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LIVING TOWARD DEATH:

the enduring work of terminally ill people

A thesis presented in fulfilment of the requirements for the degree of
Doctor of Philosophy

at Massey University, Albany,

New Zealand

Elizabeth Niven

2001

MASSEY UNIVERSITY



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Errata

Living toward death: the enduring work of terminally ill people Doctoral thesis of Elizabeth Niven, Massey University, 2001

p 42 Kylma & Vehvilainen-Julkunen (1997) in their meta-analysis of the concept of hope, note that one aspect identified in the articles is the distinction between generalised and particularised hope.

p 85 'nurse' in para 2 line 3 should be 'nurses'.

p 109 para 2 line 1 should read 'Facticity is used by Heidegger . . .'

p110 para 1 line 1 should read 'These ideas suggest . . .'

p127 para 1 line 1 (beneath quote) should read 'Jan portrays herself as someone who is coping well with the dreaded cancer diagnosis and treatment.'

p 130 (in quote) line 4 should read '*They have got so much to deal with when they are dying.*'

p 140 footnote 27 should read Kapanol as sustained release medication.

p 154 final para line 3 delete 'a'

p 157 para 2 line 4 should read '. . . and is answered in chronos'.

p 164 final para line 7 delete 'that'

p 187 final para line 4 should read '. . . as he considers . . .'

p 188 para 1 line 3 alters becomes alter.

P 211 para 2 line 11 Health professionals becomes 'Health professionals' assessment . . .'

p 211 para 2 line 13 delete 'all'.

p 221 para 3 line 7 'is there' should be 'there is'.

p 223 para 2 line 3 insert 'by' between 'used – professionals'.

p 223 para 2 line 5 delete 'who'.

p 226 para 1 line 18 delete 'them'.

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TO WHOM IT MAY CONCERN

This is to state that the research carried out for the Doctoral thesis entitled "LIVING TOWARD DEATH: the enduring work of terminally ill people" was done by Elizabeth Niven in the School of Health Sciences, Massey University, Albany, New Zealand. The thesis material has not been used for any other degree.

Supervisor

J.M. Kelly

Date

9.5.01

Abstract

This study explores the lived experience of terminally ill people using the personal narratives of patient, kin and nurse. Six sets of patient-kin-nurse form the sample, with data gained via individual interviews. The study is guided by the values of phenomenological philosophy while narrative theory assists data analysis. Interpretation of the data is informed by Anthony Giddens' social constructs relating to modernity and self-identity.

The diagnosis of a terminal illness usually forces major changes in the lives of patients, and often provides time for reflection. Although the experience must be individual it is also part of a common human experience that may be enriched by the knowledge of others who have lived through similar ordeals. Yet the constantly evolving nature of the social and health context suggests that the experience of terminal illness is never static and that fresh understandings of living with a life-threatening illness are always necessary.

The thesis is that living toward death can be seen as the enduring work of the patient. The patient, in response to experience and events of illness, develops a readiness for change via a process of constantly reconstructing his selfhood. Readiness for change allows him to maintain hope during uncertainty, knowing that change is certain and that he has overcome previous challenges. In this way a sense of enduring self is created that is functional for him and his kin as death comes closer. The interrelational nature of living toward death is presented in the notions of negotiating support and handing over, and these aspects also contribute to the patient's evolving selfhood.

The sense of enduring self developed by the patient may contrast with the kin and nurse expectations when they are working towards closure, challenging practitioners to renew their focus on the patient's position and putting aside already acquired assumptions of dying experiences. Similarly the patient's need to negotiate for support and care appears to question the caring actions of kin and nurse, and demands that existing understandings of caring relationships are re-examined. The study shows that the patient's sense of enduring self that develops during his terminal illness has the potential to transcend his death, and that where this happens, both patient and kin approach his death with readiness.

Acknowledgements

This work is dedicated to the participants -- patients, kin, and nurses -- who have shared their journeys with me by agreeing to take part in the study. It is also dedicated to three people whose journey's end I shared as daughter, neighbour and friend – to my father, John Niven (1918 - 1988); to my neighbour, Alma Logan (1916 - 1996); and to my friend, Dorothy Limbrick (1939 - 1999). All these people taught me what it is like to live toward death in grace and serenity.

