place with the

subject's spouse in the room for at least part of the session, at their request. All interviewees chose to be seen late morning, when they felt most comfortable and had some energy.

At the start of the interview, the participant information letter was read and discussed, and permission to tape-record each interview was requested. Copies of the letter and relevant consent forms are attached at the back of this document.

1.3.2 Researcher as instrument

Oskowitz (1997, citing Guba & Lincoln, 1985) commented that in qualitative research, the researcher is the most important instrument and as a result, trustworthy results require the human instrument to be both skilled and prepared. She emphasised that this is particularly important when sensitive topics are being explored.

A semi-structured interview took place based on the interview schedule, which focused on open-ended and wide-ranging subject prompts. This schedule is attached. It is noted that as the interviewer I made discretionary decisions on which questions to ask; for example when respondents seemed uncomfortable discussing death I did not press them, or if they were adamant that they would recover, this was not questioned in any way. The interviews generally started with a question about the onset of the patient's illness, followed by enquiries about its progress before reaching the very difficult subject of dying.

1.4 Data analysis

Material from the interviews was transcribed verbatim. Several researchers, notably DeVault (1999) and Poland (1999) have questioned what might constitute a "complete" or verbatim transcription and whether "cleaning up" quotations helps understanding of content or loses the individual nuances of speech. In this study, the interviews were initially transcribed in full, including hesitations and repetitions. Then each interview was paraphrased and quotes included here have been "cleaned up"; these summaries are available in the Appendix.

Poland (1999) emphasised that an audiotape misses much of the emotional context of an interview, which is frequently expressed non-verbally. Furthermore, he commented that ambiguous sections of the recording tend to be replaced by

assumptions about what was said; in this study words that were not clear are flagged with square brackets and a question mark (Poland, 1999). Sally's interview is particularly problematic from this point of view as significant sections of the recording were unclear. These difficulties may have been the result of the patient lying in bed rather than being seated which made the positioning of the microphone difficult, the patient receiving high doses of morphine for pain, and having a less than crisp way of speaking. As a result, there are noticeable gaps in the transcript indicated by a series of "x"s as recommended (Poland, 1999).

Once the interviews were transcribed, linguistically sensitive thematic content analysis took place. As Gertz (1999, p.351) explained:

> Analysis, then, is sorting out the structures of signification – what Ryle called established codes, a rather misleading expression, for it makes the enterprise sound too much like that of the cipher clerk when it is much more like that of the literary critic – and determining their social ground and import.

Boyatzis (1998) is one of the few writers to articulate a practical approach to thematic content analysis that specifically focuses on latent themes, in which he believes much of the richness of the raw material is found. Researchers are said to need good conceptual ability and pattern recognition to see themes in what appears to be random information (Boyatzis,1998).

In this study the analysis developed inductively, with themes derived from the raw material; thus any codes (or themes) developed were "anchored" by the raw material (Boyatzis, 1998, p.41) and developed from repeated re-reading of the material. The advantage of this approach is that anticipated meanings are less likely to colour the outcome. Both Wolcott (1994), who recommended staying as close to the data as possible, and Strauss and Corbin (1990), who advocated "close" study of the data, prefer an inductive approach to qualitative analysis (cited in Boyatzis, 1998, p.34).

Following Boyatzis's (1998) recommended procedure the raw data were first condensed through the summarising of each interview. Secondly, the themes that appeared within each interview were noted before these were compared across interviews. Thirdly, as advocated with a small, relatively homogenous sample, a further detailed reading of the literature contributed theory-driven themes that were used to re-examine the material and ensure that nothing significant had been

overlooked, and to help to clearly articulate significant themes (Boyatzis, 1998). Themes derived from the few previous studies in the area of a good death were also considered in the third step. As a result, although the analysis was primarily data-driven, aspects of both theory-driven and prior research-driven coding were utilised in a hybrid approach (Boyatzis, 1998) that acted as a form of methodological triangulation (Kelly, 2002).

Finally, each code or theme was detailed in the following five ways: labelled or named, defined in terms of its central characteristic, given indicators that would "flag" it and enable recognition, described in terms of qualifications or exclusions and expressed through examples (Boyatzis, 1998, p.53).

In many cases, as DeVault (1999, p.94) noted, analysis began with a particular phrase or expression that seemed to "demand investigation"; in other words, paying attention to the *way* things were said, including difficulty in articulating hard-to-share thoughts, was critical to the process.

1.5 Ethical considerations

There are a number of important ethical considerations around both the procedures of this research and the use of the material gathered, as a result of the highly sensitive nature of the topic concerned. Terminally ill patients have been termed a vulnerable population because their "captive" nature may mean they lack defences against intrusion and thus are at risk of harm (Lasagna, 1970, cited in Beaver et al., 1999).

1.5.1 A vulnerable population

A number of articles have recently explored the ethics of this kind of research (Aranda, 1995; Barnett, 2001; Beaver et al., 1999; Seymour & Ingleton, 2005). Seymour and Ingleton (2005) discussed commentators ranging from de Raeve (1994), who believed that their dying status excludes people from research, to the opposite point of view held by Mount et al. (1995), who proposed that it is morally essential to do research in order to identify and meet palliative care needs.

It is appreciated that numerous negative psychological consequences may follow a cancer diagnosis, in particular high levels of depression, sadness, anger, frustration, panic attacks, anxiety and suicidal ideation (Grandstaff,1976, and Jamison, Wellisch & Pasnau, 1978, both cited in Shapiro et al, 2001; Lloyd-

Williams, 2002) and that these might be exacerbated by being declared terminally ill. As a result, it was important that participants in the study had access to support and counselling. The availability of ongoing emotional support for each participant was explored with the social services department at Houghton Hospice and the name and contact number of an experienced counsellor was given to each participant at the interview; see the attached Participant Information Letter.

1.5.2 The possibility of benefit

It is possible that the opportunity to talk about their experiences may have been beneficial to participants. Kleinman (1988, p.xii) described an experience as a young doctor of holding the hand of a badly burned child while her dead and infected tissue was painfully pulled away in a surgical bath. He observed that, while distraction did not help her, asking her how she tolerated the daily procedure was beneficial:

> She taught me a great lesson in patient care: that it is possible to talk with patients, even those who are most distressed, about the actual experiences of illness, and that witnessing and helping to order that experience can be of therapeutic value.

In addition, a number of participants appeared to take pleasure in still being useful and able to contribute; Seymour and Ingleton (2005) described this as an empowering opportunity for those who feel disempowered. In a paper arguing in favour of well-regulated research with terminally ill patients, Barnett (2001, p.158) noted: “Many have lost identity and independence: being consulted as individuals could arguably restore a sense of purpose”. In her study of 109 terminally ill patients, 66% were glad they participated and 34% had no strong feelings; no patients wished they had not participated (Barnett, 2001, p.158).

However the principle of beneficence may apply less directly to those interviewed, but to a hope that their comments may be used to improve patient care for others; this is an altruistic benefit. In this regard it is noted that in August 2005 the findings of this study were presented at Hospice in-service training, which includes doctors, nurses and social workers.

1.5.3 Consent

Informed, written consent to participation in the research and to tape-recording the interview was obtained in advance from the participants. It was made clear, both verbally and in writing, that participation in the study was absolutely voluntary and

there would be no negative consequences for not taking part. All participants were informed that they had the option of stopping their participation at any stage, and the right to answer only those questions they were comfortable with. Despite this, it is likely that gratitude towards Hospice was influential in the decision to participate and that, in this situation, it may be difficult to get full consent from people who are dependent on health care staff; describing a similar situation, Seymour and Ingleton (2005, p.141) suggested there might be "degrees of consent". "Consent is implied by people's willingness to invite the researcher into their home and is not something that can be captured on a piece of paper" (Aranda, 1995, p.45).

1.5.4 Doing no harm

The interviewer tried to follow the principle of non-maleficence (Norval & Gwyther, 2003) and do no harm by remaining aware of the interviewees' physical and psychological comfort: when James sounded breathless, she stopped the interview for ten minutes to allow him to rest; when Gavin became distressed discussing his business, the interviewer moved on to another topic; when Sally wanted to focus on her spiritual concerns, the interviewer listened to her. As Beaver et al. (1999) noted, participants spoke in detail about the history of their illness, which had been intended as a subject opener; as a result some interviews were longer than intended. "In being sensitive to the needs of individuals with a terminal illness the research design has, of necessity, to come second to patient considerations" (Beaver et al., 1999).

Confidentiality and the interviewees' right to privacy are considered important. As a result, this researcher did all transcriptions personally, with the exception of the interview with Sally which was difficult to hear; the researcher asked a colleague to listen to it in the hope that she might pick up parts of the interview that were unclear. The names and identifying details of subjects interviewed were altered in all material included in the research document. The tape recordings will be erased once the final research report has been examined, both by the university and the external examiner. However, it is noted that, given the small sample of six patients, those who referred patients for the study are likely to be able to identify them. Other researchers, notably Seymour and Ingleton (2005) have also commented that anonymity may be harder to uphold in practice than is theorised.

In addition, it is worth noting that the researcher was a volunteer pre-death and bereavement counsellor at the Houghton Hospice in Johannesburg for two-and-a-half years. While this may have resulted in increased subjectivity in terms of the research, from an ethical standpoint some sensitivity towards the research subjects and some skill and experience in interacting with death and dying issues was present.

Participant summary – biographical information

	Stephen	Gavin	Sally	James	Keith	Moira
Gender	Male	Male	Female	Male	Male	Female
Age	49	47	37	52	50	52
Profession	Company Director	Own Business	Child Minder	IT Contractor	Appliance Repairs	Teacher
Marital status	Married	Married	Married – reconciled after separation	Divorced	Widowed	Divorced
Children	3 children (18, 16, 12)	2 children (12, 10)	1 child (6)	2 children (22, 16)	2 children (28, 22)	3 children (27, 24, 21)
Additional Dependents	None mentioned	None mentioned	None mentioned	None Mentioned	Mother	None mentioned
Parents	Mother alive, Father died 5 weeks earlier	Both parents alive	Both parents alive	Both parents dead	Father dead, mother alive	Both parents alive
Family support	Yes	Yes	Some - family conflict	Yes	Yes	Yes
Financial Situation	Good	Good	Struggling Husband unemployed	Good	Struggling	Good
Medical aid	Yes	Yes	No – state hospital	Yes	Yes – daughter's	Yes
Religious	Yes Jehovah's Witness	No	Yes practising Christian	No	Yes Christian but not active	Yes practising Christian
Counselling	Family members - each separately	No	No	No	No	Yes – church & Hospice

Participant summary – medical information

	Stephen	Gavin	Sally	James	Keith	Moira
Type of cancer	Kidney	Media Stinum (between lungs)	Breast	Colon	Neck / head	Ovarian
Date first diagnosed	Oct 2000	July 2004	2000	July 2004	Early 2004	2000
Treatment	Surgery Interleucin (IL2)	Chemo (2 types)	Surgery Chemo	Surgery Refused chemo – alternative	None Inoperable	Surgery Chemo
Metastases	Lungs Liver	Tumours on internal organs	Lungs Bones	Lymph glands around Lungs	? Brain	Colon / internal organs
Date mets diagnosed	May 2002	Present at first diagnosis	2001	Jan 2005	Slow growing - still fairly localised	Annual recurrence
Further treatment	Alternative	Chemo	Chemo Radiation for pain	Continued alternative	Radiation - palliative only	Annual chemo Surgery Jan 2005
When told terminal	July 2004 Given three months	When first diagnosed given six months	Mid 2004	Jan 2005 Given weeks	Early 2004 Given two months	Given 2/3 days - Jan 2005

Participant summary – interview information

	Stephen	**Gavin**	**Sally**	**James**	**Keith**	**Moira**
Date of interview / s	1 October 2004	22 November 2004	21 & 23 November 2004	16 February 2005	4 March 2005	18 March 2005
Date of death	28 October 2004	11 February 2005	21 January 2005	21 February 2005	26 July 2005	14 April 2005
Pain during interview	Discomfort	Discomfort Breathless – on oxygen	Pain – given morphine	Breathless – on oxygen	No	No
Others at interview	No	Wife at end	Husband - at start of first interview	No	No	No
Where Interviewed	Own home	Own home	Hospice IPU	Friend's home	Own home	Sister's home

CHAPTER FOUR
FINDINGS

The key findings from a thematic analysis of the content of the interviews will be presented in two sections: firstly thematic content which is subject-focused and descriptive, and secondly, thematic content which is affect-focused. It is acknowledged that this may be an artificial distinction and all this material is emotional by virtue of its subject, however it is believed that separating out the overtly affect-laden findings resulted in greater clarity in identifying themes and in detecting the absence of themes that might have been expected. The latter will be explored in the Discussion chapter.

In both sections, the findings will be considered in relation to four topics that were prominent in the interview material: medical matters, death and dying, relationships, and finally values and beliefs or ways of coping.

A. TOPIC-FOCUSED THEMATIC CONTENT ANALYSIS

1. Medical matters: entering the kingdom of the sick

Before commencing with the presentation of findings it is worth noting that three interviewees, Stephen, Sally and Moira, were all initially diagnosed in 2000, with cancer of the kidney, breast and ovaries respectively. This was followed by various treatments before they were considered terminally ill in 2004; thus their diseases had a fairly long trajectory. In contrast, Gavin, James and Keith were initially diagnosed in 2004, with Cancer of the media stinum, colon and neck respectively. While Gavin and Keith were immediately considered terminally ill, it was only with the recurrence of James' cancer in January 2005 that his status became terminal. Thus the latter three participants had a very short disease trajectory with an almost immediate terminal prognosis on top of their cancer diagnosis.

1.1 Becoming ill

1.1.1 Seemingly innocuous symptoms

In response to the opening question of the interview, "can you tell me about how you discovered you had cancer", it was notable that most of the patients had initially ascribed their symptoms to a relatively innocuous cause.

Keith thought he had a tooth abscess, but was told he had cancer of the neck and head. James had interpreted his stomach cramps as a bad case of gastro-enteritis, but it was colon cancer. Gavin had believed his aches and sore chest were the results of flu; his doctor initially thought he had pneumonia and it was only when he did not respond to the antibiotics that further tests revealed he had advanced cancer of the media stinum. He noted: "I think I knew there was something wrong with me but I didn't know what it was". Stephen acknowledged that he had felt "occasional pain" high in his back at gym, but "like many men I took pain casually". After he passed blood a large tumour was found on one of his kidneys.

For Sally, the situation was somewhat different. She had been concerned about a lump in her breast, but was reassured by the doctor she consulted that this was nothing to worry about. He examined her but did no further tests and concluded that the lump was merely a blocked milk gland. Sally's husband Larry described the doctor saying: "Don't worry my girl, you're too young blah blah blah. And we thought, right, well we've been to the doctor, great. And we left it." Sally said she did not worry any more about the lump, which grew bigger and bigger, until "eventually I couldn't hang my curtains up it was so big".

1.1.2 Diagnosis - cancer

When interviewees first talked of their illness, their language was fairly factual and descriptive; it seemed as if they spoke of their illness as unemotionally as a doctor might have spoken to them about it. For example, Sally said "they told me it was malignant … this was about a Thursday and I think by the Tuesday my breast was off – it was so quick."

Stephen described in detail the size of the tumour on his kidney: "it was the size of my fist and they think it must have been there for two-and-a-half to three years". He then explained that chances of a recurrence were generally estimated at between 5 and 35%, but his tumour was large so there was a 35% chance that it would recur despite surgery. He remained clear for eighteen months after the removal of his right kidney before he developed cancer in his lungs.

Gavin stated in a matter-of-fact way:

> I've got I think it's four big tumours. One sort of almost on my voice box there, it goes down either side of my heart. And there's one big one behind my stomach, so it's like your whole central passage. And

> what I've got is the original culprit – and from there it goes apparently quite easily up to the lungs - which is where I was feeling the effects, not from the stomach or behind the heart or the voice box [but the tumour that had made his right lung collapse].

It was also apparent that some interviewees had investigated their condition extensively. Both Stephen and James described carrying out in-depth Internet research and both actively participated in their own treatment: James resisted the recommended chemotherapy and chose to follow an alternative route, while Stephen explored both conventional and alternative treatments available in other parts of the world as his type of cancer was known not to respond to either chemotherapy or radiation treatment. In contrast, Keith demonstrated a far more passive point of view towards his illness. When asked for more detail about his cancer he was vague and said: "my daughter knows more".

1.1.3 Prognosis - terminal

Keith told the story of receiving his prognosis without overt emotional language, but with repetition after repetition of the word "he said" as if to emphasise the impact each clause had made on him:

> He said I might as well go home. He said I've got two months left. He said – enjoy your life! Go smoke, go drink, enjoy your life. He said two months, he said, then you'll probably go into a coma and die.

Gavin emphasised the impact the news had on him by narrating what each different doctor had told him as they conveyed how serious his illness was. The surgeon said: "it's advanced and it's not good". After the biopsy, the physician "gave us the truth of it. Look, it's cancer and it's really not a good one." Then the oncologist said: "You've got a big problem and it's not something that goes away, you know. It's not curable."

1.2 Cause of the cancer: why me, why this?

All the interviewees seemed to have wondered about why they had developed cancer, which in no case seemed clear. They offered explanations ranging from random, to lifestyle and emotional or stress-related causes. However, this information was prompted by a question, rather than spontaneously given. Gavin's initial attribution was that his cancer was linked to his mother, who had survived both colon cancer and breast cancer; however he had been informed that his cancer was not hereditary. He then said, laughing:

> We joke about all one's sins and what you've done wrong – it can't be that. I mean, I know people that are much worse than me and are fit and healthy, so it can't be that.

This seems to imply that part of him sees his illness as a punishment.

James did not seem altogether surprised by his diagnosis and he revealed that his father had died at almost the same age, around fifty, from what in retrospect is likely also to have been colon cancer. His father had an operation for kidney stones and when they opened him up they found he was "riddled" with cancer. Although this is a cancer with a proven hereditary link, James did not verbalise a concern that he could have or should have been proactive in preventing it.

For Moira, there was no doubt about the cause and she emphatically noted that it was "stress, 101%". She believed that something was wrong with her marriage, and suspected her husband of having an affair. "I became aware of this and became aware of two large uncomfortable feelings on my tummy – and that was the ovarian. A sad experience." She believed each recurrence had been caused by further loss, for example her daughter moving out of home to live with her father, and that her most recent recurrence was the result of the sale of "my beautiful home". She saw this as "the real finality of our beautiful twenty-seven years of marriage." In Moira's mind the breakdown of her marriage and the cancer were intertwined.

Sally also had a firm opinion about the cause of cancer: "I think it's through emotions, I really do." She went on to explain that she had been thirty-two years old when she had given birth to her son Jack and her husband had left her; this had been a very stressful time during which she had "nearly had a nervous breakdown".

While Stephen clearly stated: "I don't blame myself. It's chance. Like driving along and being hit by the proverbial taxi", in contrast, Keith said immediately:

> It's *my* fault. If I'd lived the life that I'm supposed to, that I could – not smoke, not drink, not do this, not do that. What's happened to me is my problem, my neglect. So I can't blame anybody else except myself.

James, who had been divorced in 1994, also gave a lifestyle-orientated explanation: "I think being a couple modifies your whole eating pattern" and you have a "more balanced" way of living. He contrasted this to his tendency as a single person to eat fast food and go drinking with his mates. He

observed that, unlike him, the couple he was staying with always had a bowl of fresh fruit available. James also noted that for about six years between his divorce and 2000 he had been through a phase in life "where I always seemed to choose the wrong thing. You know how it gets sometimes, when whatever you do turns to mud rather than gold?"

It was noteworthy that although Keith did associate his cancer with not taking care of himself physically, he did not appear to make any links to a major event in his life - the death of his wife in a car accident a year prior to his diagnosis. In fact he only mentioned this in relation to an explanation of why he was now on his daughter's medical aid, when he had previously been on his wife's. Keith's wife had been driving long distance at night while he was sleeping in the passenger seat and there had been a head-on collision with a truck after she had possibly gone to sleep at the wheel. Keith described the horror of finding her "with a whole piece of her head gone" and trying to wake her up. It seemed to the interviewer from his gestures that his wife's head had been damaged on the right side, almost exactly where Keith's tumour had grown. However, he did not seem consciously aware of this possible link. Keith blamed himself for the accident as they had been driving to the funeral of someone in his brother's family.

1.3 Treatment – hoping for a cure

Without prompting, most interviewees described their various forms of treatment as a natural follow-on from talking about their diagnosis. During this description, questions were usually asked only to establish clarity and confirm understanding. Stephen, Sally, James and Moira had surgery immediately after diagnosis; Gavin and Keith's cancer was considered inoperable. Gavin, Sally and Moira all had various types of chemotherapy, the women several times over the years of their illness; Stephen had intensive intravenous interleucin, and immune-boosting treatment. Sally and Keith both had palliative radiation aimed at symptom reduction rather than cure.

1.3.1 Surgery – "cutting it out"

Most patients did not comment in detail on their surgery, which may indicate that they viewed it as a positive process; these included Stephen, Sally, James and Moira. For Gavin and Keith, having tumours small enough to cut out would have been an advantage. It is possible that the cutting out of a diseased part and

getting rid of it makes sense both rationally and emotionally, so there was very little need for discussion. Moreover, for Sally and Moira surgery was immediately followed by chemotherapy, and for James by a choice not to have chemotherapy.

It was also noteworthy that Sally's mastectomy and Moira's hysterectomy may have been expected to elicit comment on issues of femininity; however, nothing related to this topic was mentioned. It is possible that in the face of loss of life, the loss of these symbols of womanhood may become less significant. Their surgery had also taken place four years earlier and had perhaps been superseded by more recent experiences.

1.3.2 Chemotherapy – "killing it off"

In contrast to surgery, chemotherapy was associated with polarising views and elicited spontaneous comment. At one extreme Gavin described his experience of chemotherapy in dramatic detail saying: "The muti burnt my veins. It burns as it goes in. That hurt like hell." He went on to talk of the effects:

> I vomited all the time, everything I touched I got sick. I didn't eat for four or five days on the trot. The constipation, the headaches, I had everything.

In acute contrast, Moira said that the doctor's rooms where her chemotherapy was administered were "beautiful" and a "wonderful place", and she used to "run in" to have her treatment feeling "excited". She repeated: "Chemo was my best friend. It was my best friend."

For Sally, difficulties with chemotherapy treatment, particularly "vomiting all the time", were tied up with how difficult life was while they were living on the coast and needing to travel into the nearest city for treatment:

> Really we had problems with money. Larry couldn't find work. He was working but he was exploited, you know. And um we really found things difficult. Our combi would break down halfway and jeez … Anyway, we managed five chemo's.