Ethical approval for this study was gained from the Massey University Human Ethics Committee and from the North Health Ethics Committee.

I acknowledge the support of the Fieldhouse Trust and the Mary Lambie scholarships, without which this study would not have been possible. A grant from the Faculty of Health Science & Technology, UNITEC, provided writing time at the end of the project, and this is acknowledged with gratitude.

I thank my supervisors, Dr Judith Christensen, Dr Philip Culbertson and Dr Julie Boddy for guidance, support and faith. Judith's early work helped clarify the bounds of the study; Philip's encouragement and gentle critique helped develop the scholarly quality of the work; and Julie's firm guidance at the end ensured that the thesis was completed in a discipline specific quality.

I thank my family, particularly my mother, Natalie Niven, who has always encouraged me to continue. The calm assumption of my children, Robert and Katie Sturch, that the work would be completed was confidence building. Various family have supported in their own specific and special ways, and I am grateful for these contributions.

Colleagues and friends have been part of this journey. I have valued the debate and encouragement of our doctoral study group both as group and as individuals. My colleagues at work have kept an interest and belief in the study, and this has been helpful. I thank my colleagues involved in palliative care whose work is the basis for the study, and whose belief in the value of the project was always a stimulus to continue.

Warren Limbrick has offered friendship and critique throughout the project, even at a time when he had to live a journey similar to that of the kin participants. His faith has kept me true to the course.

Always, I give thanks to God for life, for faith, for work.

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Chapter one – the study topic

It hath been often said, that it is not death, but dying, which is terrible.

Fielding (1987)

While death is a universal prescription, it does not become a personal experience until each individual's fate is identified and confirmed. The topic of this study is the change that takes place when a diagnosis of life-threatening illness moves death from the general to the specific. Chapter 1 introduces the research topic that guided the study: **An exploration of the lived experience of terminal illness from the perspective of the patient, family caregiver¹ and palliative care nurse.** The chapter opens up some of the issues that were important, reflecting on the context and persons relevant to the study. The contemporary New Zealand context is discussed, including the historical background and an outline of a typical terminal illness experience. Personal information that relates to the study is outlined, and assumptions recognised as far as it is possible to do so. The chapter concludes with an explanation of language and terms used throughout the thesis and an overview of the content of the thesis.

The history of the question

As a nurse-teacher I accompany students into hospitals for their clinical experience. During one such period of work I was standing beside a patient's bed while the student went to prepare some equipment. The man and I fell into conversation, and I was interested to hear about his life as he was moving toward death in his terminal illness. Later in the day his wife came in, and finding him asleep began chatting to me. She shared with me how this time was for her and her husband. At the change of shift the morning nurses summarised the situation of the man and his wife for the afternoon nurses, providing a third version of the same events.

¹ The term 'caregiver' was later refined to 'kin' which is used from this point.

I noted that the accounts differed in various ways, containing similarities but also some contradictions. I reflected on the situation, finding it fascinating and wondered to what extent the accounts differed and to what extent they were similar. I wondered what was the reality, and did it matter what the truth was, if there was a truth. It seemed to me that each narrator spoke as though his or her account were the key story, the reality against which the other was to be measured, and I wondered how each individual's understanding might affect communication and subsequent events.

I was already aware that each group commonly accounts for differences in perception by negating, justifying or explaining the other view. For example, nurses will say of patients: 'they don't always take in the information'. Patients will say of nurses and other health professionals: 'they don't tell me everything'. Family will say of patients: 'they're under a lot of strain and don't always remember the details of what is said'. These comments are part of a larger truth, and seemed to indicate to me that each person in the larger group had a story that was not heard properly by the others.