Chemotherapy had such a bad reputation in James's opinion that he was not willing to try it: "They basically take you away for six months with chemo, drug to the, whew, limit and send you home to die." James was the only respondent who did not have radiation, chemotherapy or the immune system stimulating treatment, interleucin that was the only treatment available for Stephen as his type of kidney cancer is "refractive to both chemotherapy and radiation".

1.3.3 Radiation – “burning it away”

Only two interviewees seem to have had radiation treatment, Keith and Sally. Gavin specifically commented that radiation treatment was not an option, as the position of his tumours meant that the radiation would have “burnt through” vital organs.

When he was initially diagnosed early in 2004, Keith had been told that he could have chemotherapy and radiation, but that these would just give him “an extra month of hell”. In contrast, well over six months later when Keith had radiation treatment, which had been recommended by the Hospice doctor for symptom relief, he had a positive experience. In an excited voice he announced that after ten treatments: “All of a sudden it changed! It was shrinking!” He emphasised that he was getting better and that many people were praying for him; he believed the swelling under his chin was “something else” that was making it difficult to swallow.

Sally was given radiation to reduce the pain of the cancer that had spread into the bones of her arms, neck, spine, hips, elbows, “everywhere”. She described the treatment as “amazing” saying that it “really helped to take pain away”.

1.3.4 Alternative ways to heal

On the advice of his brother and a friend who were strong believers in homeopathy, James made dramatic alterations to his diet and lifestyle after the surgical removal of part of his colon. He focused on a raw vegan diet (no meat, chicken or fish and no dairy products) as well as taking a range of vitamins and other supplements. However, he described this as “closing the door after the horse has bolted”. It was notable he did not express regret about his choice to follow alternative treatment rather than chemotherapy. Instead James believed that the spread of his cancer into his lungs was his fault, saying “maybe I wasn’t strong enough with my treatment [the diet]” and “I’m sure many people have been cured”.

After the failure of the only conventional treatment for his type of cancer to do more than halt the growth of the tumours in his lungs, Stephen also explored alternative therapies and travelled to Germany to receive these. He believes they “kept him stable” until the cancer in his lungs spread.

1.4 Doctors: those in the know

Most respondents had interactions with general practitioners (GP's), surgeons, oncologists and other specialists. Many of their comments around these interactions were communication orientated. For example, Gavin described asking the oncologist for his prognosis: "I think in everybody's nature is to find out well, okay, how bad is bad?" He described himself getting "down to the nitty gritty" and saying:

> Assuming I don't have this treatment which you have said is the only treatment available for lung cancer, assuming I didn't have any treatment, what's the prognosis you know? And she said um six months. And that was almost the end of my discussing things with her. I'd heard enough now. And obviously I just wanted to go home.

James had notably different reactions to different doctors, with a positive response to his surgeon and the Hospice doctor, and a very negative one to the oncologist; these will be discussed further in the emotional content section of the findings. After his x-rays revealed that his cancer had spread into his lungs, James's GP sent him to the oncologist to be given this news. James commented that his GP "knew but he wasn't telling me"; when asked what this might have been about, James said he could not understand the doctor's reluctance.

Sally also struggled to get information from doctors both at the coastal hospital she attended and in Johannesburg. Her husband Larry referred to this as being "like trying to squeeze water out of a stone". Sally had recently been part of a large hospital study and Larry emphasised that they were "grateful for the medicine" but the way the doctor concerned "speaks to my wife and the way he has treated her – it's absolutely appalling". Sally emphasised that it was not just them who were treated that way and they both agreed that this doctor was like this with everyone in the hospital but that he probably treated his patients in his private practice better. Larry noted: "I mean I suppose it would be different if we were paying a private doctor. I suppose they would be a lot more helpful to us."

However, Larry also offered another explanation for Sally's difficult interactions with doctors and nursing staff at hospitals:

> He [the doctor] didn't like her, nor his sister, and quite a few people get irritated by Sally's nature, because she's very much of an individual person. She's got different values and sees things differently to them. And a lot of people get intimidated or offended by that. Like when she was going to the [coastal] hospital for treatment, sometimes she'd have two or three street kids with her who were tagging behind her, and they didn't like things like that you know?

Sally was interviewed while an in-patient at Hospice. She had been admitted for improved pain control. Larry noted:

> I've seen an improvement in Sally since she was here. She's a lot more rested, more relaxed. She can go into the garden. They seem to have found a balance between um having no pain and not being so drowsy all the time. You know? You just need to find that middle line … because when she takes the morphine she's like totally out of it, you can't have a conversation with her.

James contrasted his avoidant GP with the Hospice doctor who was "the first person that actually explained to me what those x-rays meant". For James, it was "a relief to know exactly, 'cause I said to her I want it straight up, not beating around the bush". This doctor explained and drew pictures "which made it easy to understand my pain". She "put it in a nutshell" and said compassionately "this is not years, but months or even weeks. So let's get you medical and palliative care so you are as comfortable as possible for the time remaining."

2. Dying: not in the distant future but soon

All the patients in the study had been told they were terminally ill and had also been told how much longer they were likely to live. In some cases this was accurate (e.g. Stephen), in other cases, dramatically off (e.g. Keith). In July 2004, Stephen was told he had three more months; he died at the end of October a month after his interview. Sally died two months after her interview in November 2004. James was diagnosed with metastases in the lymph nodes around his lungs in January 2005; he died four days after his interview on 21 February 2005. When he was first diagnosed in mid-2004, Gavin was told he would be lucky to live six months; he was interviewed two-and-a-half months before his death in February the following year. Moira was told in January 2005 she had only a few days left; she was interviewed in mid-April and died almost a month later. However, Keith was told early in 2004 he had between one and six months to live; he was interviewed a year later and died in July 2005, suggesting that while he was terminally ill, the expected trajectory of his disease was inaccurate.

2.1 The language of death

The interviewees used a number of euphemisms when talking of death. After Stephen had commented about the openness of discussion in his family saying, "I think it helps them to prepare well in advance, although there are some things that you can only deal with when it happens." When the interviewer asked what the

"things" or "it" was that he was referring to, Stephen answered: "*It* is death. It's very much there. We try to get it on the table." This was the first use of the word death in this interview.

James spoke of his mother having "passed away" and of his own death as "the big sleep". Others spoke of "the end". Stephen said, "death is not a final black hole", it is "like a deep sleep". Although Gavin spoke of "six months to go", and "I probably won't be around", it was only when he reported doctors telling him he was "dying now and you won't last long" that this word was used. Towards the end of his interview Gavin said:

> The first month all I thought about was dying … what is dying? And all the dreadful thoughts about how you're going to die. You know, added to the fact that you're going to die, now *how* are you going to die?

2.2 *How* will I actually die?

This proved to be a major concern for all patients. Stephen noted, "It's not so much death as what I have to go through to get there that worries me". Moira clearly articulated this anxiety:

> I'm not scared of dying. I am, I was and maybe I still am, anxious of the means to die. Will I be riddled with pain? Will they be able to control my pain? How will I be emotionally? How will the people around me be? Where will I die? How will I die? Who will be with me? All these questions of the uncertainty and the unfamiliar.

Sometimes this concern was related to what a patient might have been told, as Keith explained: "They said to me that this is going to burn my throat away … and they'll have to put pipes in my chest to help me breathe." He later mentioned that both his throat and his head had been sore recently, particularly at night.

2.3 Practical preparations for death

2.3.1 <u>The will and financial arrangements</u>

This is a practical area that interviewees made a point of tackling as soon as they heard that their death was in the near future; there seemed to be some reassurance gained from being able to accomplish something in contrast to a lack of power around their illness.

James noted: "I'm an accountant by training so everything must be in its place". He went on to say that he was selling his boat, sorting out his will, insurance and tax papers and getting everything sorted so "my house is in order" and there would

be no fighting over what was left to his children. Moira said in a pleased voice: "I've sorted it all out! Got the will up and going, I've sorted out my home – I've given it to my children. I've got it all sorted out."

When asked what he would tell anyone else in his position, James commented that it was important to "get your ducks in a row" as soon as possible. Gavin reiterated this, with particular emphasis on sorting out your own business: "The only thing I could do is tell people get your will, get your house in order, if you've got a company make sure it's written in your will correctly, you know, that this is how it must be." He emphasised the need to make sure bank accounts did not get frozen so the business and the home could carry on functioning.

2.3.2 The care of dependents

Sally was the only respondent with a young child and without a spouse in a stable position; this was clearly a very stressful position to be in. She was interviewed on two separate occasions: first on a Sunday, when a major theme of the interview was that Jesus would heal her if she continued to believe; this interview was interrupted by the arrival of visitors. The completion of the interview took place on Tuesday after Sally had seen the Hospice social worker. A number of issues had been discussed and it had been impressed on Sally that even though she still believed God would heal her she needed to make contingency plans just in case. For Sally this was a difficult subject because her husband did not feel able to look after their six-year old child, as he did not have stable employment. A substantial portion of the second interview thus involved a debate about what would be best for Jack. On the one hand Sally was pleased that her father had agreed to pay for her child's schooling at the church school she wanted him to attend; on the other she was concerned about leaving Jack with her stepmother after her own experiences when growing up. There were also disadvantages to leaving Jack with her mother who lives outside Johannesburg.

James commented sadly that his father had died when he was thirteen years old, so he knew what it was like to lose a father. He realised that his son was a few years older, aged sixteen, but his absence in his son's future was of concern despite not having Sally's concerns about where her son would live and who would raise him. Although Keith's children had promised they would look after his mother (their grandmother), he remained anxious about those he was leaving behind.

2.3.3 Planning your own funeral

Apart from Keith and Sally, respondents reported having discussed their funerals with their spouse, other family members or friends. This was clearly a difficult subject to talk about, perhaps because imagining an event that is all about your death brings home your absence from all life to come. Most wanted to be cremated, and several were adamant that they did not want to be viewed once they were dead. Stephen stated:

> The funeral has been planned. My friend took care of that and we talked about this is how we think we should do it. I want to be cremated, but a very simple ceremony – intimate, just family. Then a separate memorial service.

After James described what he wanted he was understandably visibly moved and needed to blow his nose:

> They mustn't open me up and display me in a coffin and all that. I want to be cremated and take my ashes to the Vaal Dam. Have a bit of a party and scatter them in the water.

Gavin's wife Allison said that "some subjects are very difficult to discuss, even for the two of us" and the funeral was one of these. However, they had discussed special music and how to have a "send off" both Gavin and his friends would understand. Gavin said, "Not that I'm too fussed about that; as far as I'm concerned, it would be much better if they took me away and that was the end of it." Allison emphasised that the funeral was "not for you really babe, it's for the people around you" and "you've got to allow people to say goodbye". However she also said, "no viewing of the body … I think it's disgustingly awful … very traumatic and there's going to be children there".

2.4 What happens after death?

This was an area in which interviewees had definite views, either firmly believing in something after death, or equally convinced this was not so. James put forward the latter view:

> We are organisms, and the ant, whatever, that's the same thing. It has a spark of life in it, but it doesn't mean some big guy up there switched the switch. When we die our bodies start decomposing, then that's it, we just switch off ... I might be pleasantly surprised, who knows.

In contrast, Stephen believed that "death is like a deep sleep or a rest to await the resurrection call." Moira, Sally and Keith had similar beliefs; their faith will be discussed under Coping in Section B.

3. Relationships: a profound source of comfort

All the respondents had family who were dependent on them, either emotionally or financially or both. Stephen, Gavin and Sally were married; Keith was a widower and James and Moira were divorced. All had children, who ranged in age from six (Sally's son) to twenty-eight years old (Keith's daughter). James was the only respondent with both parents deceased. Most respondents seemed to have active support from family and/or friends; Keith appeared to be the exception to this. These relationships generally seemed a source of comfort as related below, but the same subject discussed in the following section (B 3.2 and 3.3) will reveal some of the distress associated with the loss of close relationships.

3.1 Family

Some interviewees, notably Sally and Gavin, described a number of their illness experiences using the word "we". In other words, their relationships seemed to contribute a strong sense of not being alone in this difficult situation. Stephen spoke of his mother coming to stay with the family so there would be someone with him all day as he became more ill, and Gavin poignantly talked of having his mother by his bed when he was really sick:

> She sat here over my worst periods and you know, she'd sit here for four days, and when we weren't sleeping we were sitting here together. She didn't walk around the garden; she sat here and tended to everything. She'd make tea, or she got fruit salad or whatever I needed, or, you know, she was just the most amazing support.

Moira emphasised that her decisions had been made with the agreement of her family, for example her choice not to have further treatment after annual cancer recurrences for five years had resulted in five treatments with chemotherapy:

> I of choice am not even going back to see the oncologist, because I've given my best of chemo and I've given my family my best and with my family's blessing they are very happy that I'm just living a good quality life now.

However, Sally described her husband Larry not being with her for her second programme of chemotherapy and how difficult this was. Moreover, her "family were putting a lot of pressure on me to do what they wanted":

> They wanted, they saw a different life for me. I had my dogs, I had my child, and they sort of wanted me to conform to something else. If I did then they would help me. If I couldn't then they couldn't help me. And I couldn't so I just had to stay quite strong.

The way Stephen presented his history, he saw himself as an individual responsible for himself and his own decisions; for example after exploring his

treatment options he said, “then I had to decide about the next step”. It is possible that this is an extension of his professional role as a leader and decision-maker. In contrast, Keith spoke of himself as “I”, but in a way that conveyed a sense of him having to deal with a difficult situation alone. This may be a response to being newly widowed.

3.2 Others who care: friends and colleagues

James did not have as supportive a family as some of the other interviewees - his parents are dead, he is divorced, his twenty-two year-old daughter has a baby and lives out of Johannesburg, while his son is sixteen. However, he frequently mentioned being able to call on his friends and their generosity. Various friends took him to hospital, ordered and paid for his oxygen and he was staying in the home of friends while he died. He had been very touched by this support, but also saddened by those who had not called or sent a message to him.

Stephen noted how kind his colleagues had been and Moira observed that she had received a lot of support from parents, teachers and children at her school. She had been teaching Grade 0 “so that gave me all the love and support that my empty tank was carrying around”.

4. Beliefs and values: a compass

There were three practising Christians among the respondents, Stephen, Sally and Moira; Keith prayed but did not attend church. James and Gavin were both quite critical of organised religion. Most respondents seemed to have re-considered their values since they became ill.

4.1 Beliefs: “when it’s your time”

A number of respondents believed in a version of the following statement made by James:

> I have a philosophy that when it’s your time to go, it’s your time to go. There’s not a damn thing you can do about it. Some people never abuse their bodies, they die young. Other people abuse their bodies all their lives and they die old.

For others, faith is part of this philosophy, as Keith said: “If it’s my time, it’s my time. It’s not up to me to say it, it’s all planned out by God.” This may not necessarily be comforting, as Moira noted: “God makes and he takes … despite

my will." However, Moira believed there was a purpose in her experiences: "This chemo is the most amazing thing. I've regarded cancer, and this is really the truth, cancer and chemo as a gift from God." She had found it helpful "knowing that I'm on this earth for a reason and my time is up when He calls it not when I call it." Sally noted, very simply: "I believe in heaven, I believe in Jesus".

4.2 A reassessment of values

Stephen, Gavin and Moira all noted that material possessions and the pursuit of money lost its significance in their circumstances. Moira noted: "I would love a future but I realise that so many of us think our future is in the getting of possessions. They don't mean anything when the chips are down." She related a story about a recent weekend away when her friends had gone into a shop and were "anxiously buying, frenetically buying things" and she did not want another ornament or a mirror. She concluded that life is about interpersonal relationships: "it's got to do with love and care and support". This seemed a sentiment that most respondents agreed with.

B. AFFECT-FOCUSED ASPECTS OF THEMATIC CONTENT ANALYSIS

Understandably, the diagnosis of a life-threatening illness, with the announcement, either immediately or after a time of treatment, that a cure is not possible and the illness will lead to death in the near future is an emotionally charged series of experiences. As a result the emotive aspect of the topics identified as themes in the previous section of the thematic analysis will now be explored.

1. Medical matters – entering the kingdom of the ill

1.1 Getting bad news: the shattering of a world

It is no coincidence that bad news is "broken". For all the interviewees, the sense of shock that they felt on initially hearing their diagnosis still had not been accommodated. Essentially, their world and its assumptions of normality were rocked to its foundations, as Gavin described:

> I never heard the word cancer. I looked at my wife and she was in tears, and I thought, you know, what was that about? And she said, he just told you you had cancer.

When Sally was told the growth was malignant and they needed to remove the rest of her breast, "at first my brain said you are lying" and then "all I wanted to do was jump into the car with my child and run away". When Keith was told he had two

months to live, he said: “You go blank. I just said thank you and I walked out. And then you cry. You try not to but you do whether you like it (or not).”

James commented that although he wanted information as he “would rather know where I am going”, “it’s a very big thing to get your head around. Five months down the line and it’s still a difficult thing to swallow.” When he had heard four weeks ago that he had secondary cancer in his lungs, he said, “it was absolutely unbelievable” and “I’ve certainly gone upside down, that’s for sure”.

Stephen noted: “I was forty-six. It’s young. It was a big shock, a major blow.” When Stephen was told that he had kidney cancer, he recalled thinking: “It’s serious. Let’s see how you fight it. You don’t give up in the first stage.” He went on to explain that he had done a lot of research into his condition.

Gavin recalled an appointment with the oncologist who said, and she “didn’t mince her words. “I mean really, you’re just not going to live. This is something that’s going to kill you.” She did it very nicely, but still …” He went on to express his disbelief at this having happened to *him* by saying that he had only had two days off sick in the twenty-two years since he had come to South Africa: “I was physically strong. I hadn’t been sick in for a hundred years. I always had too much weight, but I was physically strong and I was never ill.”

Sally described the doctor telling her that although they could give her more chemotherapy once the cancer had spread into her bones, “there’s only a 10% [chance] it might work so basically it’s a waste of money”. Sally was being treated at a government hospital and she and Larry believed that further chemotherapy was not given because it was considered a waste of the state’s money.

1.2 Intense feelings towards doctors: kill the messenger

Stephen felt “pissed off” that his regular company medicals had not picked up the kidney tumour, which had apparently been growing for three to four years: “It should have been picked up earlier. The medicals were inadequate”. He told his friends and colleagues that they needed to get regular abdominal ultrasounds before they could know they were healthy.

James said at the beginning of his story that he hated going to doctors and he seemed to have his distrust of the medical profession confirmed by his

experiences. He described his meeting with the oncologist as follows: “I wasn’t terribly impressed with the guy – miserable fellow as far as I was concerned”. He believed that while surgeons do a great job as they “fix and repair things” he was not as confident about other doctors. He emphasised, rubbing his hands together as he spoke, that oncologists were just out to make money and were “heartless” with “no compassion” as they knew that when one patient died, the next would come along and they would get more money then.

Larry felt angry with the doctor his wife Sally had initially consulted about her breast lump, and who had said that there was nothing to worry about without doing a biopsy or mammogram. A year later there was a two-month delay in giving Sally the results of the tests that diagnosed cancer, as she missed an appointment with the same doctor. Larry had spoken to a lawyer about these interactions, but the lawyer had told Larry, “Don’t even bother trying to sue the medical profession because you won’t win”. While Larry insisted, “I blame that guy for my wife’s condition”, Sally herself said “Shame, I don’t blame him, I just feel he’s a person.” She went on to emphasise that she believed God would heal her.

In contrast Keith, who was still alive a year after being told he would die in two months, said he felt nothing towards the doctors concerned: “That’s what they thought. They were honest. I think it’s better than telling you a whole lotta lies.”

1.3 Triumph at disproving doctors’ predictions

Trying to beat their predicted death date or living longer than predicted gave several patients a feeling of pleasure. Stephen demonstrated the former when he said: “‘I might surprise the GP who thinks less than three months”, while Moira exemplified the latter: “I know that the doctor is not God either! It’s been proved. He didn’t think I’d come out of hospital. And it’s been eight [weeks] very full of quality life.” Moira had also enjoyed being assertive: the doctors had wanted to give her morphine, which she had refused as she was not in pain and was concerned she “wouldn’t have been able to talk properly or live properly if I’d been gaga on morphine”.

1.4 Cancer: “it’s unforgiving”

Although most subjects’ initial descriptions of their illness were relatively neutral, as the interview progressed, their language seemed to become more emotive. For example, Stephen said the cancer “showed up again in my lungs”, suggesting an

unwelcome guest. Moira spoke of her cancer having "reared its head again", relating it to an untameable beast. Later she said: "it's a killer, cancer's a killer". James described his cancer "chewing up" the lymph glands around his lungs so he is "starved of oxygen".

Gavin noted: "the whole cancer thing is a big dark hole. I don't think anyone really knows too much. To me, it's not scientific." He went on to express his amazement that man can go to the moon but cannot cure cancer:

> Why should a few lumps in your body kill you, with the way they transplant this and clone that, why should this be an issue? But I don't ponder that much 'cause it's life isn't it? … There's no cure for all the cancers.

1.5 Chemotherapy: "poison" or a "friend"?

As discussed previously, Moira saw chemotherapy as "her best friend". In contrast, several interviewees spoke of their intensely negative experiences of treatment. Stephen had chosen to have interleucin administered by a drip in hospital, although there was only a small chance it would work "but I thought 5% was worth trying". However, "it was really bad. Ten days in hospital at a time. You live your life by the second."

Gavin described chemotherapy as "a dreadful thing" and continued, "it's just raw poison and it's hoping to kill". He had reacted badly to the first type of chemotherapy he was given:

> For as many as three or four days afterwards, it can feel like somebody's poured boiling water down your veins. In the bath all the veins were lit up, with lights in it.

As a result Gavin had not completed his course of therapy, although his oncologist had told him in July: "without chemo I'd be surprised if you were here in January". However for him:

> I'd rather take lots of painkillers than go through that, because that wasn't living that's for sure. … If there was a switch I could have reached it would have been off. I didn't want that. It really wasn't worth it.

He added that he had felt "very sorry for myself" but qualified his comments by saying that he realised that his was a very individual response to chemotherapy. He noted that there had been other patients having very similar chemotherapy regimens at the same time as his, whose bodies had not reacted in the same way. He wondered if the problem was that his cancer was so advanced that his body

was overwhelmed trying to manage both the toxins from the cancer and the chemotherapy.

1.6 Pain

The respondents had a variety of physical sensations ranging from no pain, to discomfort, difficulty in breathing and extreme pain. When describing how he currently felt, Gavin spoke of the tumour "hanging onto the stomach" which was uncomfortable. Moira emphasised that not having pain was "the greatest blessing" she had. Unfortunately, Sally's breast cancer had spread not only into her lungs but also into her bones, which is known to be particularly painful; during the second interview her elbow was particularly sore. She described the pain she gets saying "you know, it shoots and takes me by surprise". Gavin said, "it's a crappy pain in that it's a deep sort of aching throbbing and occasionally [I] even get sort of long stabbing-like pains". He explained that one of his tumours is between his stomach and his spine where there are a lot of nerves and "I'm sure you know, movement and lying down it can press against those nerves and that can be very uncomfortable and hurt".

2. Dying soon

2.1 Fear of dying

For Sally, the youngest person interviewed, there was a sense of absolute disbelief at her situation: "people do die, and I do get scared. And I should never, never, never be someone this happens to, I should never die". Articulating each word, Sally emphasised, while coughing: "I don't want to go. Basically … I don't know that if you really don't want to go, you don't go. I'm not sure."

After being given his prognosis, Gavin described: "I thought a lot at first about *how* I would die – not be able to breathe, suffocate, have a heart attack" and his wife added "he couldn't sleep for a month".

2.2 Sadness at losses

Some aspects of life seemed easier for interviewees to give up than others. For Stephen, stopping working was not a big loss: "It didn't worry me. I've never defined myself by my job. I enjoyed the job and the challenges of it, but didn't define myself with it."

However, for Gavin, letting go of a business he had created and built up was hard, and along with discussions of his family, was a subject that caused him to become emotionally distressed to the point where it was hard to breathe. Gavin was particularly expressive about what he missed:

> I miss the ability to live, to be able to run up the stairs, to know my son is going to have a father. I'm leaving my wife and my mother who's seventy-eight. It's backwards.

Moira also said: "I've still got two parents alive … the order's wrong."

A sense of loss at the way he used to be, was expressed by James, who said he found the way he was now so frustrating "I could pull my hair out". He explained: "I can't do a thing! I can't walk from here to there without puffing and panting." This made him feel "hopeless".

However, the loss of family was particularly difficult. Sally mourned: "To be given a six year-old child to die on him, to me that just doesn't make sense". When James spoke of the loss of his father when he was thirteen, he said "I know the things I missed out with me" and this added to his sadness about losing the future with his sixteen year-old son:

> One of the things I wanted to do with him is obviously to get him educated. That's top priority. And then I wanted to tour around a little bit with him. Go and actually see the university of life … you know when you go into places and you mingle and you get to meet the local people and you see their traditions and that sort of thing. Go into a pub and listen to a brawl going on. Not that I was a big fighter ever, but you know, how to handle himself. Take him to the bush with me. You know, experiment and look at things.

2.3 Resignation: "I'll just take what comes"

The participants described having come to terms with what was happening to them in a number of different ways. These included an awareness of the lack of any further treatment options and daily reminders that they were dying from their progressively failing bodies.

After discussing the remaining treatment options available to him, including participating in a double-blind trial in the UK in which he would not know whether he received active treatment or a placebo, Stephen decided: "None of that sounds hopeful so I'll just take what comes and go the palliative route." He said: "I am not desperate but I am sad' and later said, 'I feel sad that I am dying but I don't feel sorry for myself."

This was similar to Moira who said: “it doesn’t really matter what the stage [of the cancer] is I’ll go with it as it goes. It’ll just take its course.” However, she emphasised that coming to terms with dying was not “a sudden realisation, acceptance and move on”, but a process: “it’s a back and a fore, a back and a fore, a back and a fore”. Her faith took her forward in the process, and “fear, uncertainty, lack of control, fear of loss, not fulfilling dreams in my children, disappointing my family” all took her backwards.

Gavin described the locations of his four large tumours and said, “there’s no sort of instant cure you know, where they can get it out and throw it away.” He had tried two different types of chemotherapy and not only had he reacted badly, but the cancer had not responded. He said: “There’s nothing else. What can you do?” and “So that’s where I stand. I’m still here and it’s December and you never know.” He noted that he hoped to still have a few good days among the “rotten” ones, before admitting that he no longer had good days, just “good time slots”. At a later stage in the interview, Gavin commented: “I’m tired of being sick … I’m sick of being sick”. He explained:

> I was not a person who sat still so these things are mentally challenging for me – to get up and walk to the loo and back can take ten minutes. Walking up a flight of stairs is like a marathon.

Moira also articulated surrender to the will of God in line with her faith: “If God wants me He must take me. Obviously I’m finished with my work here. I’m very aware – I’m not of choice ready to go but I’m not fighting. I’m not fighting.” In notable contrast to the other five patients, Keith, who had been resigned to his terminal diagnosis early in 2004, was so elated by the response of his tumour to radiation treatment, that he now believed he was getting well and would recover.

2.4 Satisfaction at getting things in order

James emphasised the need to sort all his documentation so it was “all clean” and “tied up”. He recalled how easy this had been when his mother had died and they had found her papers all prepared in a box. He said “I want to go in the same boat”. This image is noteworthy, given James’ passion for sailing.

For Gavin getting his affairs in order was all about caring for his family and he wished he could have made his death less traumatic for them financially: he

regretted not having bought more life insurance policies when he could have. However, he was relieved that he had been given enough time to sort out his business so that all he had "built up [didn't come] crashing down". The picture he described of what would have happened if he had died suddenly was of the business crashing like a plane with nobody flying it, and his wife with no rights at the bank and his employees not listening to her and running away. His wife described this anxiety as "freaking him out" and said "I think if he knew I was safe and I wouldn't have to worry, that trauma … wouldn't even be playing on his mind".

James also applied the tidying process to areas of conflict and he described his relationship with his daughter as "nicely knitted at the moment" after earlier problems. However, Sally struggled to find a similar sense of resolution. In the following quotation she shifts between satisfaction and doubt:

> I bless my father, because he's paying for school next year, and the school uniform, which is amazing. So I kind of think things moved along, you know, that he kind of saw it that we all a team now, for the first time, 'cause it always used to be just Jack and me. We had to make all the decisions you know. (cough) My husband came back and then they sort of came around. Now they really are on our side. Then I think gee, do I really know what I'm doing? … My stepmother you know she was really wicked. You know, she's got a side to her that's malicious and horrible. When I see that, I worry about leaving my child there.

2.5 How they want to die

This subject was openly discussed only with those respondents who seemed willing to do so; this did not include either Keith or Sally. The death James wanted was to be "just quick" and he would like to "just go out gracefully". He expanded on this: "I hope to just be able to close my eyes and that's it. Go for the big sleep and that's it." He was asked if he would like others to be there, and replied: "I'd prefer people not to be there at the end, rather just remember me the way I was and get a phone call to say I'm gone." James was emphatic about what he did not want:

> I certainly don't want to be put on a lung machine and all sorts of things. … I certainly don't want to be pumped full of goodies and gafters and things to prolong my life – for what? Where's the quality of life?

Stephen wanted to die nicely sedated, with no pain and no suffering so he could just drift off. He wanted his death to take place quietly at home, leaving "no ragged ends". He wanted his family to witness his death only if it was quiet and peaceful. Moira wanted to die at her sister's house and specified that she wanted others with

her; even if she went to the Hospice IPU she was comforted by the thought that there was a bed in her room for a family member.

3. Relationships: nothing else matters

3.1 "A legacy of love"

Gavin emphasised that he loved having his family close and this was his only comfort. He said that he would like to have his wife with him all the time and described holding her hand as "an injection of life", emotional life. Gavin also spoke of receiving "a real warmth" from his mother when she sat with him. He did not believe they were closer than before, as they had always been close, he was just very grateful for her presence. He emphasised that "my life has changed so drastically", as it had for those close to him, that "love is all there is, there's nothing more to it".

In contrast to concerns about leaving well-ordered financial affairs, Stephen said: "I'm making sure that the legacy I left was one of love for the family. Nothing else matters really. Financial things are taken care of." He was doing this by talking regularly, one on one, with each of his three children so they could talk about their feelings and their fears. He also noted the immense stress of the process: "When you're living with it, fighting it weekly, monthly, it does affect your personality. My wife said I was more sensitive and irritable".

However, it was apparent that relationships may be bittersweet, either because of existing conflict or because of the pain of loss involved in separation from loved ones. For two interviewees whose marriages had ended, the first through death and the second through divorce, less comfort was available. Keith, a widower, does not appear to have an open relationship with his remaining family. He said: "I tried being … no, you know. But I don't talk to them about it. I just try to act like nothing's wrong. I've got nobody to talk to." He explained that his mother is very deaf, and that although he loves his son and his son loves him, they used to fight "like cat and dog". He said: "Sometimes you wish a person could talk about [it], you see?"

Moira stated that she believed that people "marry for better or for worse, in illness and in sickness" (sic) and called divorce "the cruellest thing that is ever on this earth". She described the depression that had followed as a "surface [that] is too

cold and too sore". She went on to say that men did not stay around when their wives got cancer and described men as scared, egocentric, selfish and unable to deal with the realities of life. However, she said: "I don't hate men". For Sally, her relationships during her illness had been difficult. At times her husband Larry had been working overseas and she had struggled to support her son. She described her family of origin as willing to help her only if she would "conform to something else" which she refused to do, as described earlier.

3.2 Pain at the suffering of witnesses

Two participants, Moira and Gavin, had observed that their mood affected others. Gavin related: "You're depressed, they're depressed. You're on a high, they're on a high with you big time." Moira described this process as being the "barometer" for those who cared about her. She found this stressful as it put pressure on her to pretend that everything was all right even when it was not.

For some interviewees watching their family members suffer as witnesses to their death was acutely painful and this exemplifies the bittersweet benefit of close relationships. Gavin noted: "All my pain and suffering, although horrible, isn't five minutes of Dad's pain. I'd have about fifty times if I could take my Dad's pain away." He described his father as "burning up" and "terribly sad. These are the things that hurt". He believed the experience his family was going through was harder than his experience of dying and they were "breaking" and "devastated". He continued:

> It's them I feel for. You know often now I believe it would be nice to just end it so they suffer no more… They come and I've lost a bit more weight or I'm feeling really awful at the time, it saddens me that they witness it.

3.3 Anxiety at how survivors will cope

Keith was particularly anxious about who would look after his mother. Although his children had promised to do so, "you worry if you go then what's gonna happen here?" He believed his daughter would be fine and noted that she already looked after him rather than the other way around, but he felt less sure about his son. Keith related this anxiety about others to his misery after his wife's death when he had thoughts of suicide: "You think of killing yourself a lot" but he had felt too scared to do this as "I most probably mess it up." "You think it would be better to be dead. But I think it would just make it worse so I really try. I do try."

Stephen was concerned that all the responsibility of the family would fall on his wife's shoulders and knew this would be stressful, but he hoped she would realise how many people wanted to help her. Stephen also commented that his daughter was writing Matriculation exams that year and "it's the pits for her". (It is worth noting that she was expected to start writing her exams on 24 October 2004 and her father died on 28 October.) Gavin had handed his business over to his wife to run and also felt this was a heavy load for her to carry as well as the family and the household. For Sally anxiety about those left behind was the most distressing part of dying: "I've thought about dying, actually thought about dying. You know to leave my six year-old son is just too much! I can't do that to him. I can't even think about it."

It was noticeable that all the men seemed to have particularly strong relationships with their sons and all spoke in more detail about this than about their daughters. This may relate to a desire for continuity and a sense that through a son the family name carries on, as does a "likeness" of the father.

4. Coping: sources of strength

4.1 The maintenance of hope

Gavin quoted a Hospice doctor when he said: "there is always a chance, as remote as it might be, there's always a chance. It's a day to day thing and the more one predicts what might happen, then the worse it is for the patient." He noted that when he felt fine he gave himself "a whole stack of hope". However, "cancer is not forgiving" and sooner or later the symptoms or the pain return and hope goes again – "it's very draining".

At times the need for hope is overt. Keith said: "I'm getting better!" However, he also conveyed a covert message of hope for recovery against the odds when he repeatedly returned to his recovery from a very bad car accident years before that had involved him needing to learn to walk again and use his hand. Moreover, he told a story about his three-legged cat, the symbolic message of which seemed to be a hope that he still had value, despite the changes in his appearance:

> And that cat when he came crawling in here with tears in his eyes, I could have told the vet to put him to sleep and the vet said to try and fix it wouldn't work [the cat's leg, so it was amputated] … But look at him! He looks perfectly healthy doesn't he? He can jump and everything.

Sally insisted: “The Lord is talking to me about healing so I know this is even his plan for me, I really believe that. I really believe that.” In contrast, Moira said: “I don’t have a future, I don’t have a hope because it’s no use even going and buying another bunch of flowers ‘cause who knows how long it will be? But I think I’m coming more to terms with that.”

4.2 Life is life

Even when there is no chance of the patient getting well, their day-to-day existence is still valuable and able to provide pleasure. Gavin’s wife Allison resoundingly affirmed she believed it was a mistake to behave as though someone was already in the morgue even though they had been “given a death sentence”:

> He’s not dead yet. And up until that point we’ll celebrate the fact that he’s still alive. And that means you joke and you still play and you have fun and you still laugh, because at the end of the day he’s still here. There’s lots of time to mourn him afterwards.

James spoke of waking early in the morning and enjoying the freshness of the day and the sound of the birds; Keith described going outside to look at the beauty of the stars when he was unable to sleep.

4.3 A shift in time

Several interviewees talked about having a different awareness of time and of the value of each day. Stephen quoted Samuel Johnson who had said that when a man is going to hang in two weeks it focuses the mind wonderfully; he believed that his perception of time and what was important had shifted. Now that he no longer worked he saw friends in the morning and slept in the afternoon so he was rested for his family in the evening.

Gavin commented on the way time either rushed past or dragged, particularly when they were waiting for the result of a blood test. After being told he had six months to live, he said: “You’ve got a mental diary and you cross a week and a month off and you say two months to go, you know?” Keith said the following about his continued survival: “I didn’t think I’d see my birthday when I turned fifty [in August]. But I was still alive, and then Christmas! And I’m still alive now.” Moira noted that she had been told she would only live four days and here she was eight weeks later; she poignantly described that, “every day I wake up and I think, another day I’m here.” James stated: “I’m

just taking it day by day, minute by minute"; looking ahead, Stephen noted "I've [still] got October".

4.4 Changing values

Priorities changed, as Gavin described: "I miss normality – the fact that you're alive and you're healthy. Everyday inconveniences that people complain about are very small when you know you're going to die.' Stephen noted that life was about so much more than a career, "making money and then disposing of that money"; instead he was more committed to people and "giving expression to [his] faith in a more meaningful way now". He believed life was about this process of change, "the learning and the enrichment":

> My father was a provider. He taught me to focus on bringing in the bacon and trying to raise your kids with a set of values that will protect them and enable them to cope in the world. I think that what this has done is made me aware to a much higher degree of the kindness that exists in people and that's humbled me. I would like to bring more of those qualities into our lives.

Moira described herself as having had "a wonderful youth, a wonderful marriage, I've got wonderful children and family and friends. If God wants me He must take me." Although her children wanted to take her on holiday wherever she wanted to go, she insisted that she just wanted to be at home with her family. For Gavin too, an evaluation of his life seemed helpful.

> I'm very lucky. I've had a very privileged life you know. I didn't do too badly at work in my own business and I've travelled and done things and survived three years in the army and I've had many experiences and I don't feel that I need to go and see the leaning tower of Pisa or the Eiffel Tower … so I've lived and I don't feel I've been done out of my life. I've done what a lot of people wish they could have done in their lifetime, you know. I've had money and I haven't had money, but I've experienced good living and I've had challenges put in front of me that I've got through.

4.5 Comparisons with others

After Stephen said "I'm sad that it happens to me when I'm young", he went on to recall the "terrible slaughter" of the two world wars and how so many of the men killed in the fighting were very young, just in their teens. Moira gained comfort from thinking:

> I'm not the only one that's dying. I'm not the only one that's in a bad place. And I'm probably in a better place than millions others who're lying in a tin shack with nobody around them, not even a painkiller. And so I try to appreciate things.

However, for Keith, comparison with others produced guilt rather than increased ability to cope. When he saw others at the oncologist's rooms who were "worse off", especially young cancer patients, he would wonder why he was getting better and not them. At this point his "why me" tended to be the anguish of the survivor. He seemed to deal with this by believing that God must have a purpose for him, a task that he needed to do even if he did not know what it was, and this was why he had survived two bad car accidents and had outlived his doctor's predictions by a year.

Gavin believed that people are very adaptable: "It's just human traits built in, you become accustomed to something because you're with it every day". He thought that even things that were appalling and horrific become normal, and it is only when strangers visit or you see the reaction of newcomers to the situation that it becomes clear how much the family has adapted. Gavin expressed concern for other sick people, including those with AIDS. He noted that even though his pain was bad, "it hasn't been giving-birth pain". He said: "so I have pain, you know, I'm sure people that lose a finger have more pain at one time, you know; it's bearable, it's just ugly".

4.6 The reassurance of faith (for those who have it)

None of the interviewees were neutral on the matter of religion and both ardent believers and vehement non-believers had opinions on the matter. When first answering a question about whether he was a religious person, Gavin stated that he was "too practical" for religion as there was "no proof" of anything. He also stated that he had no respect for the Catholic Church as the church was wealthy and did not spend enough money to eradicate poverty; moreover, he did not approve of the wars that had been fought in the name of religion. James was more vehement, saying, "I don't want any religious stuff near me, nothing" and that he believed that religion was nothing more than "self-centred bigots after their own interests".

Later in his interview Gavin noted: "It would be nice if you can believe there is something after life" but "I am not a heaven and hell person". He believed that "if there *is* something, it'll be something none of us could ever imagine and maybe soul or whatever in you lives on." He noted that when he feels sorry for himself and depressed then "all the questions come up – why me, why die, why not

something I could have overcome?" At this point he commented that it would be nice if there was a God for him to believe in.

For some interviewees the subject of religion was raised spontaneously. Moira emphasised that her illness and dying would be much harder without her faith: "I couldn't do this otherwise. Because when I get so low, what else is there to turn to?" Larry, Sally's husband, agreed: "The thing is without faith I don't think I'd survive. Faith is the hope of things you cannot see. That's that hope, that's faith." Sally talked of a time when she had looked after street children without having any money as having "a pattern of really waiting on God and praying, not knowing what to do". She had felt her illness was a similar experience and was comforted by the frequent appearance of a particular scripture about God as a healer. She emphasised: "I really believe Jesus will heal me." However, she noted that when a woman with three children who had also believed in God died from cancer, she had found this "very hard for me to swallow".

Moira expressed confidence about the future: "I'm going to the next world – He promises that and I'm holding onto that." However Keith felt less sure of his path: "I think I'll go to heaven … see my loved ones in heaven. I just hope I'm good enough to get there." Stephen also wanted to be reunited: "I focus on this being not an end but an interruption. There will be an opportunity to see them once more under better conditions." He quoted from the Bible, "you'll be with me in Paradise" and said: "that sustains me and takes away the sting [of death]. Sadness we still have to deal with, but the sting we can deal with [with faith in being reunited]". Furthermore, Stephen quoted Ecclesiastes, specifically God setting "eternity in the hearts of men" and believed this hope would be met.

4.7 Being able to help others.

Moira in particular emphasised that she was not "sitting around wasting time" and was still useful. She had taken an advocacy stance to help her deal with her illness and she explained that she had "ministered to others that it's [chemotherapy] not such a dread". Since she had been talked through the likely experience of the dying process by the Hospice social worker, she had also been explaining this to other people. She wished there could be more discussion on television about death and dying as she noted that it comes to everyone, and millions of people needed to know there was no need to fear. This focus seemed a continuation of her vocation as a teacher.

All the participants appeared to enjoy being able to assist the researcher, saying that they hoped it helped her and other people. With typical diffidence, Keith said he did not think his story was very interesting, but hoped it had been helpful anyway. When James was thanked for his time and for sharing so much, he said: "I've got nothing to lose and it's a different viewpoint". He hoped it had helped the interviewer's studying and given her something to work with. These comments tended to be made in response to a closing question about how the participant had found speaking about the difficult subjects of death and dying.

4.8 Humour (when it's no laughing matter)

Several interviewees seemed to find humour a way of managing painful and difficult situations. Moira joked about the effects of chemotherapy: "Have you read the book about the Apache Syndrome? A patchy hair here, a patchy hair there …' Gavin's wife teased him about his continued survival, saying he was "past his sell-by date".

CHAPTER FIVE
DISCUSSION OF FINDINGS

This chapter will be presented in seven parts. The first three parts articulate the research findings with the literature in terms of the key findings: the experience of a terminal illness itself, actions to facilitate good dying and ways of creating a good death. The fourth part takes the form of attempting to answer the research questions, while the fifth part concerns itself with noticeable absences as these draw attention to some of the more unexpected findings; in this instance, unexpected means not reflecting dominant aspects of the literature. The sixth part examines the findings in relation to the influence of the sample, particularly its demographics and cancer as an illness. The seventh and final part involves reflections on the nature of the research.

Three key themes dominated the findings: firstly, a focus on the *experience* of a terminal diagnosis and having this confirmed by the progressive deterioration of the body; secondly a concern with actions to facilitate a *good dying process*, and thirdly ways of *coming to terms* with rapid change which help to create a good death. These will now be described and considered in relation to the relevant literature.

1. The experience of being terminally ill

This study set out to give a voice to terminally ill patients themselves and thus it is not surprising that the findings are dominated by a strong focus on their experiences, specifically the events, physical feelings and emotions that impacted particularly strongly on them.

The first noticeable experience for most interviewees was the shock and trauma of the cancer diagnosis and terminal prognosis; this was associated with a significant fear of dying. Inextricably linked to this was a theme of the experience of suffering, which was physical, emotional and in some cases spiritual. Finally, there was a strong sense that dying in mid-life was a disruption of what is widely believed to be the “natural order” and was accompanied by an associated alteration in the sense of time. All these themes seemed to be more prominent in this research than in previous studies: one explanation for this may be associated with the form of this research itself, with its focus on the vividness of people’s own words as they

attempted to capture the unique and intense aspects of their experience. Another possibility is that these experiences are more acute or powerful for people in mid-life experiencing an untimely death than for the elderly people who feature in most studies.