I wondered whose account was more powerful, and if the dominant account varied over time. The ways in which people listen to each other, and how they interpret each other's accounts, could vary. Their ability to remember could be affected by contextual events or other influences. The effect of a number of different accounts of the same event might be enriching for those involved but it might be confusing - perhaps there was an optimum number for clarity. I was particularly interested in the significance of the patient's account, especially when it was markedly different from other versions.

I thought it would be useful to understand this situation better. In seeking a question for study it was important for me to have a significant question, one that would be worth answering. The interest was not just for the issue itself, but also because increased understanding could lead to better communication and other potential benefits for patients, kin and nurses.

Personal history and its influence

I trained as a nurse with the Sisters of Mercy in Auckland in the 1960's. The Order had opened a Hospice in 1952 (Timms, 1999), and as students we provided care for terminally ill patients. Care of the dying was a very important skill and

the respect for the dying person the Sisters imparted remained part of my nursing knowledge. Death was not the 'last enemy' (1 Cor. 15:26) for these women of faith that it often was for others in the community. Most medical practitioners, nurses and the general public saw death as a failure of treatment, and as such it tended to be hidden and not discussed. The attitude of the women in the Order, while congruent with their religious beliefs, was in advance of mainstream health developments.

During the seventies, as a mother of young children I worked night duties. On one night, which I remember clearly, I found Kübler-Ross' 1969 book *On Death and Dying*, and read it cover to cover. This was an epiphany for me, as I moved from the idea of providing loving, empathetic care, to the realisation that the experience is singular, individual, and may be active rather than passive. Night time is often a time of quiet, sleeplessness and much reduced activities. It was an enormous privilege to be with suffering people during the quiet hours of the night. Patients would discuss their anxieties, seek comfort, share their experiences, and develop insights through our conversations. I reflected, read, listened, and enlarged my expertise and commitment to this field of nursing work.

Although I worked in a variety of areas of clinical nursing through the eighties, my interest in dying and the developing specialty of palliative care remained. Personal encounters with my father's death from cancer in 1988 and a neighbour in 1996 provided some insight into the role of family member during a dying experience. Biographies and autobiographies of illness, both chronic and acute, have always formed a large part of my reading, and the burgeoning of the consumer involvement in health care of the eighties added to this field. Accounts of illness written from the perspective of the patient and from that of the kin or close family member became common, appearing in both books and magazine articles. The commonest themes in them were triumphing over adversity, or the quest for self-actualisation, though a small number recorded experiences of unrelieved distress. Professional records of the patients' experiences were also being written. These were commonly interpreted from an objective, etc view, where the professional was the authoritative voice for the events.

Considering the contemporary context with this personal interest, and the clinical experience described above, further questions arose, initially related to philosophy.

Questions of life, death and philosophy

The mysteries of life and death have long been the substance of philosophy and the following discussion sets out some of the key questions in terms of their philosophical exploration. Reflective philosophy is not the only way to understand matters of life and death but, because of the long relationship between philosophy and life and death issues, it is useful to begin by examining the subject from this viewpoint before using the lens of human experience.

The juxtaposition of life and death that presents itself to patient and kin at the diagnosis of a life-threatening illness is a philosophical as well as a pragmatic issue. If there were simply two states - being alive and being dead - then it would be less problematic for humans. A simple dichotomy presents either/or, limiting possibility and reducing anxiety. However there are a number of variations that exercise our understanding in relation to the ontology of death.

Mortality is normally contemplated from the comfort of generality, where one's death is part of the whole human condition, but not yet personal. Occasionally the individual is confronted with death as personal, as when in immediate danger, or in the death of someone close. These glimpses are uncomfortable, and more uncomfortable when more possible. Anxiety in the face of death, according to Heidegger (1962), is relieved by assigning death to 'Others', thus keeping death away. That death is a 'fact of experience' (p. 301) helps to keep it empirical and not personal, and it is this work in keeping 'fleeing in the face of death' (p. 298), Heidegger claims, that emphasises its ever-present threat. Giddens (1991) describes the avoidance of the chaos of death as being achieved by the individual organising an 'as if' environment (p. 37) which shuts out the threat of disasters. An 'as if' environment is one that proceeds as if chaos and disaster were highly unlikely to break into ordinary life. It does not deny the possibility of risk and danger, but acknowledges that in everyday life their threat is small. Both these views recognise that the individual does not live his daily life in full contemplation of his mortality, with Giddens' understanding seeming more pragmatic and Heidegger's explanations based on a present, but hidden, fear or