1.1 The trauma of the diagnosis

All the interviewees expressed shock at the sudden impact of a cancer diagnosis with its attendant threat to their lives; with the terminal prognosis there was "the sense of being caught out by death" (Berridge, 2001, p.244). It could be said that what is often assumed to be the common denial of death was suddenly shattered, and from being distant (Ariès, 1977, Elias, 1985), death now came very close. This experience echoes the initial shock of receiving the bad news described by the few terminally ill people quoted in the literature: "[it was] the worst kind of nightmare, as if there is an explosion in your head" (Helman, 1988, as quoted in McKay, 1994a, p.51).

Death suddenly intruded into their lives, shattered their security and fragmented any sense of coherence. A vivid description of the chaos and disorder of a progressive and invasive disease with a known terminal outcome at a time of life when this was unexpected seemed prevalent throughout the findings. Thus the focus of the research on the idea of a good death appeared to concentrate on how participants attempt to find a new balance in a suddenly confused and even anarchic landscape. Only one author, Salander (2002, p.726, citing Janoff-Bulman, 1992), wrote in a similar way of the disruption caused by this break in the continuity of experience: "Being diseased may imply that an unarticulated preconscious idea of order in life is replaced by disorder". He further noted that this disorder is accompanied by a frightening sense of a lack of control and a loss of trust in life itself as well as in previously protective institutions like medicine.

For most participants, it seemed that the news of the terminal nature of their illness was not a negotiated disclosure as is recommended by Salander (2002) and Vachon (1998) among others, but a single abrupt announcement that caused intense distress. The doctor's diagnosis and/or prognosis was such a shock that Gavin did not hear what the doctor said; although Keith's good manners took over and he thanked the doctor before walking out, he then burst into tears; Sally wanted to run away; and James found the news "hard to swallow". Gavin vividly described this intrusion:

> I wasn't used to being sick so it was a big shock for me to go from being well to what they thought was pneumonia to dying now and you won't last long. It was a very very hard thing.

As Levy and Lemma (2004) noted, a trauma is an event that breaks through the protective shield that shelters the mind from too much stimulus; this is usually associated with the threat of harm or even death. It is clear that a diagnosis of a life-threatening illness, and the news that this is terminal, complies in most respects with the definition of a trauma: the shocked and distressed reactions of each patient, their level of fear and lasting difficulties with sleep, for example, as well as their ability to recall the occasion of hearing this news in detail. However there seems to have been very little literature on the association between terminal illness and trauma. This may be because most trauma literature, for example Judith Herman's (1992) classic text "Trauma and Recovery", focus on *treatment* and a return to health, which may be particularly difficult in terminal illness with its progressive losses that may take place rapidly.

Trauma is frequently associated with a loss of safety in the world: Garland (2004, p.48) described this as a "life-breaking trauma". It was poignant that for most interviewees this loss of safety included a loss of trust in their bodies. Symptoms they associated with a minor ailment, like a tooth abscess, a blocked milk duct or stomach cramps, turned out to be deadly. This resonated with the "secret invasion" described by Sontag (1977, p.5). Something apparently minor in their bodies turned into a monster that the interviewees were told could, and eventually would, kill them. This cancer was described as devouring, "eating" them, out of control, everywhere, "a killer" and "unforgiving". In many ways, this is a theme from human nightmare – the invasive alien being that takes over the body, grows rampantly and is unstoppable.

> Cancer is often referred to as the 'illness of modern civilization', referring to the toxicity of our environment, physical and mental. But cancer may also be an illness of our century in defying science's efforts to control decay, suffering, the body, and death. For the body in cancer is not the famous docile one – to the contrary. It is the body asserting itself, out of control of its 'owners' and 'curers', on its own, producing its own monsters that science and medicine are called upon to control. (Gordon, 1990, p.292, as quoted in Lawton, 2000, p.81)

For several interviewees, this loss of a sense of safety in the world was associated with disillusionment with doctors and a loss of trust in the medical profession. This may have been expected from the literature, which described medicine as a

secular religion (Berridge, 2001; Elias, 1985). Moira angrily spelt out the discovery that doctors, frequently seen as godlike figures who save lives and "give" diagnoses and time (as in "she gave me six months"), have feet of clay. She said: "the doctor is not God either". Participants spoke bitterly of the failure of regular medical check-ups to detect a tumour that had apparently been growing for three-to-five years, expressed anger at doctors who withheld information and felt disappointed at man's ability to travel into space, for example, but not to get rid of a few lumps in the body. Although some good interactions with doctors, particularly those at Hospice who provided information and reassurance, were described, it seemed hard to "forgive" the bearers of bad news. Thus Gavin and Stephen aimed to beat their "deadlines", and Moira expressed triumph at proving her doctors wrong in her continued survival.

1.2 Fear of dying

All the respondents expressed fear about how they would actually die, particularly fear of uncontrollable pain and difficulty in breathing. Gavin was unable to sleep thinking about this:

> The first month all I thought about was dying … what is dying? And all the dreadful thoughts about how you're going to die. You know, added to the fact that you're going to die, now *how* are you going to die?

Keith had been told that the tumour in his jaw might cause a series of strokes that might paralyse him; this scenario was understandably terrifying. In part the fear of dying seemed to be a fear of the unknown as indicated by Moira's anxious questions:

> Will I be riddled with pain? Will they be able to control my pain? How will I be emotionally? How will the people around me be? Where will I die? How will I die? Who will be with me? All these questions of the uncertainty and the unfamiliar.

It seemed in many ways the picture of a "bad" death involving suffering and pain was very strong for respondents and it was hard for them to move past it. Stephen noted, "It's not so much death as what I have to go through to get there that worries me". In some ways this seemed to be an ongoing reaction to the shock of the diagnosis/prognosis in which a sense of fear and of being under threat dominates. In addition death is the loss of "the reassuring sense of going on being that we take so for granted" (Lemma, 2004, p.114).

As mentioned in the Literature Review, few authors distinguished between the fear of *dying* and the fear of the state of being *dead* (Baltes et al., 1995, cited in Röcke

& Cherry, 2002). While it seems possible that the other fears associated with death, like fear of oblivion and fear of the unknown outcome of death were experienced by the respondents, there was interestingly no direct evidence of this.

However, in her study of the dying process undertaken at a hospice in the United Kingdom, Julia Lawton (2000) provided a convincing explanation of how the rise of Western individualism places a great emphasis on the ability of the individual to be bodily active, self-contained and autonomous. This embodiment is essential to a sense of self and the attack on bodily autonomy by a terminal illness therefore erodes both this active self and the web of social relationships it sustains (Lawton, 2000). The relentless loss of capacity in younger patients in particular may be very rapid. When James was interviewed he struggled to get enough breath to be able to talk despite being on oxygen and it was hard to believe that just a month previously he had been sailing his yacht. So it is understandable that this rapid experience of uncontrollable disintegration is unnerving and the process of dying may come to dominate experience:

> Many of the patients I worked with in the hospice deteriorated so fast and suddenly that they simply did not have time to make adjustments to a loss of capability or functioning before another loss … occurred. (Lawton, 2000, p.183)

When Lawton's explanation of the dying process in Western societies as presented above is considered in the light of historical attitudes to dying, she seems to be suggesting that the rise of individualism means that Western people are significantly more attached to their youthful bodies as a definitive part of the self than those in other cultures or other times were. Dying young with an active body withering before your eyes is thus very different from Ariès's (1974) notion of the "tame death" in which he suggested the personality is put to sleep but not lost or the later "death of the self" in which it was taken for granted that the soul continued, either in heaven or hell. Instead, during the dying process today disintegration of the body is accompanied by an intensely anxiety-provoking diminishment of the self, which is inextricably linked to embodiment (Lawton, 2000). This implies that the fear of dying is less about the loss of bodily life alone and more about the loss of the essence of the self and thus a terrifying sense of falling apart, a loss of integrity and wholeness.

This conception seems to challenge the self-concept discussed earlier as part of quality of life in the literature review, which sees the four components

of the self as relatively separate, notably the body self (comprising both physical self and body image); the interpersonal self (psychosocial and sexual interaction); the achievement self (both job and role functions) and the identification self (spiritual and ethical beliefs) (Foltz, 1987, cited in Allison et al., 1997). Theoretically, people "downgrade" an aspect of self that they are unable to feel good about, as argued by McCrae and Costa (1988, cited in Allison et al., 1997), and during a severe physical illness would thus switch focus from their body and achievement selves to their interpersonal and identification selves. This may be called "maintaining personhood" (Kabel & Roberts, 2003, p.283). However, Lawton's (2000) conception of the modern Western self as inextricably embodied implies that a terminal illness impacts dramatically on all four of these components and threatens to shatter self-concept, defined as all "that a person feels about him or herself" (Schain, 1980, cited in Allison et al., 1997, p.225). Freud (1984, p.364-5) described the ego as "a bodily ego" and explained: "the ego is ultimately derived from bodily sensations, chiefly from those springing from the surface of the body". This link tends to be forgotten in times of health, but when both the external skin and internal organs feel under attack by painful treatments and advancing disease, it may be difficult to have any sense of the self that is whole and capable.

1.3 Suffering

As may be expected from the discussion above, participants movingly described their distress during this process. They spoke of three modes of suffering which though interrelated can be categorised as physical, emotional and spiritual suffering.

1.3.1 Physical pain and bodily disintegration

Not only the diagnosis itself, but the prescribed treatment was disruptive and an assault on the body. Several patients described uncontrollable vomiting and suffering that was horrible enough for Stephen to say he lived his life "by the second" and for Gavin to speak of reaching a point of desperation that made him want to turn off a switch if he could, in other words to end his life. Lawton (2000, p.130) suggested that symptoms involving a loss of the "boundedness" of the body, such as incontinence, vomiting or suppurating wounds caused particularly acute distress and a heightened loss of sense of sense of self. This fearful sense of bodily disintegration may be related to very early infantile fears of "leaking, falling

or dissolving into endless, shapeless space" (Ogden, 1989, p.138). Babies feel more secure when firmly wrapped or able to use the feeling of their skin against the breast to develop a sense of shape and boundary (Ogden, 1989). In adults who feel under attack by rampantly growing tumours and who are in pain from physical contact, with the bed for example, it may be hard to create soothing sensory experiences.

Furthermore, the shock of receiving a terminal diagnosis might be exacerbated by having patiently endured intrusive and painful treatment that "should" be rewarded. Noticeably, only Moira found chemotherapy positive, her "best friend" in fact, and spoke of being excited to receive it. The hyperbole of this response, in defiance of most patients' experience, may be explained as a "manic repression of feelings of loss and despair". Similarly, Keith's certainty that he was being healed could be seen as an insistence that his internal wishes override external reality (Lemma, 2004, p.111).

As the cancer spread, it interfered with essential bodily functions, like the ability to breathe in James and Gavin. Or it caused intense pain, as it did for Sally so that higher and higher doses of morphine (which made her drowsy and unable to interact with others) were needed for her to be comfortable. Or cancer simply eroded their strength, so men who had previously taken pride in their strong bodies talked of "going downhill" and getting weaker and weaker so normal activities like walking a few steps became a challenge. Gavin and James, possibly those who had taken the greatest pride in their bodies, found this especially distressing and noticeably frustrating. James's weakness left him feeling hopeless: "I can't do a thing! I can't walk from here to there without puffing and panting". In this regard, Lawton (2000, p.82) referred to the shift in a deteriorating patient from a "body-subject" to a "body-object" with an accompanying loss of selfhood as weakness increases. Here the exception was Moira who had no pain at the time of the interview, just three weeks before her death, and was still able to be active some of the day.

The only interviewee who mentioned feeling suicidal was Gavin, and this was during his chemotherapy treatment when his physical suffering was extreme: "…that wasn't living that's for sure … If there was a switch I could have reached it would have been off". When these symptoms abated, as far as the interviewer is aware, there was no recurrence of this wish to die. This seems to correlate with

Chochinov et al.'s (1995) study which emphasised that suicidal ideation in terminally ill cancer patients is related to depression and also tends to be transient. If physical suffering, especially pain, is managed, this is not a common phenomenon.

1.3.2 Emotional anguish

While all the interviewees had relationships that were important to them and frequently a source of considerable support, the tearing apart of these bonds was agonising. The emphasis placed by all interviewees on this experience reiterated Seale's (1998, as cited in Currer, 2001) highlighting of the pain of breaking social bonds as a fundamental aspect of the dying process. For example, James felt anguish about his son having to grow up without a father in the same way he himself had after his father had died and found this was the "hardest part" of dying. He said: "I know the things I missed out with me". Sally found the very idea of leaving her six year-old child without a mother too painful to think about:

> I've thought about dying, actually thought about dying. You know to leave my six year-old son is just too much! I can't do that to him. I can't even think about it.

Moreover despite an intense appreciation of their love, for Gavin the suffering of his family witnessing the progression of his illness and his decline was hard to bear: "The hardest thing for me is knowing that they are sad over me." It was agonising for him to be aware of the way in which he and his illness had become the giver of distress rather than being a source of love and protection. Thus for respondents the knowledge of impending loss made even the most supportive relationships bittersweet. It is noted that "trauma always involves loss", both actual and symbolic (Lemma & Levy, 2004, p.xv).

Moreover, in families in which there was already some stress, this was understandably exacerbated by the challenge of terminal illness. Although by the end of her life Sally had achieved some reconciliation with both her family of origin and her husband, her illness initially intensified rifts. Despite Moira's desire to reach some form of closure with her ex-husband, he was refusing to communicate with her and she said: "I can't make closure with the sore that's actually ripped open and sitting waiting."

Keith and his family were still coping with the death of his wife a year before his diagnosis and he seemed to experience impediments to discussion about the

severity of his illness: “I just try to act like nothing’s wrong. I’ve got nobody to talk to”. These closed doors and communication blockages at a time of great need resulted in loneliness and seemed expressive of Elias’s (1985,p.3) “early isolation of the dying”. However, even with people who communicate well there were difficulties. As Gavin’s wife noted, although she tried to “put on his shoes” and feel what he was going through, the truth was that he was dying and she was not. Essentially, dying is an experience undertaken alone, in a loneliness that is intensified by incomplete relationships and avoidance of talking about the painful reality. Yalom’s (1980, p.9) understanding of the “final unbridgeable gap” between individuals that results in a sense of existential isolation seems relevant here.

Keith, who mentioned suicide in relation to his despair after his wife’s death, seemed to fit criteria for a clinical depression, including lethargy, anhedonia, loss of appetite and suicidal ideation. It was noticeable that both Moira and Gavin referred to their “happy” pills; it is unclear whether Keith was on anti-depressants. For these patients, psychiatric problems seemed to have been addressed, in contrast to the literature that reported significant levels of under-diagnosis of depression in terminally ill patients (Kleespies et al., 2000). This indicates that, in this regard, the Hospice ideal of total care of the patient seemed to be realised.

1.3.3 Spiritual despair

For Sally in particular her illness was a test of her faith in God and she thought if she kept faith, she would be healed; that this did not happen is likely to have challenged her beliefs. She found it painful to have to make plans *despite* her belief that God would heal her and asked how she could have been given a six year-old child only to have to abandon him. This crisis is far from unusual, as discussed by Speck (1998) who spoke of the “dark night of the soul” that a terminal illness, with its agonising sense of “unfairness”, might trigger.

It is possible that some of the participants felt anger against God for the perceived injustice of their situation. However, this may be so uncomfortable for a committed Christian that this rage is instead unconsciously projected onto “godlike” figures that had let them down, like doctors. Possible examples of this are suggested in how bitter Stephen and Moira both of whom were devout, felt towards the medical profession. Stephen spoke of feeling “pissed off” that his annual medicals had not

detected a tumour that had been growing for up to four years: “It should have been picked up earlier. The medicals were inadequate.”

It is also possible that Western society’s prohibition against the expression of strong emotions, like anger in particular, may also have come into play. Thus the sentiments expressed by Dylan Thomas’ well-known poem “Do not go gentle into that good night” may be more prevalent than this research suggests:

> Good men, the last wave by, crying how bright
> Their frail deeds might have danced in a green bay,
> Rage, rage against the dying of the light. (Simpson, 1972, p.336)

1.4 Disruption of the natural order

Analysis revealed participants struggling with their sense of the natural order of things having been disrupted in two ways: firstly in alterations to a sense of time and secondly in a profound sense of wrongness that they should be dying in mid-life while their elderly parents lived. There seemed a sense that continuity was broken.

A changed relationship with time was a prominent thread that ran through most interviews and was raised in a number of different ways: the suddenness with which lives were changed by their diagnosis; the loss of a future resulting from the knowledge that their deaths were imminent; the cutting short of an expected life span; the feeling that a given period of time was being counted down; the importance of weeks, days and hours with loved ones. This theme of an altered relationship with time did not seem to be highlighted in the research literature, but was present in the narrations of other terminally ill people, most notably and poignantly, Ruth Picardie (1998, p.11) writing of her own pending death:

> I wish there was some way they could just give you five years. Five years is such a long, long time. Who needs eternity … when you’re running out of time five years is a whole eternity on its own.

The interviewer had a sense of the interviewees being pursued by the evil crocodile with the clock ticking in its stomach, which is so memorable in the J.M. Barrie’s children’s book “Peter Pan”. Captain Hook speaks of the crocodile that has followed him relentlessly since it devoured one of his arms and is likely to prove his nemesis. This description seems an evocative picture of the experience of the cancer patient who is haunted by a sense of time running out:

> "It liked my arm so much, Smee, that it has followed me ever since, from sea to sea and from land to land, licking its lips for the rest of me."
> "Smee," he said huskily, "that crocodile would have had me before this, but by a lucky chance it swallowed a clock which goes tick tick inside it, and so before it can reach me I hear the tick and bolt." He laughed, but in a hollow way.
> "Some day," said Smee, "the clock will run down, and then he'll get you."
> Hook wetted his dry lips. "Aye," he said, "that's the fear that haunts me." (J.M. Barrie, 1911, p.68-69)

A sense of continuity being disrupted was also present in the dislocation of order among generations, as described by Schultz and Hall (as cited in Leming & Dickenson, 1998):

> The way I see it, we die in the same order we were born.
> It's the only fair way of working it!

However, only James was dying after his parents, in the same order he was born. In contrast, Gavin, Moira and Sally were all dying before both their parents, while Keith and Stephen still had mothers alive. Gavin noted: "I'm leaving my wife and my mother who's seventy-eight. It's backwards" and Moira said: "I've got two parents alive … the order's wrong".

In a further reversal of the natural order, these adults were nursed by their mothers during this last illness, a poignant reversion to childhood dependency and need. Moreover, while all the participants had children, Gavin, Sally, Stephen and James' children were particularly young, but these parents no longer had the time to raise their children to adulthood, and were already unable to parent in the way they wanted to and had in the past. Gavin sadly said: "I miss the ability to live, to be able to run up the stairs, to know my son is going to have a father." He seems here to be linking the ability to be strong and active with the ability to parent. Percy Helman, whose wife described his terminal illness, commented:

> The question of feeling a "lesser" person is a very real one for seriously ill patients. Apart from the loss of dignity that is a natural consequence of dependency on others, there is an inescapable feeling that because health and strength have disappeared, the image that others have of them, which is all-important, has somehow diminished as well. (Helman, 1988, as quoted in McKay, 1994b, p.55)

Leming and Dickenson (1998, p.196) described this disengagement from roles, together with the spatial isolation of the patient and the terminal (coming-to-the-end-of-time) diagnosis as giving the patient "a status somewhere between the living and the dead". Moira seems to be suggesting something of this inbetwen

status when she is able to speak of her pleasure in meeting a friend for coffee that afternoon but also to say there was no point in buying another bunch of flowers because she had no future.

2. Actions to facilitate "good dying".

A second set of themes concerned good dying. This appeared to involve actions that attempted to restore order and help manage the chaos and disruption described in the experience of a terminal illness articulated above: the trauma of receiving the diagnosis; fear of dying; physical, emotional and spiritual suffering and disruption of the natural order. In this sense, good dying focused on symptom control and managing the practical aspects of dying such as writing a will and settling financial affairs. The need to settle areas of personal conflict was also noted. It may be considered that these first two sets of themes around the experience of the sudden reversal of their lives and managing the disorder this had caused focused on dealing with the present.

2.1 Symptom control

Managing symptoms, especially pain, appears to be the bedrock of achieving a good dying process. If the patient is in pain, struggling to breathe or nauseous for example, dealing with other tasks becomes more and more difficult. The difference good symptom control can make was noted by Sally's husband who was pleased her pain could be managed without the dose of morphine being so high that it made her so sleepy that he could not communicate with her. Keith's palliative radiation had shrunk his tumour and reduced symptoms and Sally's palliative radiation had reduced pain; several patients were being treated for depression, and this seemed to make it easier to access their strengths. The problem of physical weakness seemed less amenable to treatment, as previously discussed.

Patients in the Pierson et al. (2002) study ranked symptom control as most important for a "good" death and linked the presence of pain to a "bad" death. In this study of young patients with AIDS, quality of life was seen as very physical, and described as "being in a comfortable state, being without suffering and not having prolonged dying via life support" (Pierson et al., 2002, p.590). In a study of elderly patients (Vig et al., 2002), dying quickly without pain, while sleeping, without suffering and, importantly, without knowledge of the impending death, were the themes associated with a good death.

2.2 Getting your house in order

All the interviewees attempted to impose order upon the chaos of their lives since their terminal prognosis. It is suggested that this practical preparation for death was empowering: sorting out a will and other personal and business financial arrangements seemed to help to reduce anxiety and provide some sense of completion. Some studies have associated making these preparations with maintaining quality of life as the preparations indicate independence and managing one's own affairs (Leightentritt & Rettig, 2001). Just five days before he died, James said:

> I'm trying to get everything sorted, so it's all clean. You know it's not like I'm going to go tomorrow, so I've got a few days to, or a few weeks whatever, to get my house in order. Going through my will and documents and tax papers and insurance policies, just to make sure that it's all like that! So there's a box, tie it all up.

Although they found this understandably difficult, several interviewees also planned their funerals with their family or friends. All these actions may also be associated with maintaining a sense of control and autonomy (Twycross & Lichter, 1998). These tasks involve problem-solving coping skills to manage the problem (Lazarus & Folkman, 1991) and provide a satisfying sense of accomplishment.

2.3 Settling conflict

When these practical matters were underway, relationship-focused mending also took place. James spoke with relief of things with his daughter being "knitted" and Stephen did not want to die with any "ragged ends". As described above, when this ordering could not be managed, as with Moira, there was significant distress. However, she replaced a meeting with her ex-husband with a letter to him and found some closure in doing so. Sally enjoyed the sense that she and her family were all "a team" and "on our side". The process of creating a biography that integrates and acknowledges life events, including conflicts, and takes the opportunity to resolve pertinent issues is considered a way to facilitate acceptance of death (Röcke & Cherry, 2002).

3. Accessing personal strengths, or the creation of a good death

Thirdly, there were themes that could be associated with a good death, without ever spelling this out explicitly; another way of conceptualising these is as ways of accessing personal strengths:

> Many dying persons use coping mechanisms they have learned in previous crises while others retain a flexibility that enables them to try new ways of coping … so that, for them, the experience of dying may even be a growthful one. (McKay, 1994b, p.58)

Most prominent among these areas of strength and support was the importance of loving relationships, particularly family. In addition, the benefits of open communication and a personal philosophy that facilitated a form of acceptance of death, while being determined to live fully until the end, were observed. Finally, the support given by the maintenance of hope, meaning and faith were noted.

It is acknowledged that all the participants showed tremendous courage in the face of the challenges facing them, and pointing out possible defences or roles (such as the brave cancer patient and teacher played by Moira or the independent decision-maker epitomised by Stephen) is not intended to denigrate this. Instead, it is hoped that such analysis will shed some light on the range of coping mechanisms that may be brought into play in the work of creating a good death. Furthermore, as Kalish (1985, p.10) proposed, "it appears logical that we cope with our own foreseeable death in much the same manner as we cope with other highly stressful situations"; McCormick and Conley agreed (1995). Not only is this logical, but McKay (1994b, p.59) suggested that it is congruous. He believed that an appropriate death is not an ideal death but "one that is consistent with the person's ego-ideal. In other words the person dies as the person she thinks and believes she is."

3.1 Relationships: love and loss

Loving relationships provided an enormous comfort and security. Gavin described holding his wife's hand as "an injection of life" and said: "Really the only good feelings I have is because of family, you know, and they've been incredible." In many cases this awareness of the importance of relationships came as a result of the re-evaluation of aspects of life previously considered important:

> Dying is a distilling process for the person at the edge of life and for families, friends, and even those providing professional care. It forces us to look at what is essential, at what has been covered over by the distractions to real living we cultivate daily in a society that denies life as much as it pretends death is an aberration. (Thomas Moore, forward to Murphy, 1999, p.xi)

It was clear that mourning had already started in the pain felt by the witnesses to the death of a loved one and those who were losing their lives. Managing the

sadness of these losses of present connections and future dreams was very challenging. Moira put together albums for her children, while Stephen had regular one-to-one chats with each of his children so he could answer their questions and give them space to express their hurt and anger. At times, creating order in relationships may simply involve doing your best to make a workable plan, as Sally needed to do for her son Jack.

Dying has also been described as a process of separation from attachments to life, family and friends and ultimately one's own body (Speck, 1998). As Elias (1985, p.56) commented, "a human's life cannot be independent of what this life means for other people" and rituals, like the conversations and albums described above, formally recognise the importance of these connections and the pain involved in tearing them apart. Thus Seale's (1998, as cited in Currer, 2001) emphasis on the breaking of social bonds rather than the individual dying process appears to be particularly pertinent in relation to participants in mid-life with their attachments to spouses, ageing parents and young children.

3.2 Communication: "opening doors"

A theme around communication was woven through the interviews with a number of participants. Moira commented on discussions with her family and friends: "I talk very openly about death and dying – it's not a big-c, it's cancer and it's chemo and it's death and it's dying and it's loss and it's funerals and we talk openly." At times achieving this open communication required some help as Gavin's wife noted: "We tried to make it easy for others to talk. We opened the door on the subject." This implied that, without help, some friends might have felt too awkward to broach painful subjects like Gavin's illness and deterioration. Stephen explained how he made time for his children to tell him how they felt. These examples illustrate some of the benefits of talking openly about death and dying and the way this kept these participants connected to others.

However, for some participants like Keith, not being able to talk openly with his family left him feeling very much alone. He experienced the sense of alienation a seriously ill patient feels from those who are healthy that is spoken of so frequently in the literature (Bertman, 1991, Terkel, 2001); this can result in social death while the person is still alive (Elias, 1985). This alienation may be heightened by medical staff with a paternalistic attitude, the difficulty many doctors seem to have in treating the person rather than the disease and the tendency of some doctors to

withdraw from their terminally ill patients (Elias, 1985; Kleinman, 1988). Bridging these barriers through open talking and attentive listening between those who are ill and those who are well, and between doctor and patient (Sullivan, 2002) may thus be a significant part of a good death.

James and Sally and her husband expressed frustration with doctors who did not share information with them and help them make informed choices. In addition, unilateral decision-making, for example as Sally's oncologist is reported to have done in stopping her chemotherapy as it was a "waste of money", is likely to be seen as disrespectful (Costello, 2000; Fallowfield et al., 2002). The attempt by Sally's family to get her to change her unconventional lifestyle before they would help her during her illness, however well meaning, added to her sense of having to deal with her disease on her own.

In contrast, several participants reported that access to doctors and nurses who would explain was helpful, especially in calming the fear of all interviewees of dying in pain. James found the detailed explanation and drawings by the Hospice doctor a relief despite the poor prognosis she gave him, and Moira felt comforted by the social worker's description of the slow withdrawal of the dying process. These open-door communications about a difficult, sometimes taboo subject seemed to remove some of the fear of the unknown. This aspect of a good death is dependent on open awareness of the terminal patient's status between medical staff and the patient, and the patient and their family (Glaser & Strauss, 1965, as cited in Currer, 2001). As Peberdy (2000, p.76) noted: "If the possibility of dying can't be faced, a hope that goes beyond insistence on recovery cannot emerge."

Open communication also helps the patient maintain some sense of control, for example Moira's decision not to continue with chemotherapy. Open communication with medical personnel as well as with family members facilitates negotiated decision-making, demonstrates respect for the will of the patient and prevents the ill person feeling banished to an isolated "kingdom of the dying" (Feigenburg & Schneidman, 1985). It is noteworthy that Moira said she had her "family's blessing" to stop chemotherapy. Thus whether it applies to relationships with friends and family or with medical personnel, an "open door" approach to communication seems to be part of a good death.

3.3 Resignation: “when it’s your time, it’s your time”

The failure of modern medicine in a technologically sophisticated age, posed challenges for the interviewees in terms of the meaning of their illness and their impending death in their thirties, forties or early fifties when they might reasonably have expected to live for three-score-years-and-ten. Some interviewees attributed this to bad luck or chance, as Stephen said, “like being hit by the proverbial taxi”. Others like James and Keith spoke of a version of the belief “when it’s your time, it’s your time and there’s not a damn thing you can do about it”. This implies a sense of helplessness and lack of control. Some thought their death at this time was God’s will although they found this hard to accept. Moira stated: “God makes and He takes despite my will”. In either case, there was an impression that the individuals involved believed their concerns or life plans had been swept aside in the “crisis of the knowledge of death” (Pattison, 1977, as quoted in McCormick & Conley, 1995, p.238).

This thought was expressed by Muller (2000, p.30), who described the terminally ill patient, with the exception of the very old person who has lived a long and full life, as “enveloped in a cloud of ‘never ever’ or ‘never again’”:

> Whatever was introduced by the notion of ‘sometime’ will fill them with bitter wistfulness, since life for them has not yet been sufficiently and adequately lived and its termination will always be experienced as premature and a cessation (Muller, 2000, p.30).

James said: “If this had been a month away or six weeks ago I don’t think I could have talked. But now I’ve accepted what’s happening so I just get it out and talk.” Moira described the acceptance of reality of impending death as “a back and a fore and a back and a fore” rather than a once-off event. For her, backwards movements tended to be associated with regret or loss and forward with faith that her life and her death had meaning. This staggered negotiation seems more realistic than seeing acceptance as Kübler-Ross does (1969) as a stage that is reached once and for all.

The exception here is Keith, whose position was “never give up”. He was determined that God was giving him second chance with a meaning or purpose he had yet to discover.

3.4 Living until the end: "he's not dead yet"

Even if what is hoped for is limited, as in Gavin's wish for "good time slots" each day, hope is important in maintaining good living until the moment of death. The rousing comment by Gavin's wife that "he's not dead yet and up until that point we'll celebrate the fact that he's still alive" was a thought more quietly conveyed by James:

> I may as well enjoy till right until like, I don't know any more. So here's where I am – day by day. Minute by minute. And I'm here.

This celebration of ongoing life could be seen as a defiance of social attempts to place dying people into a separate kingdom (Feigenburg & Schneidman, 1985). Instead it seems more likely that, as Benzein et al. (2001, p.123) described it, terminally ill cancer patients belong to "two worlds simultaneously", "to both life and death", with movement between the two depending on how they are feeling and how they are perceived by others.

The ability to contribute to others and to feel useful seems particularly important in keeping the dying person in the world of life. Altruism among participants was noted by both Greenstein and Breitbart (2000) and Yalom and Greaves (1977) in the running of group processes for terminally ill patients. This may explain the participants' willingness to be part of the research and the interest they all expressed in helping others, both the researcher and other terminally ill people.

3.5 Hope in uncertainty

Initially hope took the form of action: undertaking treatment, however unpleasant, in the hope that this might bring with it the possibility of a cure. There might even have been an un-stated belief held by some (excluding James) that the worse the medicine the better it must be for you. Others, most noticeably Keith, seemed to choose to maintain hope by *not* finding out the details of his illness, stating that his daughter was looking after him and she knew more. Moira also seemed to consider it more helpful not to know the final stage of her cancer or the extent of its spread.

During the illness, the source of hope kept shifting as is compatible with the literature (Benzein et al., 2001). Once there was no further hope of a cure, respondents hoped to be free of pain or to have their breathing eased; this may be called living in hope rather than hoping for life. In palliative care, hope is described as "built on the belief that better days or moments can come" (Benzein et al., 2001,

p.117). For example, Gavin's hope shifted from having good days to having good time slots in a day. It was observed that holding onto hope is not incompatible with reordering life and creating a good death (Benzein et al., 2001). However, if an unrealistic hope interferes with necessary action it is no longer constructive but destructive. Thus, considering that Keith's tumour was slow growing at the time of his interview, his belief that he will be cured may be part of managing his world in the wake of the extreme shock of his diagnosis a year prior to the interview. For a time, this may help people like Keith and Sally to avoid being overwhelmed.

Therefore although James commented that "we all wish for a miracle", the dying process appears to fluctuate between hope and resignation to the reality of weakness, shortness of breath and declining functionality. Hope is considered essential in providing the "will to live a little longer" (Benzein et al., 2001, p.119). If all hope is lost, however, despair sets in, with "no point in buying another bunch of flowers" as Moira said and no reason to get out of bed, as both Keith and Moira described. The importance of hope as a theme in this and other research makes it surprising that it was not included in Kübler-Ross's five stage theory or the additional five experiences suggested by McCoy (1974, as cited in Kalish, 1985).

3.6 Meaning and faith

Greenstein and Breitbart (2000) distinguished the concept of meaning from religiousness and explained that while a sense of meaning may come from a belief in the existence of God, other senses of order and purpose are also valid. Meaning may be defined as:

> … the cognisance of order, coherence and purpose in one's existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfilment. (Reker & Wong, 1988, as quoted in Greenstein & Breitbart, 2000, p.491)

Moira overtly described a spiritual meaning to her early death in terms of a mission accomplished. She continued to find vocation-orientated meaning by teaching about cancer and dying in an attempt to reduce peoples' fear and expressed pleasure in continuing to contribute to others.

For Gavin and his wife meaning seemed to be created in a celebration of love and life as seen in their statements "he's not dead yet" and "love is all there is". Along with his regret at lost time with his son, James was able to construct the meaning of his life in reminiscing about the past: "we had good times" he said, and talked

with pleasure about building a boat together and sailing it as recently as two weeks previously. These memories of the "therapy" of "time on the water" and of teenagers playing in the mud rather than at malls seemed sustaining for him, a legacy he was leaving his son. Röcke and Cherry (2002) described the importance of creating meaning through reminiscence that helps in seeing life as a continuum and integrating life events, as did Caffrey (2000) and Baum and Gallagher (1987).

Stephen too spoke of a legacy, one of love, but as a very committed Jehovah's Witness he was particularly sustained by his faith and the belief that death was "merely an interruption" and he would be reunited with his family. In other words, he saw death as a door not a wall, and dying as part of a journey not the end implied in the word "terminal". In fact Stephen spoke specifically of paradise, and Keith and Moira of heaven. However, it was noticeable that while faith may lessen the fear of death, it did not appear to have any impact on the fear of dying. Neither Lawton (2000) nor Feifel (1974, cited in Lawton, 2000) in his study of terminally ill patients observed any difference between "believers and unbelievers" with regard to dying itself. Lawton (2000, p.175) proposed that this was because the disintegrating body was "this-wordly" and the dissolution of self as the body suffered made faith harder.

Although these five aspects of utilising existing strengths and resources as a way of learning to bear the unbearable approach of one's own death have been presented as separate themes, they all overlap and interlock. Thus the paramount importance of family and other relationships, opening the doors of communication, living in hope, accepting that when it's your time it's your time, finding faith and meaning, and living until the end combine to make up the umbrella concept of a good death. All of these are made possible by medical staff providing good symptom control, without which it is hard to think of anything but the pain, the nausea or the next breath, and which contributes significantly to feeling less scared of the dying process.

> The good death has been recognised as a multidimensional phenomenon based on physiological, personal, interpersonal, social and cultural domains of life that incorporate past, present and future time periods. (Leichentritt & Rettig, 2001, p.86)

However, while probably accurate, comments like the one above are so all-encompassing they almost become meaningless and it is hoped that the use of

everyday language to give examples of key themes in this project brings the concept of a good death alive in a more useful and informative way.

4. Summary discussion of findings

This part of the discussion aims to use the findings to answer the two key research questions. The first of these is: in the opinion of the patient who is dying prematurely, what is a "good" death? For example is there an expectation that certain preparatory work, which may be practical, emotional or spiritual, needs to be done in order to achieve a good death? The second research question is: does the dying person experience any internal or external pressure to die in a certain way? If so, where does this pressure appear to come from? For example, does it appear to stem from the expectations of patients themselves, family members, spiritual advisors or Hospice staff members?

4.1 In the opinion of the patient who is dying prematurely what is a "good" death?

When this research study was planned, it was based on a preliminary view that a good death involved a *resolved* death that would be the result of preparatory emotional and spiritual work, and the reaching of a sense that one's life was complete despite being foreshortened. In other words, the notion of acceptance was considered vital to a good death. Some surprise was felt at the vagueness of the term "acceptance" in the literature and the lack of specific research as to what this might mean to patients themselves. The level of emphasis participants gave symptom control, specifically positioning good management of physical symptoms as the foundation of good dying rather than just an item on the list, was unexpected. However this makes sense and reiterates the findings in other studies, for example Bertman (1991) and Bradbury (2000) among others.

This research seemed to indicate that participants tended to feel resigned rather than accepting of their fate. James emphasised his philosophy that "when it's your time to go it's your time to go. There's not a damn thing you can do about it." Gavin pointed out his lack of options, "there is nothing else, what can you do?" and finally "I'm tired of being sick … I'm sick of being sick". Moira expressed her surrender to the will of God:

> If God wants me He must take me. Obviously I'm finished with my work here. I'm very aware – I'm not of choice ready to go but I'm not fighting. I'm not fighting.

It is possible that, while the dictionary (Collins, 1989, p.6) definition of acceptance is "taking or receiving something that is offered" which implies an active process, and "favourable reception" which suggests an attitude of welcome, acceptance of death is a dynamic process rather than a static single event. Moira spoke of this "back and fore process" with "fear, uncertainty, lack of control, fear of loss, not fulfilling dreams in my children, disappointing my family" taking her away from acceptance and faith moving her forward. Thus a participant may be anywhere on this continuum at a particular moment, influenced by many factors such as how sick or how hopeful he/she feels.

This is slightly different to Lawton's impressions, as she seems to have observed more tired resignation than either a peaceful or hopeful acceptance:

> When patients talked about their own imminent deaths their words did not, as a general rule, indicate any obvious sense of anger. Yet its opposite – a peaceful sense of acceptance (see Kübler-Ross 1969) – also seemed absent. The overwhelming sense I gained from patients was that their feelings were those of dulled resignation; of apathy, lethargy and exhaustion; of finally giving up. (Lawton, 2000, p.79-80)

As described in the previous chapter, in contrast to expectations of a good death being a resolved death, participants understood a good death to be closely related to, if not equivalent to, a good dying process. Although these last days or hours were not clearly defined as a fixed time period, they could possibly be described as the time when what is usually described as a last autonomy or independence is surrendered. In this regard, participants described good dying as not being in physical pain or discomfort, but just going quietly to sleep and drifting gently away. None of the participants wanted to be alert or able to interact at the end. While some had preferences for being in their own homes rather than at Hospice, this was not a particularly strongly held view. There was a split between those who wanted loved ones with them, like Moira, and those who preferred to be alone, like Stephen and James, mostly, it appeared, to protect others from a potentially distressing scene. It is worth noting that, in the Pierson et al. (2002) study, sixty percent of participants saw the dying process as a primary component of a good rather than a bad death.

A key part of the researcher's conceptualisation of what the idea of a good death might include was a sense of completion or fulfilment, which it was believed would make acceptance of dying easier. One participant who seemed to have reached some form of acceptance in this way was Stephen as seen in his comment: "I am not desperate, but I am sad" and "I am very sad to be dying, but I don't feel sorry for myself".

A second anticipated answer involved the "work" it was thought dying people might believe they needed to do in order to earn a good death. This notion had evolved from a belief, erroneous as it turned out, that just as the Protestant work ethic teaches that a good life needs to be earned through hard work, so a good death also needs to be earned by doing the "right" things. Curiosity about what these "right" things might be led to the second half of this question, which is answered in the next section.

4.1.1 Does certain preparatory work need to be done in order to achieve a good death?

This question was developed in the expectation that as Sylvia Poss (1981) said, dying involves "work" which implies effort and the application of energy and, as the task theories (Corr, 1992, cited in Currer, 2001) suggest, an active engagement with the dying process. A wide range of different kinds of psychological work, particularly in the emotional, spiritual and even moral arenas, was anticipated. This may have been presented as participants saying something like "I've been working on letting go" or "I've been meditating to help me be less scared". In the book "A time to live and a time to die", Mark Pelgrin (1961) described this work from his point of view:

> When I came home from the hospital I realised I had a big job to do to find meaning in this strange life of mine … to work at the task of some kind of completion of myself, to find fruitful relationships with those around me, and to learn to be. (quoted in McKay, 2000a, p.53)

In contrast to these expectations, however, it was noticeable that interviewees focused on practical preparations for death, including settling their financial affairs, making a will and planning their funeral. There appeared to be considerable satisfaction in getting their "house in order" and their "ducks in a row" in this area, as James described these arrangements. This relief may be attributed to the regaining of some sense of agency and the ability to contribute in a meaningful way to their family's wellbeing through completing tasks.

It is also possible that there is some sense of completion in making plans and untangling possibly difficult situations like Gavin's business, which had been very dependent on his leadership. This business had been his creation and his "baby" and making plans for it to be administered by his wife may have been highly significant for him in the relinquishing of his previous roles. Similarly, James's sale of the boat he had built and the conscious letting go of his weekends at the Vaal River with all the pleasure these had involved may have symbolised for him the letting go of his life. Planning of this nature required participants to look their terminal status in the face and is not possible if one is in denial. Letting go of lost passions like the business and the boat mean acknowledging that lost strength and energy will not return and is also part of a grieving process.

These ordering activities also applied to healing personal relationships and James expressed satisfaction at having "knitted up" the loose ends of his relationship with his adopted daughter. Stephen mentioned the time he set aside to listen to his children's thoughts and feelings about his pending death. Moira's failed attempt to reach some closure by talking to her ex-husband caused her considerable distress and she had written him a letter as an alternative way to express her feelings. Sally spoke of the sense of being on the same "team" as her father for the first time in years when they discussed the heartbreaking need to make a home for her young son. Keith spoke of his discomfort at not being able to speak to anyone in his family about his situation.

Several interviewees commented on how difficult it had been to plan their funeral. It seems possible that thinking about this event, which is about them but at which they are not present, brings home dramatically their permanently altered status as someone who is dead and gone from the living. Moreover, the ongoing existence of the bereaved family that continues despite its incompleteness without them is highlighted; thus these difficulties may be part of the process of severing social bonds (Seale, 1998, as cited in Currer, 2001). Gavin and his wife, as well as James, spoke with repugnance of the idea of an open coffin. This may be a final desire to protect the family from distress, but seems more likely an expression of horror at the reality of death and being seen or seeing a loved one as a corpse.

It is apparent that the practical plans discussed above had strongly symbolic functions and thus were in some sense more than the practical preparation for death that they initially appeared. However, it was noted that participants did not

directly express any need to prepare themselves spiritually or morally for their death, although it is possible that this may have been considered a very private matter and thus not appropriate to discuss with a researcher at a first meeting. Thus it seems likely that the processes described in various conceptualisations of dying, for example task theory (Corr, 1992, as cited in Currer, 2001), loss theory (Bowman, 1997; Muller, 2000) and the pain of severing social bonds (Seale, 1998, as cited in Currer, 2001; Elias, 1985) do take place but in a far less conscious way than might be suggested by the presentation of the theories. Thus there seemed to be a gulf between the "dryness" of the theories and the indirect and yet emotionally-laden ways in which these processes were discussed by people in the midst of the dying experience.

4.2 Does the dying person experience any pressure, internal or external, to die in a certain way?

The second broad aim of this study was to explore whether patients felt pressured to die in a certain way, and if so, where this pressure might come from. This question originated in part from the romanticised picture of dying in literary and cinematic conventions; examples include films such as "Love Story" and "Terms of Endearment". These conventions feature the dying person in bed surrounded by members of their family, with each of whom there is a tearful farewell; the dying person is still able to speak, possibly even to pass on words of wisdom. They are portrayed as physically weak but emotionally calm and courageously accepting of their fate. This aspect of dying as a dignified "final performance" which takes place fairly publicly was described by Ariès (1974) as a feature of historical dying and it is interesting that it has persisted in cinematic convention. However, it is apparent that "dying well" in this way is associated with being alert while dying and none of the interviewees who described how they wanted to die wanted this; all wanted to drift away or go for "the big sleep".

It may also be that as awareness of Connelly's (2003) "responsibility to die well" increases this becomes more of an issue. However, it is noted that Connelly's thoughts seemed to focus on dying as a last achievement in life, a final creative opportunity, which might "fit" better with the final life stage for the elderly rather than with a foreshortened life. This form of "conscious dying" is also proposed by a number of authors on the subject (Levine, 1984, 1986, 1987; Murphy, 1999; Wilber, 1991). Like Connelly (2003) these authors believe in the possibility of self-actualisation while terminally ill, which may include self-forgiveness for failures and

the healing of old emotional wounds. McKay (2000b, p.57) suggested that it is possible to "die healthily". He related the word health to its origins in the Old English word "hal" meaning whole:

> To die healthily, therefore, is to die in wholeness, meaning that as the body disintegrates the human spirit is able to assert itself.