dread. These views, like others, reflect both the philosopher and the contemporary context of their creation. Heidegger's writings belong clearly to the first half of the twentieth century, with their roots in ontological questions and personal meaning. Giddens, as a late 20th century sociologist-philosopher, is concerned with people's social being in the world, and making sense of their lives in a social construction. Whether these, or any other understandings of the individual's relationship with his own death would be relevant in this study was an open question.

Being and non-being

The nature of being is never as stark as when threatened with non-being. It is possible to believe that one could be dying, and that one could die: to imagine oneself dead involves the brain in some elaborate contortions. One does the imagining with one's *being*, yet it is the non-being state that one is trying to comprehend with that being. That the physical being can cease to exist is more easily recognised – most people have experience with death and decay of animals and plants, and there is the knowledge that all who have ever lived have died, including some known personally.

The relationship between the body and that part of the self which is not physical is a part of the terminal illness experience, along with issues such as whether that 'other' is soul, spirit or mind. The extreme difficulty of establishing and measuring interdependence and influence of the physical and the spirit keeps these questions largely philosophical in nature. The mind-body split explored by Descartes may be both comforting and confusing. *Cogito ergo sum* – but thinking involves brain cells, so if there are no brain cells is there no thinking, and no *sum*? Campbell's discussion on body and mind identifies a spiritual aspect to 'mind' that defies analysis. He notes:

But human mental life also embraces awareness by phenomenal properties. Such awareness is also, we must suppose, caused by changes in sense organs and brain. How this is done we do not know. Because the non-material seems to thwart our attempts to account for its operations, I suspect we will never know how the trick is worked. This part of the mind-body problem seems insoluble. This aspect of humanity seems destined to remain forever beyond our understanding.

(Campbell, 1984, p. 131)

While 'being' suggests a state and 'non-being' an absence of that state, the words 'life' and 'death' contain different connotations. Life includes holding the spark or breath that demonstrates living, suggesting that 'being' has been activated and has an element that maintains life. 'Death' or 'being dead' does not equate so well with 'non-being', because the terms indicate a 'state' of death, not an absence of state. The paradoxical statement : "when I *am* dead" suggests that death is envisaged as a state, perhaps not of being in the way temporally known, but still a state. It is a state that seems superficially to be the opposite of life, not merely its absence; it is something else. So death includes not living as part of its state, but not not-being, for that is an absence. If death is the opposite of life, then what is before life? It cannot be death, as death follows life fulfilled. Mostly beyond science at this time, these questions belong to theology, to tradition, to culture and to speculation. However, recent studies in near-death experiences, undertaken with careful scrutiny and control, seem to show a continuation of existence, recalled by the patients, after they were clinically dead and before successful resuscitation (Telegraph, 2000).

Dying

Framing being and non-being as dichotomous invites further exploration of the nature of dying. Common oral language includes inaccurate phrases like half-dead, and half-alive, yet the speaker knows there are no half-measures, the power of the phrases being in their ambiguity. How does one move from living to dying, and is it possible to move back to living? The patient is re-assigned from 'living' to 'dying' by a judgement made by an individual, usually a health professional. The enormity of the shift from living to dying makes such a re-assignment extremely significant and confers great power on the health professional. Both the judgement and the power inherent in it are therefore proper issues for consideration in the study. What is the effect of the term 'dying' on people, kin and communities? It conjures up both a fighting spirit, and hopelessness. It has a powerful place in literature and art, and contains its own language and traditions, often culture and religion specific. There is usually, for example, in Western society, an exemption from normal responsibilities and a moral right to special treatment when a person is diagnosed with a terminal illness or is near death.