Thus it was also anticipated that participants might speak more about the challenge of dying, of how they would like to be courageous but feared they may not be, perhaps even linking this to other challenges in their lives. In other words, some form of self-evaluation was expected which did not take place. One participant who came close to some of this thinking was Stephen, who spoke of some of the mistakes he had made along with his belief that this type of learning was one of the purposes of life. Gavin also spoke at length of how he felt he had been lucky in life, particularly in terms of all the experiences he had had. It is possible that a larger sample or a longitudinal study, with a series of interviews with the participants may have revealed more in this area as it is very intimate and may be felt to be exposing.

4.2.1 <u>If so, where does this pressure appear to come from?</u>

In the literature, several authors cautioned that notions of a good death could become based on others' ideals and in this way would be prescriptive rather than helpful. The interviews were analysed with this possibility prominently in mind. Bradbury (2000) warned that those who work with the dying may have personal ideas of "good" and "bad" deaths which influence the way they treat the dying, the dead and the next of kin, who may not spontaneously share these ideas. Currer (2001) raised a similar point, noting that theoretical understandings may block clear perception of the individual, and Davy and Ellis (2000, p.111) commented:

> Palliative care professionals may sometimes be tempted to over-romanticise the idea of a 'good death'. Conversely, they may be so familiar with the routine occurrence of death in palliative care that they fail to recognise the unique nature of every death.

Thus it was expected that participants might feel external pressure from their nurses or other Hospice staff to reach some sort of "acceptance" of their terminal status, however this might be defined. No such comments were made, perhaps because no such pressure was experienced. Alternatively, as contact between participants and the interviewer had been organised through Hospice, it may not have felt safe for participants to express any criticism of the organisation. The

positive comments that were volunteered about Hospice make this seem relatively unlikely, however.

However, when the research findings are further considered, this question is answered indirectly rather than explicitly. Moira spoke of being the "barometer" for her family and Gavin described: "You're depressed, they're depressed. You're on a high, they're on a high with you big time". This sense of being responsible for the wellbeing of others was acknowledged as stressful because the dying person sometimes felt the need to pretend to feel better than they actually were. To some extent therefore, dying well did mean dying bravely and suffering privately in a way that was protective of others. Gavin in particular was very conscious of how those around him were suffering as they observed his deterioration. He noted that "it's them I feel for" and commented that he wanted to hasten his death to limit their suffering. While Moira's and Gavin's interactions with their families cannot be seen as overt external pressure, they may be considered a covert internal urging that had particular impact on those people who perhaps habitually take responsibility for how others feel.

Sally experienced a different kind of pressure in her own insistence that God would heal her if she only held onto her faith firmly enough. Although the interviewer had limited exposure to this struggle, it seemed to be a spiritual struggle within Sally herself that may be related to a "dark night of the soul" in which her faith in an omnipotent God was challenged by her distress at being terminally ill while a young mother. While no mention was made in the interview with Sally of other religious believers augmenting this pressure, this may have been possible. Stephen mentioned his irritation at visitors' comments that he was a "good person" so God would heal him, and Gavin's wife mentioned her mother's conviction that if they had faith and enough prayers were said he would be healed.

Leming and Dickenson (1998) provided some explanation of this process in a description of value systems, noting that these are related to particular societies and cultures. In societies that view death as evil, "cultures prescribe what one must do to lead "a good life," and [there is an unspoken promise that] if one leads a "good life" he or she will be protected from a tragic fate at death" (Grolman, 1989, cited in Leming & Dickenson, 1998, p.195). It is suggested that individuals confronted with death cling to their moral values and can feel deeply betrayed when some of these values do not hold true. This may apply as much to secular

beliefs in the “miracles” of modern science and medicine as to religious beliefs in unwavering faith being rewarded.

5. Noticeable absences in the research findings

In this part of the Discussion, themes that might have been expected to be present after a review of the literature but were noticeable by their absence will be considered. These include the lack of attention paid by the participants to the outcome of being dead rather than the dying process; surprising little concern expressed about personal dignity; and no apparent gender differences in the findings.

5.1 The absence of a concern for what happens after death

As mentioned above, it was apparent that while there was a clear focus on the importance of a good dying process very little overt attention was paid to a wider sense of a good death, which could be said to have two components: the absence of a concern for the world continuing without the dying person in it; and an absence of a concern for what being dead might be like.

Firstly, no participants expressed their distress at life continuing without them. After some experience counselling terminally ill patients, the interviewer had expected comments of this kind, for example a concern about a beloved spouse remarrying and how children might get on with a new stepmother or stepfather. Or participants might have expressed concern about how long they would be remembered, particularly by a young child like Sally’s six year-old son. Further concerns could have been around whether certain beliefs or practices would be continued with children: Sally’s relief that her father would continue to send her son to a Christian school come close to this. The most likely explanation for this absence is that such sentiments are extremely intimate as they involve deep anxieties about personal worth and fears of being forgotten; this is an aspect of the fear of oblivion described by Kastenbaum and Aisenburg (cited in McKitrick, 1985, p.228). These fears are likely only to have been expressed if participants had known the interviewer better and gained a deeper sense of trust.

There was also very little said about what being dead might be like. Even among those patients with firm beliefs about an after-life or going to paradise, there was little exploration of this, apart from a hope of going to heaven (expressed by

Stephen, Sally, Moira and Keith) and a longing to be reunited there with family members in the future (emphasised by Stephen and Keith).

There may be several reasons for this absence. One is that the shock of being told they had a terminal illness was so great that it was hard to get beyond the fear and horror this provoked. It may be that trauma debriefings around the events when diagnosis and prognosis were received would enable these to be more fully processed and reduce the sense of panic so that clearer thinking may follow. A second possibility is the difficulty of absorbing the imminence of personal annihilation or its opposite, the eternity of being in another form; perhaps both of these are simply inconceivable to the human imagination. Gavin commented: "If there is something it'll be something none of us could ever imagine and maybe soul or whatever in you lives on".

5.2 Little attention paid to death with dignity

Given the prominence of the theme of death with dignity in the literature (Enes, 2003; Poss, 1981), this was expected to be noticeable in the interviews. However, unexpectedly, only two patients used the word dignity and this was brief. Of these, only James specified not wanting to be attached to life support equipment or to have his life prolonged in any way: "I certainly don't want to be put on a lung machine and all sorts of things … to prolong my life – for what? Where's the quality of life?" The focus on this issue in the media made this absence particularly surprising. It is postulated that the participants' choice of Hospice care with the knowledge that this choice precludes life support, including a feeding tube unless specifically requested by the patient, meant this issue had been resolved prior to the interview.

Furthermore, it may be that concerns about personal dignity are significantly associated with distress at the gradual loss of independence particularly experienced by the elderly and those who have suffered a lengthy chronic illness. The study by Singer et al. (1999) of dialysis, AIDS and elderly patients, was one of the few to specify avoidance of inappropriate prolongation of life as part of a good death. Cancer patients who are terminal in mid-life tend to have a relatively short dying trajectory. As far as is known, none of the patients interviewed had a long period in bed; several were still up and mobile, although tired and weak, until a few days before their death.

Concerns of personal dignity were more prominent in the Hospice in-patient unit (IPU) studied by Lawton (2000). A number of these patients were admitted for care because of hard-to-manage symptoms such as uncontrollable diarrhoea or vomiting and festering tumours that produced strong odours. The humiliation of these symptoms for the patient and the disgust felt by visitors created significant suffering and in several cases requests for euthanasia (Lawton, 2000). It is suggested that this is a group whose dying process was particularly difficult and these findings seem to emphasise the importance of symptom control for a good dying process.

In a broader view of this topic, McKay (1994, p.59) commented:

> Dying with dignity is only possible when dying persons are consistently regarded as responsible people who are capable of clear perceptions, honest relationships, and purposeful behaviour despite their physical decline and disability.

In light of this, it is possible that participants felt they were being treated with respect at the time of being interviewed and thus the issue of death with dignity did not need to arise. All but one participant were seen at their or a friend or family member's home. In these environments they felt loved and secure, and were cared for by a visiting hospice nurse. Sally and her husband's descriptions of how they had been treated at various state hospitals suggest that if she had been seen while a patient in one of these rather than at the Hospice IPU, the question of dignity may well have been more prominent. Instead, seemed to have made herself at home as is encouraged, and was eating some plums that she had picked from the garden.

5.3 No apparent gender differences

While it is acknowledged that this was a very small sample with only six respondents, four men and two women, no real gender differences were apparent in the experiences or expectations about death of the men and women terminally ill participants. The nature of the cancers that initially developed in Sally and Moira, specifically breast and ovarian cancer, might have been expected to trigger comment on the surgical removal of these parts of the body, but this did not take place. It is possible that the loss of femininity and womanhood associated with these areas, which is so prominent in the literature on breast and ovarian or cervical cancer survivors (Bliss & Johnson, 1995; Loh, 2004; Lupton, 1994; Rafferty, 1995), pales into insignificance compared to the loss of life itself.

Moreover, both women were in their fifth year of battling cancer and their surgery was at the beginning of the process, so time may have healed those wounds.

If gender stereotypes are considered it might have been expected that grief and anxiety around losing children would be more profound with women participants while concerns about the family's future income would be more prominent with men. However, this was not the case. The loss of relationships was as prominent a theme for men as for women. All four men expressed real sadness and regret at the loss of their children and in particular leaving their sons. Frequently, the loss of a future was expressed in terms of not being able to do things with children. James mourned: "One of the things I wanted to do with him is obviously to get him educated. That's top priority. And then I wanted to tour around a little bit with him. Go and actually see the university of life." Moira felt sad she would not see whom her sons would marry and what they would do with their lives. Stephen spoke specifically about shifting from being concerned about being a provider and money earner to focusing on people; however, so did Moira who emphasised her satisfaction at being able to leave a house for her children.

6. Findings in relation to the sample

As is typical with a small, qualitative study, it is acknowledged that the specific sample of participants targeted in this research has had an influence on the findings. While the respondents' age was the most significant variable that was explored in this study, it is also considered worth evaluating which findings may be particularly associated with other demographics, specifically class and culture. In addition the effect of the type of illness, in other words cancer itself rather than another illness with a potentially terminal outcome, needs to be considered. These factors might produce significantly different findings if a similar study on terminally ill AIDS patients in South Africa was conducted.

6.1 Influence of the demography of the sample: questions of age, class and culture

6.1.1 Age

There seems little doubt that the interviewees' ages, which ranged from thirty-seven to fifty-two years old, exacerbated the challenges raised by suddenly developing a life-threatening illness, undergoing invasive and challenging treatment, and discovering that, nonetheless, they were terminally ill. This trauma triggered chaos in lives that were for the most part established and successful,

interrupting marital, parenting and career roles. The existence of dependents seems to have intensified the struggle to live by trying various forms of treatment, for example Stephen thought a treatment with a five percent chance of success was worth trying, despite how much suffering it produced. The sense of leaving spouses and children to manage alone made the attempt to impose order through careful attention to planning for family survival after the death of the patient more important.

It is unlikely, for example, that elderly participants would have an active business to hand over (as Gavin did), dependent children (as Stephen, Sally, Gavin and James did) or an elderly mother to consider (as Keith did). Older participants may also have had less of a sense of leaving their lives "unfinished" and experienced less distress at the disruption of a "natural order". On the other hand, if terminally ill participants in their late teens or twenties had been interviewed, they are equally unlikely to have had dependents to worry about. However, as an even younger group, they may have expressed more rage at the things they had not been able to do in their lives, including relationships and careers, for example, and may not have been able to say as Gavin did, "I have been lucky in my life". Without being able to leave either children or accomplishments (such as a business) behind them, they might have significant concerns about being forgotten without a trace.

6.1.2 Class

One of the clearest contributions of the choice of middle class subjects in the sample was the absence of real financial concerns. Only two people in the sample had difficulties with money, but even for Sally and Keith, their situation was not desperate and both were receiving financial help from family members. Five out of six respondents were on medical aid and thus had access to private health care, including specialists and second opinions if they wanted them. While access to Hospice is not restricted to those with money and Hospice does offer free treatment, there are very few Hospices, specifically two in the greater Johannesburg area and one in Soweto. However, it is likely that knowledge of this sort of service may be limited to those who have access to information and resources.

Furthermore, most respondents seemed to have financial assets like a house and/or life insurance that would help support their families after their deaths. Thus although Sally was anxious about the future of her six year-old son, as any mother

would be particularly given her husband's unstable work situation, there were close family members who could afford to raise him. As a result, she was able to say 'bless my father" and feel grateful that he would be paying for her child's school fees and uniform the following year so she did not need to worry about that. It is worth noting that Moira was very aware of the relative privilege of her situation:

> I'm not the only one that's dying. I'm not the only one that's in a bad place. And I'm probably in a better place than millions others who're lying in a tin shack with nobody around them, not even a painkiller. And so I try to appreciate things.

It is likely that if the situations of AIDS patients in mid-life with dependents were explored many of these may be working class or even unemployed. A shortage of money is likely to have a negative impact on treatment, with difficulty in accessing good health care, and even more limited access to treatment, for example anti-retrovirals (ARV's). Thus people whose lives could be extended may not receive the medication they need and the knowledge of dying unnecessarily is likely to increase suffering and make finding meaning in dying in mid-life even harder. Being ill may mean time off work for breadwinners and even losing an income, so that the family may be struggling financially long before the patient dies. While such a family may have a burial policy to pay for the funeral, they are unlikely to have other financial assets like funds for children's education. As a result, for an adult who is dying, the sadness at leaving one's children may be compounded by a real dilemma about who could afford to take care of them and understandable distress at leaving them in a potentially unsafe situation.

6.1.3 Culture

Attitudes towards death and dying are socially and culturally related so this is likely to play a significant role in an exploration of untimely death (Irish, Lundquist & Nelson, 1993). Meanings associated with this among black South Africans may include interpretations of illness caused by supernatural forces or the evil wishes of those who wish to harm the participant. This is a complex area that would involve in-depth preparatory reading and investigation.

6.2 Influence of the particular illness

The nature of the specific illness is likely to have a direct influence on how participants understand their illness and its causes. As Susan Sontag (1977, p.3) commented: "It is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped."

This study featured cancer patients and there is a strong association between cancer and a painful death. Gavin and Sally in particular spoke of the physical pain they were feeling and several respondents spoke of their fear of dying in pain. It is unclear whether the significant fear of dying found in this study would be less prominent in research featuring participants with other illnesses that are not associated with pain in this way.

Additional meanings associated with the illness in the literature, for example cancer's disturbing reminder of "unpredictability, uncertainty and injustice" (Kleinman, 1988, p.20), were apparent. While a number of participants, for example Stephen, Gavin and James, expressed their frustration at the lack of knowledge of why cancer develops in one individual rather than another, it was clear that all patients saw stress or their own emotions as playing a part in their development of cancer; however only one patient, Keith, overtly blamed himself and his lifestyle.

The link between cancer and the poor handling of stress and emotion is the dominant discourse at present in attributions of the cause of cancer (Guex, 1994; Lupton, 1998). Even Stephen, who saw his illness as being as random as being hit by a taxi, considered stress a possible influencing factor. It is possible that the primacy of individualism and the associated need for a sense of control in modern Western culture (Lawton, 2000) makes the idea of being subject to complete chance an anathema. However, it is noted that there is not yet any evidence linking stress and cancer: "whether psychological variables can directly contribute to cancer causation remains unclear" (Barraclough, 1999, p.vi). In her discussion of the high correlation between each era's complaints and the suggested origins of cancer, Susan Sontag concluded: "Theories that diseases are caused by mental states and can be cured by will power are always an index of how much is not understood about the physical terrain of a disease." (1977, p.55)

While there may be some reticence in disclosing being diagnosed with cancer, it is likely that most friends and family would be supportive. Several participants, for example James, mentioned their hurt that some people had not contacted them; however, this may be part of the discomfort associated with death and dying rather than cancer itself. Certainly, no one spoke of being frightened to admit to having cancer or of being ostracised for having it.

However, it is acknowledged that in a similar study of terminally ill AIDS patients a major role would be played by the meanings associated with this disease. Some of these may involve cultural beliefs around witchcraft and the blaming of others for using bewitchment to cause the illness. While most middle-class cancer patients have some understanding of the *how* of cancer (in terms of uncontrolled cell mutation causing tumour growth and the use of cytotoxic drugs like chemotherapy to try and kill cancer cells) the *why me* is unclear. This situation may be reversed in patients with AIDS. For example, participants' understanding of the development of the HIV-virus into AIDS and how antiretroviral treatment works, which are very complex processes, may be unclear or even distorted. Unfortunately, understanding of these processes is essential for managing the disease and avoiding further infection. However, *if* the link between HIV and transmission through unprotected sex is accepted, there is likely to be much less doubt about "why me". Instead there may be significant guilt over how the virus was contracted, or rage at the person who passed on the infection.

Participants are likely to be very fearful of disclosure of their HIV-AIDS status as they may be punished or even killed as a result. There may be a number of consequences of this fear including a reduction in open awareness of the illness and its terminal outcome and thus less communication, considered one of the key aspects of a good death. Furthermore, in an atmosphere of mutual pretence that a person is not seriously ill, practical preparation for dying in terms of making a will and other financial arrangements may also not take place. A sense of completion is likely to be harder to achieve and social support may be lacking; in fact social death may take place sooner as ill people who are suspected of having HIV-AIDS may be ostracised by the community and even family members.

However, notwithstanding these differences, it seems likely that most people, whatever their age, class, culture or illness, would consider knowledge of their impending death difficult. As Gavin said: "I'd much rather have driven into a bus by mistake, [or] had a heart attack out of the blue. Knowing you're going to die is 'poofie', not nice!"

7. Reflections on the research process

Two key aspects of the research process, specifically the credibility of the key findings described in part one of this chapter, and the influence of the researcher's personal experience, will now be discussed.

7.1 Credibility of the findings

Gubrium and Holstein (1999) commented that the crisis engendered by post-modernist self-consciousness may undermine any sense that a research report is authoritative or authentic. Instead they emphasised the need for a healthy scepticism in qualitative research, an appreciation for the researcher's subjectivity, a tolerance for complexity, a focus on process and an awareness of variety and detail. They concluded that "everyday life is not straightforwardly describable" (Gubrium & Holstein, 1999, p.131), hence the importance of "thick description" (Geertz, 1973, cited in Wolcott, 1994).

In order to "represent the participants in their own terms" (Patton, 1999, p.158) numerous quotes from the subjects have been included. The only person who knows whether his or her experience has been authentically portrayed is of course the participant, thus one recognised form of validation is to check findings with the subjects themselves (Gubrium & Holstein, 1999). Unfortunately, the nature of this study meant this was not possible; one subject, James, died three days after being interviewed and at the time of writing, no participants were still alive. A second form of validation develops out of reaching a point of "saturation" and a sense that the material has been thoroughly explored (Kelly, 2002, p.422). However Spence (1983, as cited in Kelly, 2002) emphasised the need for critical reflection on the process to ensure that the conclusion has not been reached prematurely or the researcher seduced by the desire for an orderly narrative. This concern may be particularly relevant in this study as a key theme was the participants' need for order in a situation of chaos. Furthermore, the distressing nature of the material may also provide unconscious pressure for a "neat and tidy" conclusion.

Interviews are dynamic meaning-making interactions, thus different occasions are likely to produce different results and answers given are not replicable (Holstein & Gubrium, 1999). Emphasising that the researcher is the instrument and that this may result in changes from tiredness or increasing experience, Patton quoted Guba and Lincoln (1981): "But this loss in rigor is more than offset by the flexibility of insight, and ability to build on tacit knowledge that is the peculiar provenance of

the human instrument" (cited in Patton, 1999, p.143). As a result of the co-creation of the interview data with the participant as well as the subjectivity of the researcher in identifying themes, the validity of the findings will be explored in the following discussion of the researcher's personal experience, while bearing in mind Woolcott's (1994) assertion that there may not be a single correct interpretation of data but simply an attempt to increase understanding by making experience more intelligible.

7.2 Influence of personal experience

A number of researchers have emphasised the need for critical self-reflection in ethically responsible research (Aranda, 1995; Kelly, 2002; Seymour & Ingleton, 2005). This may be particularly relevant in the field of death and dying:

> To look at death with relative clarity, it is necessary to abandon the value biases that ordinarily color our outlook on life, but death is laden with powerful feelings of dread. Around it swirl not simply emotions but some of our most important values. (Kamerman, 1989, p.137)

The "swirling" of emotions and values was compounded for this researcher by my own life-threatening illness six years previously. This personal experience of being diagnosed with cancer, followed by surgery, chemotherapy and radiation treatment, necessarily informed the research process. Despite preparation for revisiting this experience I am aware that the research process was coloured by it in the following ways.

Firstly, some of the questions asked were determined by the researcher's personal dilemmas related to the illness rather than being directly related to the subject of a good death. An example of this is my interest in attributions of the cause of the cancer, which did not seem to be a particular concern of the interviewees, or perhaps was no longer a concern now that their illness had progressed so far. At other times the respondent's dilemmas, for example Sally's preoccupation with her spiritual issues rather than the topic of a good death, dominated the interview.

In addition to the interviewer role being influenced by personal experience I sometimes drifted into the role of counsellor with a desire to help, in an overlap with my training as a Clinical Psychologist. For example I told Keith that he was not responsible for his wife's death. He in particular seemed in need of reassurance and attempted to elicit my advice on his next steps, in contrast to the

active eliciting of personal information that took place from Moira. I recommended to his Hospice nurse that he be allocated a counsellor.

Thirdly, as Lemma and Levy (2004) noted, survival of a trauma always includes triumph at this survival and may be followed by guilt. In the process of getting to know each participant I sometimes experienced survivor guilt that was heightened by meeting distressed family members. These contacts triggered intense and painful reflection on the nature of survival and why some survive a life-threatening illness like cancer and others do not, particularly as this at times appears arbitrary. In this sense I entered into the "uncertain, fearful world of pain and disability" as recommended by Kleinman (1988, p.xiv) to increase understanding of this world.