The transition between life and death is another challenge. For those who hold that being stops at death, like a candle snuffed, there is no transition, as there is no place beyond. For these people, the matters of interest are dying, and the moment of death itself. For others who hold that there is some state beyond life the transition is of interest. The concerns of transition seem to be the leaving of life, letting go of living, ceasing breathing and moving from known. Perhaps the questions arise from a fear that there *is* nothing beyond life, or that there *may* be nothing beyond life, or that what is there is unknown and therefore frightening. These are the issues that those who care for grieving people address in what is evidently an attempt to bring solace to those left behind, and comfort to those imagining their own death. Deathbed scenes in literature, film and art provide a guide to expected behaviour of the dying and those gathered around. Convention holds that truth prevails at this time, and that the wishes expressed by the dying are of greater significance. These traditions emphasise the importance of the time of dying, when those who are among the living move from life into the company of the dead, the unknown realm. Human cultures do not abandon their dying ones, as some animals do, and some people measure the advancement of their civilisation by how the dying are cared for. Yet for all the tradition, all the literature, all the philosophy, little or nothing is known about the transition. The exit from life remains as one of life's greatest mysteries.

Suffering

When dying is not sudden there may be expected a measure of suffering. To suffer denotes to undergo, to be subjected to, to experience, and to permit. The words pain and suffering are frequently paired, so often that to say suffering includes pain to many, and the negative connotation is the most powerful. However, there is a generalised nature to suffering in dying that is recognised as being more aligned to both the specific cause and the experiences of living with the disease. As well as physical symptoms there is a belief that there will be mental, emotional and social suffering. Suffering in all these forms has been problematic for philosophers and theologians, as well as for other professionals who attempt to alleviate one form or another. For the sufferer as well, the meaning of the suffering and the problems resulting from alleviation are a modern as well as an historical concern. Where suffering is perceived as positive, perhaps because it signifies a mirroring or sharing of Christ's agony, or because it demonstrates great courage, then alleviation may be seen as antithetical to the

presumed benefits of suffering. It is possible that views of suffering as positive were a response to a lack of ability to alleviate suffering, as it would have been functional to have made a virtue of it. There was, and still is, the problem of a God, or gods, who are generally benefactors of humanity, visiting suffering on their own people. The view of suffering as punishment for wrong-doing may not be prevalent, yet continues. Some fellow parishioners of a woman diagnosed with cancer judged her disease to be a "Divine Appointment", also quoting from Psalm 118: "The Lord has punished me severely" to underpin their claim that God punishes sinners with afflictions (Brooker, 2000). Even among non-believers the response to a cancer diagnosis of 'not deserving this' is common, and indicates a deep-seated punishment view. The moral questions of suffering are many, and not easily answered.

The question of meaning, in and of life, lurks in the shadows of explorations of dying, living, death, suffering, transition and mortality. A small part of that bigger question, and one that is legitimate to open up, is the issue of making sense of life when death threatens. The purpose and achievements of an individual life are then thrown into question, as death will remove the means by which that life has proved its worth. This does not suggest that death invalidates lifetime achievements, but that its imminence may provoke a life review, a part of which may include the inherent value of that life. Illness also brings up deep questions of the meaning of illness, and of the particular illness to the individual and their kin; the purpose and deservedness of illness and the overall place of disease and illness in human lives.

The scope of these questions takes them beyond simple exploration, and they continue to challenge philosophy and theology. I hoped that the study would allow exploration of these issues and was aware that the lived experience of dying people could illuminate them in a way that could be very different from the discursions of non-dying philosophers. While the exploration processes above permitted the opening up of possible issues I also had to be aware of unexplored dimensions that could emerge during the study.

The following sections, dealing with context and person during dying, are based on extensive discussions with palliative care and oncology nurse practitioners, supplemented with personal experience and reading.

Issues of context

An individual dies in a context that includes such factors as the cause of death and its precursors, his own history and relationships, and extends to the society in which he lives. All may have some effect on the experience, and this section identifies some of these contexts that were recognised in the planning stages of the study.