Although it is recognised that being part of this "fearful world" has resulted in a less neutral process than might have taken place with a different interviewer, the results of my own illness experience may not be entirely negative. Some background experience rather than second-hand knowledge of being diagnosed with cancer may have facilitated compassionate listening. Furthermore, for researchers following a feminist tradition as articulated by Marjorie DeVault (1999, p.98), "analysis does not end, but rather begins with the recognising of their [the researcher's] own emotion" as this may facilitate insight.

Fourthly, personal disclosure about my cancer experience took place in two interviews, the first and last. At the end of his interview, Stephen asked about my interest in death and dying. Although a response about working as a counsellor at Hospice would have sufficed, I spoke of my illness. Subsequent personal reflection revealed a sense of guilt and the wish for some form of forgiveness for surviving when he would not. Generous good wishes for my ongoing health were received from Stephen. In the second case, the disclosure occurred relatively early in the interview with Moira: the trigger was again an emotional reaction, this time to Moira's description of "loving" chemotherapy. This was very different to my experience of chemotherapy and I felt angry at her assumption that it was an easy experience for everyone. Perhaps because the disclosure was made in this context, it seemed to trigger feelings of envy in Moira. For example, she asked how frequently I had check-ups and explained how she had progressed from being clear of cancer to having it "everywhere" between one check-up and the next. However, both these instances of personal disclosure were clear departures from a neutral interviewer role, and in the latter case I failed to be non-judgemental.

Further contribution to an understanding of personal disclosure was made by Song and Parker (1999, p.114) who explored the implications of occupying “an insider or outsider position” as a researcher; this seems to capture some of my fluctuating emotional experience as an interviewer. Mira Song referred to a “persistent tension between feelings of commonality and of difference” between herself and interviewees and how these perceptions and “positionings” shifted as information was shared (Song & Parker, 1999, p.120). These authors quoted Ribbens (1989) who considered that the advantages and disadvantages of the interviewer openly sharing him- or her-self had not been fully explored.

In general, participants tended to be relatively unconcerned with the next steps in the research; this may be part of a process of social withdrawal. In contrast, I continued to feel a sense of connection to interviewees and wanted to know their progress. Several participants died shortly after the interview (for example James, who died four days later) and I felt shocked and a sense of loss. I felt sad when I heard that Keith needed to have all his teeth removed, as they had turned black after the radiation treatment. In this regard Beaver et al. (1999, p.15) noted that interviews with terminally ill patients were “emotionally draining” and that researchers were likely to need debriefing.

CHAPTER SIX
CONCLUSION

This qualitative study set out to explore the idea of a good death through in-depth interviews with six terminally ill cancer patients aged between thirty-seven and fifty-two, in other words in mid-life. This age-range was selected because it was believed to be under-researched and people in this group have significant attachments to life in terms of responsibilities to children and aging parents, career commitments and plans for the future. As a result it was considered likely that particular challenges of death and dying might be revealed with concomitant highlighting of the idea of a good death. Thematic content analysis was used to examine overt and covert themes revealed in semi-structured interviews that had been transcribed verbatim.

1.1 Key findings

Although respondents did not seem to have a conscious idea of a good *death*, they had a clear concept of good *dying.* Two key components of good dying were not being in pain or distress from physical symptoms, and wanting to drift off into a final "sleep" rather than being fully alert until the end. Some participants had further specifications, for example being at home or having loved ones with them; however, others specified they would rather be alone so that watching their death did not distress others. These differences affirm the position of some theorists that good dying is as unique an experience as good living and that each individual's needs may be distinctive. It is noted that an open awareness of the patient's terminal prognosis is necessary for any exploration of the patient's wishes in this regard. However, it was also observed that, once they knew the expected outcome of their illness, patients had different levels of tolerance for medical information: for some respondents, knowledge was helpful while others preferred not to know the details of their illness.

Discussion of their requirements for good dying with nursing staff appeared to help respondents deal to some extent with their strong fear of the dying process. It was noticeable that, whether or not patients had religious convictions, relatively little attention appeared to be paid directly to a broader concept of death, including what might or might not follow the moment of death, for example an afterlife. However,

religious beliefs seemed to facilitate coping and contribute to a supportive sense of hopefulness while not necessarily reducing fear of the dying process.

Preparation for good dying included creating a sense of order by completing a will, sorting out financial affairs and, for some patients, planning a funeral. At times this preparation also included trying to mend conflicted relationships and make plans for the ongoing care of family members. It is postulated that the satisfaction expressed by participants after the achievement of these preparations had three sources: firstly taking care of practical needs re-established a sense of agency and an ability to act that had been eroded by the helplessness of not being able to stop the progress of the illness; secondly, it helped achieve some sense of closure for each individual which is particularly important for those dying in mid-life whose plans have been truncated; and thirdly, the symbolism of planning to hand over aspects of life to which the participant was particularly attached (for example a child, a business or even a boat) suggested a measure of acceptance of their dying status.

Respondents did not seem to experience external pressure from others to die in a certain way. Although one patient narrated what she had been told about the dying process by a social worker, this seemed comforting for her rather than setting up an expectation that she would or should conform to some particular standard.

However, two participants felt internally pressured by their perception of the way their mood affected family members and thus believed they needed to be brave and pretend to feel better than they actually were. A third participant experienced significant distress as a result of the dissonance between her belief that, if her faith was strong enough, God would heal her and the relentless progression of her disease. Beyond these examples, participants did not seem to experience pressure to “die well” or conform to the “performance” expectations of others such as doctors, social workers or religious advisors; their concern was rather to avoid distressing family members or friends.

1.2 Limitations of the study

This was a small study and the findings, based on interviews with just six patients, can in no way be generalised to a broader population. The sample was limited to white, broadly middle-class cancer patients, and the implications of this were explored in the Discussion chapter and will be mentioned in the section on further

research that follows. Furthermore, Hospice staff mediated the selection of patients and, because this screening had to be ethically appropriate, only patients who had in some sense come to terms with their terminal status were referred. As a result, the thoughts and feelings of terminally ill patients who were in serious denial or whose level of distress at their circumstances was extreme were not included; in addition, these patients are unlikely to have agreed to be interviewed.

While participants were remarkably open with the interviewer considering this was a first meeting, it is possible that a longitudinal study with a series of interviews over a week or two, if participants were willing to do so and felt well enough, may have resulted in more trusting relationships that allowed deeper exploration of anxieties and fears.

It seems likely that the researcher's personal experience of cancer influenced the study, as discussed in some detail in the methodology section. The resulting increased empathy for participants may have been beneficial, but the interviewer's emotional responses to patients and to the topic of death and dying certainly played a role in questions asked and avoided, and made it likely that this personal experience became a filter for the results. Thus alternative readings of the interviews may identify themes that were not highlighted here, or may give those themes that were selected a different interpretation.

1.3 Recommendations

This study was not aimed at providing recommendations for counselling practice. However, at a feedback session to doctors, nurses and social workers of both the Houghton Hospice in Johannesburg and the Mofolo Clinic Hospice in Soweto, the question of implications of the study came to the fore. During this discussion, the impact of receiving bad news as a patient received particular attention.

The way in which participants in this study spoke of having been given their cancer diagnosis and/or terminal prognosis suggested that hearing this news was a significant trauma that might have been lessened if handled differently. The amount of time patients spent describing these events, their detailed recall of exact words used, the heightened affect still attached to these memories and ongoing difficulties like sleeplessness and agitation, implied that for many patients this initial trauma had not yet been fully processed. It is suggested that trauma debriefing of these events might help patients absorb the news of the threat to their lives, which

in most cases seemed to have come as a complete shock following relatively innocuous symptoms. It is possible that this debriefing, including exploring the meanings attached to the bad news and ways in which perceptions of the world had changed for the patient, may help contain distress, at least initially.

Moreover, in accord with recent research, the way doctors communicate with patients and in particular the process of breaking of bad news seems to be an area in which further training of medical students may be helpful. While it is acknowledged that such news will always be unwelcome, these studies indicate that there appear to be ways of lessening the extent of the shock and providing some containment of the resulting distress.

1.4 Further research

A potentially promising area for ongoing research in South Africa involves the experience of terminally ill AIDS patients, many of whom are dying in early adulthood and mid-life. The meanings attached to this illness, and the complex issues around disclosure of HIV-status, are likely to produce significantly different results from those this study yielded, particularly in terms of open awareness of illness status and social death resulting in isolation prior to actual death.

In addition, the end stages of AIDS involve a wide range of opportunistic illnesses that are likely to produce considerable variation in the experience of the terminal phase of the illness. These infections may be treated allowing the AIDS patient to rally; thus the steady and relatively predictable dying trajectory of the cancer patient is somewhat different to the up-and-down process likely with an AIDS patient. These are distinct physical differences but it is postulated that the experience may not be wholly different on a spiritual or psychological level, depending on the individual's belief system.

Given that the majority of these patients in South Africa are black, cultural implications of illness and death will also play a role and are likely to be different to these implications among the white middle class participants of the study. Furthermore, a significant number of dying AIDS patients in this country are likely to be working class or unemployed and thus experience considerable financial challenges during their illness. Limited access to good health care, let alone specialist palliative care, will also affect the level of suffering of patients. The ways in which factors such as a different illness, culture and socio-economic status might

impact on the idea of a good death were briefly considered in the Discussion in the previous chapter.

1.5 Final thoughts

This was a challenging topic for me, particularly in the light of my own cancer history. The concept of this research was to some extent a personal quest for reassurance that a good death is possible even if one lives a truncated life. From this point of view, the findings present a mixed picture. While the interviews with terminally ill people were challenging from the point of view of sitting with their fear and distress which at times echoed with my own, it was reassuring to see that, one way or another, people found ways to manage their situation. Moreover, as discussed above, some indicators for a good death or in particular, a good dying process, were articulated.

However, it is clear that, as in much of life, there are no guarantees in dying. Given the difficulties of managing some symptoms, good dying remains an ideal rather than a given; numerous factors including individual personality and coping skills, the development of a particular cancer with its own distressing physical features, access to palliative care, level of social support and ability to access hope and spiritual succour, among others, may affect the outcome.

> And of course that's the problem for all of us who work with the dying and those who love them. We dare to go into a far country that borders on heaven and hell and learn a thousand different ways of saying 'I don't know' and learn to live with fewer answers but hopefully more than an empty silence. (Lunn, 1990, p.85)

However, it is hoped that the lack of a definitive conclusion in this research means that individual points of view were voiced and the trap of glibness was avoided, as stated by one dying patient: "Being invisible I invite only generalisations" (Rosenthal, 1973, p.39, as quoted in Corr et al., 1994, p.115).

Furthermore death itself remains, as perhaps it should, a great mystery, but one that has the potential, if accepted as an irrefutable part of human existence, to increase both joy and purpose in life. As Koestler observed:

> Take the word 'death' out of your vocabulary and the great works of literature become meaningless; take that awareness away and the cathedrals collapse, the pyramids vanish into the sand, the great organs become silent. (quoted by Welman, 1995, p.1)

It is possible that as death is reintegrated into Western life and we in South Africa can address the stigma currently attached to HIV-AIDS and thus reduce the horror of ostracism, levels of fear of dying may decline and, as Jung proposed, we may be able to conceive of death as "a goal and a fulfilment" whatever age we are when we die (cited in Welman, 1995, p.36). However this ideal is hard to imagine for those who die young. Hopefully, being less fearful will help us remember that the dying are still living human beings and that dying "can hold the same complexity and richness as all the other aspects of living" (Corr et al., 1994, p.102). However, in a modern Western culture that values perfect, healthy bodies and associates illness with failure (Crawford, 1994, as quoted in Lawton, 2000) it is highly unlikely that all fear of dying will cease, and the attitude Woody Allen so perfectly if lightly verbalised is likely to prevail (as quoted in Leming & Dickenson, 1998, p.187):

> I'm not afraid of dying. I just don't want to be there when it happens.

References

Adelbratt, S. and Strang, P. (2000). Death anxiety in brain tumour patients and their spouses. Palliative Medicine, Vol.14, pp.499-507.

Albom, M. (1997). Tuesdays with Morrie. London: Warner Books.

Allison, P.J., Locker, D. and Feine, J.S. (1997). Quality of life: a dynamic construct. Social Science and Medicine, Vol.45, No.2, pp.221-230.

Aranda, S. (1995). Conducting research with the dying: ethical considerations and experience. International Journal of Palliative Nursing, Vol.1, No.1. pp.41-47.

Arber, A and Gallagher, A. (2003). Breaking bad news revisited: the push for a negotiated disclosure and changing practice implications. International Journal of Palliative Nursing, Vol.9, No.4. pp.166-172.

Ariès, P. (1974). Western attitudes toward death from the Middle Ages to the present. Baltimore: The Johns Hopkins University Press.

Ariès, P. (1981 (1977)). The hour of our death. Middlesex, UK: Penguin Books.

Arora, N.K. (2003). Interacting with cancer patients: the significance of physicians' communication behaviour. Social Science and Medicine, Vol.57, pp.791-806.

Barnett, M. (2001). Interviewing terminally ill people: is it fair to take their time? Palliative Medicine, Vol.15, pp.157-158.

Barraclough, J. (1999). Cancer and emotion. A practical guide to psycho-oncology. Third edition. Chichester, UK: John Wiley & Sons.

Barrie, J.M. (1988). Peter Pan. Harmondsworth, UK: Penguin Books Ltd.

Baum, D. and Gallagher, D. (1987). Case studies of psychotherapy with dying persons. Clinical Gerontologist, Vol.7, No.1, pp.41-50.

Beaver, K., Luker, K. and Woods (1999). Conducting research with the terminally ill: challenges and considerations. International Journal of Palliative Nursing, Vol.5, No.1, pp.13-17.

Benzein, E., Norberg, A., Saveman, B.I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. Palliative Medicine, Vol.15, pp.117-126.

Bertman, S.L. (1991). Facing death. Images, insights and interventions. Washington: Hemisphere Publishing Corporation.

Berridge, K. (2001). Vigor mortis. The end of the death taboo. London: Profile Books Limited.

Bliss, J. and Johnson, B. (1995). After diagnosis of cancer: the patient's point of view. International Journal of Palliative Nursing, Vol.1, No.3, pp.126-133.

Block, S.D. (2001). Psychological considerations, growth, and transcendence at the end of life. Journal of the American Medical Association, Vol.285, No.22, pp.2898-2905.

Bowman, T. (1997). Facing loss of dreams: a special kind of grief. International Journal of Palliative Nursing, Vol. 3, No2, pp.76-80.

Boyatzis, R.E. (1998). Transforming qualitative information. Thematic analysis and code development. Thousand Oaks, California: Sage Publications.

Bradbury, M. (2000). The good death? In D. Dickenson, M. Johnson and G. Samson Katz (Eds.) Death, dying and bereavement. pp. 58-61. London: Sage Publications.

Bregman, L. (2001). Review of 'Life Lessons' by Eilsabeth Kubler-Ross and David Kessler. [On-line] Available: http://www.ebsco Downloaded 13 February 2003.

Brown, D.J.F. (1999). The problem of weakness in patients with advanced cancer. International Journal of Palliative Nursing, Vol.5, No.1, pp.6-12.

Buckingham, R.W. (1985) Hospice care in the United States: the process begins. In R.A. Kalish (Ed.) The final transition. Perspectives on death and dying series 5, pp.149-161. Farmingdale, New York: Baywood Publishing Company.

Buckman, R. (1998). Communication in palliative care: a practical guide. In D. Doyle, G.W.C. hanks and N. MacDonald (Eds.) Oxford Textbook of Palliative Medicine. Second Edition. pp. 141-156. Oxford: Oxford University Press.

Caffrey, T.A. (2000). The whisper of death: psychotherapy with a dying Vietnam veteran. American Journal of Psychotherapy, Vol.54, No.4, pp.519-530.

Cameron, D. (2003). Managing terminal restlessness. Continuing Medical Education, Vol.21, No.5, pp.254-257.

Chng, C.L. and Ramsey, M.K. (1985). Volunteers and the care of the terminal patient. In R.A. Kalish (Ed.) The final transition. Perspectives on death and dying series 5, pp.283-291. Farmingdale, New York: Baywood Publishing Company.

Chochinov, H.M., Wilson, K.G., Enns, M., Mowchun, N., Lander, S., Levitt, M and Clinch, J. (1995). Desire for death in the terminally ill. American Journal of Psychiatry, Vo.152, No.8, pp.1185-1191.

Chochinov, H.M., Tataryn, D., Clinch, J. and Dudgeon, D. (1999). Will to live in the terminally ill. The Lancet, Vol.354, pp.816-819.

Chochinov, H.M., Hack, T., McClement, S., Kristjanson, L. and Harlos, M. (2002). Dignity in the terminally ill: a developing empirical model. Social Science and Medicine, Vol.54, pp.433-443.

Collins concise dictionary. (1989). Glasgow: Collins.

Connelly, R. (2003). Living with death: the meaning of acceptance. Journal of Humanistic Psychotherapy, Vol.43, No.1, pp.45-63.

Cornette, K. (2005). For whenever I am weak, I am strong. International Journal of Palliative Nursing, Vol.11, No.3, pp.147-153.

Corr, C.A., Nabe, C.M. and Corr, D.M. (1994). Death and dying. Life and living. Pacific Grove, CA: Brooks/Cole Publishing Company.

Corr, C.A. (1998). Death in modern society. In D. Doyle, G.W.C. Hanks and N. MacDonald (Eds.) Oxford Textbook of Palliative Medicine. Second Edition. pp. 31-40. Oxford: Oxford University Press.

Corr, C.A., Nabe, C.M. and Corr, D.M. (2003). Death and dying. Life and living. 4th Edition. Belmont, California: Thomson Wadsworth.

Costello, J. (1999). Anticipatory grief: coping with the impending death of a partner. International Journal of Palliative Nursing, Vol.5, No.5. pp.223-231.

Costello, J. (2000). Truth telling and the dying patient: a conspiracy of silence? International Journal of Palliative Nursing, Vol.6, No.8, pp.398-405.

Currer, C. (2001). Responding to grief: Dying, bereavement and social care. Basingstoke: Palgrave.

Davis, C.G., Nolen-Hoeksema, S. and Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. Journal of Personality and Social Psychology, Vol.75, No.2, pp.561-574.

Davy, J. and Ellis, S. (2000). Counselling skills in palliative care. Buckingham: Open University Press.

Dein, S. and Thomas, K. (2002). To tell or not to tell. European Journal of Palliative Care, Vol. 9, No.5, pp.209-212.

DeSpelder, L.A. and Strickland, A.L. (2002). The last dance. Encountering death and dying. 6th Edition. Boston: McGraw-Hill.

DeVault, M.L. (1999). Talking and listening from women's standpoint: feminist strategies for interviewing and analysis. In A. Bryman and R. Burgess (Eds.) Qualitative Research IV. pp.86-107. London: Sage Publications.

Dexter, C. (1999). The remorseful day. London: Pan Books (MacMillan Publishers Ltd.)

Dickenson, D., Johnson, M. and Katz, J.S. (Eds.) (2000). Death, dying and bereavement. London: Sage Publications.

Dowling Singh, K. (2000). Spiritual 'signs and symptoms': toward an expanded understanding of dying. American Journal of Hospice and Palliative Care, Vol.17, No.4, pp.269-271.

Edwards, P. (2005). An overview of the end-of-life discussion. International Journal of Palliative Nursing, Vol.11, No.1, pp.21-27.

Eisenberg, D. (2005). Lessons of the Schiavo battle. What the bitter fight over a woman's right to live or die tells us about politics, religion, the courts and life itself. Time, April 4 2005, pp.20-28.

Elias, N. (1985). The loneliness of the dying. Oxford: Blackwell Publishers.

Emanuel, E.J. and Emanuel, L.L. (1998). The promise of a good death. The Lancet, Vol.351 (suppl.II), pp.21-29.

Enes, S.P.D. (2003). An exploration of dignity in palliative care. Palliative Medicine, Vol.17, pp.263-269.

Engle, D. (2001). Introduction: psychological treatment of the patient with chronic disease. Journal of Clinical Psychology, Vol.67, No.4, pp.429-431.

Enright, D.J. (Ed.) (1980). The Oxford book of contemporary verse. 1945-1980. Oxford: Oxford University Press.

Evans, B.D. (1995). The experiences and needs of patients attending a cancer support group. International Journal of Palliative Nursing, Vol.1, No.4. pp.189-194.

Fallowfield, L.J., Jenkins, V.A. and Beveridge, H.A. (2002). Truth may hurt but deceit hurts more: communication in palliative care. Palliative Medicine, Vol.16, pp.297-303.

Feigenberg, L. and Schneidman, E.S. (1985). Clinical thanatology and psychotherapy: some reflections on caring for the dying person. In R.A.

Kalish (Ed.) The final transition. Perspectives on death and dying series 5. pp.241-247. Farmingdale, New York: Baywood Publishing Company.

Ferrell, B.R. (1998). The family. In D. Doyle, G.W.C. Hanks and N. MacDonald (Eds.) Oxford Textbook of Palliative Medicine. Second Edition. pp. 909-917. Oxford: Oxford University Press.

Field, D. and Addington-Hall (2000). Extending palliative care to all. In D. Dickenson, M. Johnson, and J.S. Katz (Eds.) Death, dying and bereavement. pp.91-106. London: Sage Publications.

Freud, S. (1984 (1920)). Beyond the pleasure principle. In A. Richards and A. Dickson (Eds.) The Penguin Freud Library Volume 11. On Metapsychology: The theory of psychoanalysis. pp.269-338. London: Penguin Books.

Freud, S. (1984 (1920)). The ego and the id. In A. Richards and A. Dickson (Eds.) The Penguin Freud Library Volume 11. On Metapsychology: The theory of psychoanalysis. pp.339-407. London: Penguin Books.

Frankl, V.E. (1985 (1959)). Man's search for meaning. New York: Washington Square Press.

Froggart, K.A., Field, D., Bailey, C. and Krishnasamy, M. (2003). Qualitative research in palliative care 1990-1999: a descriptive review. International Journal of Palliative Nursing, Vol.9, No.3, pp.98-104.

Garland, C. (2004). Traumatic events and their impact on symbolic functioning. In S. Levy and A. Lemma (Eds.) The perversion of loss. Psychoanalytic perspectives on trauma. pp.37-49. London: Whurr Publishers Ltd.

Gertz, C. (1999). Thick description: towards an interpretive theory of culture. In A. Bryman and R. Burgess (Eds.) Qualitative Research III. pp.346-368. London: Sage Publications.

Goedhals, L. (1998). Common Cancers. Part II. Cancer of the cervix, oesophagus and bowel. Continuing Medical Education, Vol.16, No.5, pp.405-412.

Greenspan, M. (2003). Healing through the dark emotions. The wisdom of grief, fear and despair. Boston: Shambhala Publications Inc.

Greenstein, M. and Breitbart, W. (2000). Cancer and the experience of meaning: a group psychotherapy program for people with cancer. American Journal of Psychotherapy, Vol. 54, No.4. pp.486-500.

Greenstein, M. (2000). The house that's on fire: meaning-centred psychotherapy pilot groups for cancer patients. American Journal of Psychotherapy, Vol. 54, No.4, pp.501-518.

Grbich, C. (1999). Qualitative research in health. An introduction. London: Sage Publications.

Gubrium, J.F. and Holstein, J.A. (1999). Method talk. In A. Bryman and R. Burgess (Eds.) Qualitative Research I. pp.125-133. London: Sage Publications.

Guex P. (1994 (1989)). An introduction to psycho-oncology. London: Routledge.

Haberecht, J. and Prior, D. (1997). Spiritual chaos: an alternative conceptualisation of grief. International Journal of Palliative Nursing, Vol.3, No.4, pp.209-213.

Herman, J. (1992). Trauma and recovery. New York: Basic Books.

Higginson, I., Wade, A. and McCarthy, M. (1990). Palliative care: views of patients and their families. British Medical Journal, Vol.301, pp.277-281.

Hirai, K., Morita, T. and Kashiwagi, T. (2003). Professionally perceived effectiveness of psychosocial interventions for existential suffering of terminally ill cancer patients. Palliative Medicine, Vol.17, pp.688-694.

Holstein, J.A. and Gubrium, J.F. (1999). Active interviewing. In A. Bryman and R. Burgess (Eds.) Qualitative Research II. pp.104-121. London: Sage Publications.

Hopper, A. (2000). Meeting the spiritual needs of patients through holistic practice. European Journal of Palliative Care, Vol.7, No.2, pp.60-62.

Hulsey, T.L. and Frost, C.J. (1995). Psychoanalytic psychotherapy and the tragic sense of life and death. Bulletin of the Menninger Clinic, Vol.59, No.2, pp.145-159.

Irish, P.P., Lundquist, K.F. and Nelsen, V.J. (1993). Ethnic variations in dying, death, and grief: diversity in universality. Washington: Taylor and Francis.

Johnston, G. and Abraham, C. (2000). Managing awareness: negotiating and coping with a terminal prognosis. International Journal of Palliative Nursing, Vol.6, No.10, pp.485-494.

Kabel, A. and Roberts, D. (2003). Professionals' perceptions of maintaining personhood in hospice care. International Journal of Palliative Nursing, Vol.9, No.7, pp.283-289.

Kalish, R.A. (Ed.) (1980a). Caring relationships: the dying and the bereaved. Perspectives on death and dying series 2. Farmingdale, New York: Baywood Publishing Company.

Kalish, R.A. (Ed.) (1980b). Death, dying and transcending. Perspectives in death and dying 3. Farmingdale, New York: Baywood Publishing Company.

Kalish, R.A. (1985). Coping with death. In R.A. Kalish (Ed.) The final transition. Perspectives on death and dying series 5. pp.11-23. Farmingdale, New York: Baywood Publishing Company.

Kamerman, J.B. (1988). Death in the midst of life: Social and cultural influences on death, grief and mourning. Englewood Cliffs, New Jersey: Prentice Hall.

Keeley, P. (2001). Now and at the hour of our death. The *ars moriendi* and modern dying. European Journal of Palliative Care, Vol.8, No.5, pp.208-211.

Kellehear, A. (2000). Spirituality and palliative care: a model of needs. Palliative Medicine, 14, pp.149-155.

Kelly, B., Burnett, P., Pelusi, D., Badger, S., Varghese, F. and Robertson, M. (2002). Terminally ill cancer patients' wish to hasten death. Palliative Medicine, Vol.16, pp.339-345.

Kelly, B., Burnett, P., Pelusi, D., and Badger, S., Varghese, F. and Robertson, M. (2003). Factors associated with the wish to hasten death: a study of patients with terminal illness. Psychological Medicine, Vol.33, pp.75-81.

Kelly, K. (2002). Calling it a day: reaching conclusions in qualitative research. In M. TerreBlanche and K. Durheim (Eds.) Research in practice. Applied methods for the social sciences, pp.421-437. Cape Town: University of Cape Town Press.

Kissane, D.W., McKenzie, M., McKenzie, D.P., Forbes, A., O'Neill, I., Bloch, S. (2003). Psychosocial morbidity associated with patterns of family functioning in palliative care: baseline data from the Family Focused Grief Therapy controlled trial. Palliative Medicine, Vol. 17, pp.527-537.

Kleespies, P.M., Hughes, D.H. and Gallacher, F.P. (2000). Suicide in the medically and terminally ill: psychological and ethical considerations. Journal of Clinical Psychology, Vol.56, No.9, pp.1153-1171.

Kleinman, A. (1988). The illness narratives. Suffering, healing and the human condition. USA: Basic Books, Inc.

Krippendorff, K. (1980). Content analysis. An introduction to its methodology. Volume 5. The Sage CommText Series. Newbury Park, California: Sage Publications.

Kübler-Ross, E. (1969). On death and dying. London: Tavistock Publications.

Kushner, H.S. (2001). Living a life that matters. London: Sidgwick and Jackson.

Lamb, W. (1992). She's come undone. New York: Pocket Books.

Lawton, J. (2000). The dying process. Patients' experiences of palliative care. London: Routledge.

Lazarus, R.S. and Folkman, S. (1991). The concept of coping. In A. Monat and R.S. Lazarus (Eds.) Stress and coping. An anthology. 3rd ed. pp.189-206. New York: Columbia University Press.

Leichtentritt, R.D. and Rettig, K.D. (2001). In search of a good death. Journal of Aging Studies, Vol.15, pp.85-103.

Leming, M.R. and Dickenson, G.E. (1998). Understanding dying, death and bereavement. Fort Worth: Harcourt Brace.

Lemma, A. and Levy, S. (2004). Introduction. In S. Levy and A. Lemma (Eds.) The perversion of loss. Psychoanalytic perspectives on trauma. pp. xv–xviii. London: Whurr Publishers Ltd.

Lemma, A. (2004). On hope's tightrope: reflections on the capacity for hope. In S. Levy and A. Lemma (Eds.) The perversion of loss. Psychoanalytic perspectives on trauma. pp.108-126. London: Whurr Publishers Ltd.

Levine, S. (1984). Meetings at the edge. Dialogues with the grieving and the dying, the healing and the healed. Bath, UK: Gateway Books.

Levine, S. (1986). Who dies? An investigation of conscious living and conscious dying. Dublin, UK: Gateway Books.

Levine, S. (1987). Healing into life and death. Bath, UK: Gateway Books.

Levy, S. and Lemma, A. (2004). The impact of trauma on the psyche: internal and external processes. In S. Levy and A. Lemma (Eds.) The perversion of loss. Psychoanalytic perspectives on trauma. pp.1-20. London: Whurr Publishers Ltd.

Levy, S. and Young, L. (2004). Difficulties with potency post-trauma. In S. Levy and A. Lemma (Eds.) The perversion of loss. Psychoanalytic perspectives on trauma. pp.127-144. London: Whurr Publishers Ltd.

Lloyd-Williams, M. (2002). Diagnosis and treatment of depression in palliative care. European Journal of Palliative Care, Vol.9, No.5, pp.186-188.

Lobchuk, M.M. and Vorauer, J.D. (2003). Family caregiver perspective-taking and accuracy in estimating cancer patient symptom experiences. Social Science and Medicine, Vol.57, pp.2379-2384.

Loh, K.Y. (2004). Spiritual distress in a terminally ill patient with breast cancer. International Journal of Palliative Nursing, Vol.10, No.3. pp.131-132.

Lunghi, M. (2004). Playing the endgame: reflections on waiting. International Journal of Palliative Nursing, Vol.10, No.8, pp.374-377.

Lunn, L. (1990). Having no answer. In C. Saunders (Ed.) Hospice and palliative care. pp.85-93. London: Edward Arnold.

Lupton, D. (1994). Femininity, responsibility, and the technological imperative. Discourses on breast cancer in the Australian press. International Journal of Health Services, Vol.24, No.1, pp.89.

MacLeod, R. (2000). Learning to care: a medical perspective. Palliative Medicine, Vol.14, pp.209-216.

Magnet, M. (2002). Suffering and the end of life. European Journal of Palliative Care, Vol.9, No.1, pp.25-28.

Mak, Y. and Elwyn, G. (2003). Use of hermeneutic research in understanding the meaning of desire for euthanasia. Palliative Medicine, Vol.17, pp.395-402.

Marks, M. (2000). Mortality, metaphors and the media. European Journal of Palliative Care, Vol.7, No.6, pp.200.

McClain, C.S., Rosenfeld, B. and Breitbart, W. (2003). Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. The Lancet, Vol. 361, pp.1603-1607.

McCormick, T.R. and Conley, B.J. (1995). Patients' perspectives on dying and on the care of dying patients. Western Journal of Medicine, Vol.163, pp.236-243.

McDougall, J. (1989). Theatres of the body. London: Free Association Books.

McKay, R. (1994a). Tales of the dying. Unisa Psychologia, Vol.21, No.1, pp.51-56.

McKay, R. (1994b). Counselling in the dying scenario. Unisa Psychologia, Vol.21, No.1, pp.54-65.

McKitrick, D. (1985). Counselling dying clients. In R.A. Kalish (Ed.) The final transition. Perspectives on death and dying series 5, pp.217-239. Farmingdale, New York: Baywood Publishing Company.

McPherson, C.J. and Addington-Hall, J.M. (2002). Judging the quality of care at the end of life: can proxies provide reliable information? Social Science and Medicine, Vol.56, pp.95-109.

Miller, E.D. and Harvey, J.H. (2001). The interface of positive psychology with a psychology of loss: A brave new world? American Journal of Psychotherapy, Vol.55, No.3, pp.313-322.

Minerbo, V. (1998). The patient without a couch: an analysis of a patient with terminal cancer. International Journal of Psycho-Analysis, Vol.79, pp.83-93.

Mqoqi, N., Kellett, P., Jula, M. and Sitas, F. (2004). Incidence of histologically diagnosed cancer in South Africa, 1998-1999. National Cancer Registry. Johannesburg: National Health Laboratory Service.

Muller, M. (2000). The role of bereavement counselling in hospice work. European Journal of Palliative Care, Vol.7, No.1, pp.29-32.

Murphy, N.M. (1999). The wisdom of dying. Practices for living. Shaftesbury, UK: Element Books Limited.

Murray, M.A., Miller, T., Fiset, V., O'Connor, A and Jacobsen, M.J. (2004). Decision support: helping patients and families to find a balance at the end of life. International Journal of Palliative Nursing, Vol.10, No.6, pp.270-277.

Mystakidou, K., Parpa, E., Tsilika,E., Georgaki, S., Mavromati, A and Vlahos, L. (2002). Quality of life in terminally ill cancer patients. European Journal of Palliative Care, Vol.9, No.6, pp.252-254.

Norval, D. and Gwyther, E. (2003). Ethical decisions in end-of-life care. Continuing Medical Education, Vol.21, No.5, pp.267-272.

Ogden, T.H. (1989). On the concept of an autistic-contiguous position. International Journal of Psycho-Analysis, Vol.70, 127-139.

Olivière, D. (2000). A voice for the voiceless: interview with Dame Cicely Saunders. European Journal of Palliative Care, Vol.7, No.3, pp.102-105.

Oskowitz, B. and Meulenberg-Buskens, I. (1997). Preparing researchers for a qualitative investigation of a particularly sensitive nature: reflections from the field. South African Journal of Psychology, Vol.27, No.2, pp.83-88.

Paget, M.A. (1999). Experience and knowledge. In A. Bryman and R. Burgess (Eds.) Qualitative Research II. pp.81-102. London: Sage Publications.

Parkinson, J. (2003). Intruder in the night: cancer and the 'I' within. British Journal of Psychotherapy, Vol.19, No.4, pp.415-433.

Patton, M.Q. (1999). The nature of qualitative enquiry. In A. Bryman and R. Burgess (Eds.) Qualitative Research IV. pp.139-160. London: Sage Publications

Peberdy, A. (2000). Spiritual care of dying people. In D. Dickenson, M. Johnson, and J.S. Katz (Eds.) Death, dying and bereavement, pp.73-81. London: Sage Publications.

Perreault, A., Fothergill-Bourbonnais, F. and Fiser, V. (2004). The experience of family members caring for a dying loved one. International Journal of Palliative Nursing, Vol.10, No.3, pp.133-143.

Picardie, R. (1998). Before I say goodbye. London: Penguin.

Pierson, C.M., Curtis, J.R. and Patrick, D.L. (2002). A good death: a qualitative study of patients with advanced AIDS. AIDS CARE, Vol.14, No.5, pp.587-598.

Pillay, A.L. (2001). Psychological symptoms in recently diagnosed cancer patients. South African Journal of Psychology, Vol.31, No.1, pp.14-18.

Poland, B.D. (1999). Transcription quality as an aspect of rigor in qualitative research. In A. Bryman and R. Burgess (Eds.) Qualitative Research III. pp.13-29. London: Sage Publications.

Potter, J. (2004). Fatigue experience in advanced cancer: a phenomenological approach. International Journal of Palliative Nursing, Vol.10, No.1, pp.15-23.

Poss, S. (1981). Towards death with dignity. Caring for dying people. National Institute Social Services Library no. 41. London: George Allen and Unwin.

Postone, N. (1998). Psychotherapy with cancer patients. American Journal of Psychotherapy, Vol. 52, No.4, pp.412-424.

Rafferty, D. (1995). Body image: using women who have had breast surgery as a case study. International Journal of Palliative Nursing, Vol.1, No.4, pp.95-99.

Richardson, A. and Ream, E. (1998). Recent progress in understanding cancer-related fatigue. International Journal of Palliative Nursing, Vol.4, No.4, pp.192-198.

Rich, A. (1999). How long have I got? – prognostication and palliative care. European Journal of Palliative Care, Vol.6, No.6, pp.170-182.

Richman, J. (2000). Introduction: psychotherapy with terminally ill patients. American Journal of Psychotherapy, Vol. 54, No.4. pp.482-485.

Rinpoche, S. (1992). The Tibetan book of living and dying. London: Rider.

Robinson, S. (2005). Europe's way of death. The Terri Schiavo case has provoked a fierce debate about euthanasia in the U.S. – and a sense of bafflement among many Europeans. Time, April 4 2005, pp.32-33.

Röcke, C. and Cherry, K.E. (2002). Death at the end of the 20th century: individual processes and the developmental tasks in old age. International Journal of Aging and Human Development, Vol.54, No.4, pp.315-333.

Rogers, M.S. and Todd, C.J. (2000). The 'right kind' of pain: talking about symptoms in outpatient oncology consultations. Palliative Medicine, Vol.14, pp.299-307.

Roosevelt, M. (2005). Choosing their time. The next contentious end-of-life issue: assisted suicide. How Oregon offers a way out. Time, April 4 2005, pp.29-31.

Salander, P. (2002). Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients. Social Science and Medicine, Vol.55, pp.721-732.

Saunders, C. (1990). Hospice and palliative care. An interdisciplinary approach. London: Edward Arnold.

Saunders, C. (2002). Comment: keeping the balance. European Journal of Palliative Care, Vol.8, No.1, p.4.

Schwartz, J. (2005). New openness in the decision of when and how to die. The New York Times, Sunday April 3 2005.

Scott, P. (1966). The Raj Quartet. London: Heinemann.

Seymour, J.E. and Ingleton, C. (2005). Ethical issues in qualitative research at the end of life. International Journal of Palliative Nursing, Vol.11, No.3, pp.138-146.

Shapiro, S.L., Lopez, A.M., Schwartz, G.E., Bootzin, R., Figueredo, A.J., Braden, C.J. and Kurker, S.F. (2001). Quality of life and breast cancer: Relationship to psychosocial variables. Journal of Clinical Psychology, Vol. 57, No.4, pp.501-520.

Sheldon, F. (1997). Stress in relationships during the disease process. Continuing Medical Education, Vol. 15, No.7, pp.813-820.

Simpson, L. (Ed.) (1972). An introduction to poetry. Second edition. New York: St Martin's Press.

Singer, P.A., Martin, D.K. and Kelner, M. (1999). Quality end-of-life care. Patients' perspectives. Journal of the American Medical Association, Vol.181, No.2. pp.163-168.

Skinner Cook, A. and Oltjenbruns, K.A. (1998). Dying and grieving. Life span and family perspectives. 2nd ed. Orlando, Florida: Harcourt Brace Publishers.

Smith, E.M., Gomm, S.A. and Dickens, C.M. (2003). Assessing the independent contribution to quality of life from anxiety and depression in patients with advanced cancer. Palliative Medicine, Vol.17, pp.509-513.

Song, M. and Parker, D. (1999). Commonality, difference and the dynamics of disclosure in in-depth interviewing. In A. Bryman and R. Burgess (Eds.) Qualitative Research IV. pp.112-125. London: Sage Publications.

Sontag, S. ((1977), (1988)). Illness as metaphor and AIDS and its metaphors. New York: Picador.

Speck, P. (1998). Spiritual issues in palliative care. In D Doyle, G.W.C. Hanks and MacDonald, N. (Eds.) The Oxford Textbook of Palliative Medicine. Second Edition. pp. 977-990. Oxford: Oxford University Press.

Spiroch, C.R., Walsh, D., Mazanec, P. and Nelson, K.A. (2000). Ask the patient: a semi-structured interview study of quality of life in advanced cancer. American Journal of Hospice and Palliative Care, Vol.17, No.4, pp.235-240.

Starker, S. and Starker, J.E. (1981). A group awaiting death: the social system's perspective on a naturally occurring group situation. In R.A. Kalish (Ed.) The final transition. Perspectives on death and dying series 5. pp.127-137. Farmingdale, New York: Baywood Publishing Company.

Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M, McIntyre, L. and Tulsky, J.A. (2000). Factors considered important at the end of life by patients, family, physicians and other care providers. Journal of the American Medical Association, Vol.284, No.19, pp.2476-2482.

Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N.A., McIntyre, L.M. and Tulsky, J.A. (2000). In search of a good death: observations of patients, families and providers. Annals of Internal Medicine, Vol.132, No.10, pp.825-832.

Sullivan, M. (2002). The new subjective medicine: taking the patient's point of view on health care and health. Social Science and Medicine, Vol.56, pp.1595-1604.

Tanchel, I. (2003). Psychosocial issues in palliative care. Continuing Medical Education, Vol.21, No.5, pp.249-252.

Terkel, S. (2001). Will the circle be unbroken? Reflections on death, rebirth, and hunger for a faith. New York: The New Press.

Thompson, S.C., Sobolew-Shubin, A., Galbraith, M.E., Schwankovsky, L. and Cruzen, D. (1993). Maintaining perceptions of control: finding perceived control in low-control circumstances. Journal of Personality and Social Psychology, Vol. 64, No.2, pp.293-304.

Thompson, G. and McClement, S. (2002). Defining and determining quality in end-of-life care. International Journal of Palliative Nursing, Vol.8, No.6, pp.288-293.

Thoresen, L. (2003). A reflection on Cicely Saunders' views on a good death through the philosophy of Charles Taylor. International Journal of Palliative Nursing, Vol.9, No.1, pp.19-23.

Twycross, R. and Lichter, I. (1998). The terminal phase. In D Doyle, G.W.C. Hanks and MacDonald, N. (Eds.) The Oxford Textbook of Palliative Medicine. Second Edition. pp. 977-990. Oxford: Oxford University Press.

Vachon, M.L.S. (1998). The emotional problems of the patient. In D Doyle, G.W.C. Hanks and MacDonald, N. (Eds.) The Oxford Textbook of Palliative Medicine. Second Edition. pp. 883-907. Oxford: Oxford University Press.

Veatch, R.M. (1989). Death, dying and the biological revolution. Our last quest for responsibility. Revised edition. New Haven: Yale University Press.

Vig, E.K., Davenport, N.A. and Pearlman, R.A. (2002). Good deaths, bad deaths, and preferences for the end of life: a qualitative study of geriatric outpatients. Journal of the American Geriatrics Society, Vol.50, pp.1541-1548.

Vigano, A., Dorgan, M., Buckingham, J., Bruera, E and Suarez-Almazor, M.E. (2000). Survival prediction in terminal cancer patients: a systematic review of the medical literature. Palliative Medicine, Vol.14, pp.363-374.

Vorobiof, D.A. and Chason, M. (1998). Common Cancers. Part 1. Breast cancer, lung cancer, prostate cancer. Continuing Medical Education, Vol.16, No.5, pp.393-403.

Walter, T. (2002). Spirituality in palliative care: an opportunity or a burden. Palliative Medicine, Vol.16, pp.133-139.

Wass, H. (2001). Past, present and future of dying. Illness, Crisis and Loss, Vol.9, No.1, pp.90-110.

Weisman, A. (1984). The coping capacity. On the nature of being mortal. New York: Human Sciences Press, Inc.

Welk, T.A. (2000). Whose dignity are we talking about? American Journal of Hospice and Palliative Care. Vol.17, No.4, pp. 279-280

Welman, M. (1995). Death and gnosis: archetypal dream imagery in terminal illness. Doctoral Thesis, Rhodes University, Grahamstown, unpublished.

White, G. (2000). An inquiry into the concepts of spirituality and spiritual care. International Journal of Palliative Nursing, Vol.6, No.10, pp.479-484.

Wilber, K. (1991). Grace and grit. Spirituality and healing in the life and death of Treya Killam Wilber. Dublin: Newleaf.

Williams, A.M. (2004). Shaping the practice of home care: critical case studies of the significance of the meaning of home. International Journal of Palliative Nursing, Vol.10, No.7, pp.333-342.

Wolcott, H.F. (1994). Transforming qualitative data. Description, analysis and interpretation. Thousand Oaks, California: Sage Publications.

Wolcott, H.F. (2001). Writing up qualitative research. Thousand Oaks, California: Sage Publications.

Wright, M.C. (2002). The essence of spiritual care: a phenomenological enquiry. Palliative Medicine, Vol.16, pp.125-132.

Yalom, I.D. and Greaves, C. (1977). Group therapy with the terminally ill. American Journal of Psychiatry, Vol.134, No.4, pp.396-400.

Yalom, I.D. (1980). Existential psychotherapy. New York: Basic Books, Inc.

Yedida, M.J. and MacGregor, B. (2001). Confronting the prospect of dying: reports of terminally ill patients. Journal of Pain and Symptom Management, Vol.22, No.4. pp.807-819.