Death may be sudden, traumatic or both and in these situations reflection while dying is difficult or impossible. Dying may also be at the end of a completed life, from a surfeit of years when reflection often seems redundant and death welcome. Dying experiences that could be described as sudden, or timely, would not provide the lived experience wanted for this study. What was of interest was a considered dying, an aware dying, a dying where the patient was in effect an active participant. The dying that comes with being terminally ill would allow adequate exploration of the research question as it takes place in a time frame that allows preparation and reflection, and the sharing of the experience with others.

In addition there are multiple and overlapping contexts in which each person lives and dies. These are the historical context of the late twentieth century and the personal historical collection of knowing around dying of each person; the socio-political context of this country, and the individual socio-financial reality of each person; the attitudes to health and illness and the funding of these which arise from dominant ideologies and the health-illness beliefs and practices of each person and their kin; and the spiritual and cultural contexts of the community and of the person and kin.

The fact that dying takes place in a context of living is self evident, yet demands constant recognition. The individual lives the paradox of *being* terminally ill, dying while being alive. There are, one might say, two parallel paths one leading to death and the other continuing with living. The context of the other partners, the kin and the palliative care nurse have a different personal focus that is based on the continuation of living, not the cessation of living, so while the contexts may overlap the knowledge that divergence will come sooner or later is a potential influence.

The context of health care for the study

Not only do we carry our historical knowledge of dying with us, but also we build our present ideas about the appropriate provision of health care for dying people on the practices of the past. A brief overview of recent New Zealand history in this respect provides both background for the present beliefs and a historical understanding for the reader.

In the early days of New Zealand's twentieth century, most people died at home, as death, like birth, was seen as a natural event (Nichols, 1999). Nursing care was provided by the female members of the family, assisted by the extended family or other members of the community. Institutional health care was either expensive or charity-based up to 1938, when health care became largely free. Davis (1982) notes that between 1935 and 1945 the State's contribution to health care virtually doubled from 39% to 73%, and this access to public institutionalised health care 'normalised' birth and death as hospital events.

The development of medicine into a discipline of aggressive action against disease and infirmity led to the development of hospitals as places of super specialities (Davis, 1982). The focus on cure meant that those whose needs were care rather than cure were being poorly served. Nichols notes:

Professionals had become more focused on cure and those who could be saved; there was a sense of fear and failure associated with those who were dying . . . a discomfort with what it was one should do or say. Death was a much less acceptable part of the fabric of life - hidden as it was from public view, families stayed away, conforming to hospital rules and feeling inadequate in their own abilities to comfort and accompany their loved ones on their final journey.

(Nichols, 1999, p. 2)

In New Zealand Mother Mary Agnes, a sister of Mercy and matron of the Mater Misericordiae Hospital in Auckland, nurtured the hospice vision in the post war years. Although Mother Mary Agnes died in 1950, her dream was fulfilled in 1952 when the order's first hospice was opened in Auckland. Interestingly, the public reacted against the inclusion of 'for the dying' in the title of the unit, and the Auckland City Council withheld permits until the name was altered. Gradually the attitudes to hospice changed, hospice care itself developed

internationally, and one of the sisters, Sr Margaret Timms, was sent to Britain to study advanced care. On her return to Auckland the Sisters of Mercy negotiated with the then Auckland Hospital Board to provide a new hospice service for Auckland. The 18 bed unit was opened in August 1979, though the numbers were reduced to 15 to provide a more effective service (Timms, 1999). The relationship of the sisters with their community illustrates a pattern of concealment/recognition of death that will be explored in chapter two.

Others among the first hospices in New Zealand were Te Omanga and Mary Potter hospices in Wellington. Currently (2001) there are 37 hospice or hospice services in New Zealand, providing a variety of in-patient and community services. Interestingly, the Netherlands, a country with a public commitment to euthanasia, had only five hospices in 1997, though this was a doubling of the number of the early 1990's (Arend, 1997). New Zealand's population is around 3.5 million (New Zealand, 2000), and that of the Netherlands 15.7 million (Netherlands, 2000). While these two countries may be at opposite ends of the spectrum in these issues, the hospice movement is increasing in strength in the Netherlands, and the euthanasia movement is similarly active in New Zealand. Though both the euthanasia and hospice movements have a common aim, that of people dying free of pain and suffering, their means of achieving the goal are divergent, and thus their influences on the context of providing care for dying people can be in direct contrast with each other.

In addition to the morally driven hospice and euthanasia movements, the context of caring for terminally ill people is influenced by the levels of state funding provided and the altruistic nature of the charitable institutions making up the deficits. The influence of medicine and the dominance of allopathic medicine in the twentieth century are probably factors in the low level of state funding in hospice care, in that money tended to go where it would produce most visible benefit. The history of charitable contribution to end-of-life care is another factor, as people involved in such work still see this field of care as part of their religious or humanitarian duty to society. Hospice services are only one of the charitable or semi-charitable groups operating in the field. The Cancer Society and the Leukaemia and Blood Foundation contribute varyingly to end of life care, though their main financial commitment is to medical research, and care of patients and kin during treatment. Their volunteers provide support and assistance to

patients and kin at home and in institutions, and without them many people would not be able to remain at home. For patients and kin living in this context, the effect of moving from state funded care to care that is only partly state funded could give rise to questions of deservingness and rights to care, and this issue is enlarged below.

Palliative care developed as a response to the need identified when cure-focused medicine had come to the limits of its practice. Where hospice care attended to the patient and kin at the end of life, palliative care recognised that there were needs between the end of curative treatments and the time to die. Palliation of symptoms includes holistic care² and may encompass such things as radiation³ and chemotherapy⁴ to reduce discomfort. Aranda offers four main principles that guide palliative care:

- an approach to care emphasising living and acknowledging death as an intrinsic part of life;
- centred on the patient and family as client and emphasising the client's role in the direction of care;
- utilising a multidisciplinary team in recognition of the need to offer care that is holistic and meets the complex needs of the dying patient and family;
- and focused on comfort and the full relief of symptoms rather than cure of disease.

(Aranda, 1998, p. 22)

The development of the discipline of palliative medicine, now sufficiently complex to provide challenge and satisfaction to medical practice, has raised the profile of the field (Ashby, 1998). At the same time, those long involved in palliative and hospice *care*, as opposed to the area as a *medical* speciality, have concerns that medical dominance will shift the focus to treatment of symptoms rather than the traditional holistic approach (Street, 1998).

² Holistic care includes all the aspects of what it means to be human, such as spiritual, physical, emotional, social and cognitive components.

³ The use of radiant energy such as from x-rays and radio-active substances in the treatment of disease, mainly cancer.

⁴ While technically this refers to the treatment of any illness by chemical means, or drugs, it is commonly taken as cancer treatment.

The final contextual influence to be explored here is that of self-determination. This value, derived from the development of individual rights that emerged from the cultural and industrial revolutions in Europe of the 16th and 17th centuries, has become central to legislation in New Zealand. Individuals have rights to refuse treatment, rights not to be experimented upon, rights to a standard of health care and the right to seek redress for infringement of these rights (Bill of Rights Act, 1990, Health & Disability Commissioner Act, 1994). These Acts contribute to the individual's expectations about health care and his part in the decisions relating to it. Choices include main-stream medical care, alternative treatments or no treatment, and are influenced by the degree of faith the individual has in the outcomes of each. The right to a reasonable standard of health care is part of this legislation, and the person who is dying may wonder why his care is no longer fully funded. Has he perhaps less right to health care if he is going to die at the end of it? Perhaps the move to part-charitable care subtly influences the patient and kin to minimise their demands, as they may be more aware that money is limited. These issues, too, are part of the context of the study.

A snapshot of care of the dying at the time of the study

It is clear from the above that there is continual evolution in the provision of care for dying people in New Zealand. There are also local and regional variations in services offered. In the city in which the study took place this variation exists both locally and temporally, so what is outlined below is a general account of what prevailed for the people in the city, and therefore the patients and kin in the study, at the time of data collection.

Most cancer diagnosis and treatment takes place in the State-funded public system.⁵ Some surgery and diagnostic tests are undertaken in the private system, particularly when individuals believe that a delay in diagnosis or surgery could affect the outcome of their condition. The usual course of events is that disquieting symptoms are reported to the person's general practitioner who carries out whatever tests he or she believes are warranted. After discussion with the person, the doctor makes a referral to a specialist. This is commonly someone

⁵ Funded by the tax payer via central government.

within the public system, as general practitioners are aware that if chemotherapy and radiotherapy are needed it is better for the patient to already be part of the public system. Treatment options are usually discussed with the patient, often including family members, guided by the medical team. The majority of people opt for treatment at this stage if it is offered. Sometimes the medical team will have to inform the patient that there are no realistic treatment options, and practice experience shows that patients find this devastating news is conveyed insensitively. At the same time, medical practitioners generally try to communicate bad prognoses as carefully as possible, so whether it is possible to share such shocking news without some trauma remains open.

Once treatment is over, the patient is cured, in remission, or unable to be cured. The transition from aggressive treatment to palliative care is a difficult one, as Panek-Hudson (1998) describes, writing of her experiences in a Bone Marrow Transplant Unit in Australia. She notes that the separate agendas of palliative and acute care environments are difficult to reconcile in practice, with one focused on pain and symptom relief and the transition to death, while the other is concerned with active and curative intent treatment.

The move from treatment to palliation differs from one service to another, with such variables as the patient's age, potential for cure and public attitude towards the disease probably affecting the ability of the team to facilitate the transition. The aim of all services is to care for patients in the community as much as possible. Both medical and nursing assessments identify needs for care, support and education of patient and family, and plans are made to meet these needs. Patterns of visiting are established, and varied as the situation changes. A common pattern is for the home visits to be shared between the oncology district nursing team and the hospice team. These nurses communicate after each visit, sharing impressions, information and plans. They instigate referrals to the primary oncology service, facilitate treatment changes and advise on any aspect of living with a terminal illness. Short visits to the hospice for symptom review and management are arranged as necessary. A plan for dying may be made openly, or it may be allowed to evolve. Nurses counsel patient and kin to keep open minded on this aspect, reminding them that it is possible to go in to the hospice for the last few hours or days, or, if already in the hospice, to come home for those last days or hours. It is important to remain fluid about the place of

death, as sometimes what is wished for is not possible, and sometimes the patient will make a last-minute change of intention.

Equipment that is needed to care for the patient at home is provided, including beds, wheelchairs, commodes, as well as treatment materials such as syringes and syringe pumps.⁶ Personal care assistants can be arranged to bathe the patient, or to do housework, and physiotherapy and other services visits can be provided as necessary. Some respite care is possible in prolonged illness to give kin a break, depending on such factors as the age of the patient, and the diagnosis. It is not uncommon for kin to refuse respite care, out of concern that 'things could change' while they are not there.

If the patient requires 24 hour care at home, assessments will be made to determine the level of subsidy available, and kin will be expected to cover the cost of what is not provided by the state. Where there is willing and capable extended family and the time envisaged is relatively short, this works well. If not, the patient may need to be admitted to a private hospital whose primary function is care of the elderly, and this may be distressing for the patient and family, particularly if the patient is relatively young.

The situation for those in this study was normally that they retained access to the specialist unit where they had had their oncology care, though the primary responsibility for care was transferred back to their general practitioner in partnership with the hospice service. In the early stages of the study (1996) the hospice service worked with the district nursing service to provide home care, though later (1997) a specialist oncology district nursing service was established for the area. In some situations a Cancer Society volunteer also visited to provide shopping, gardening and company. Where all professionals in these services work as colleagues, respecting one another and keeping communication open, this works well, but in some situations kin and patients felt the lack of a key figure who was 'in charge'.

Participants

The people seen as significant to interview in this study were those who most shared the lived experience of a person with a diagnosis of a terminal illness.

⁶ Used for the administration of morphine and other drugs via continuous infusion.

Clearly the patients themselves would be interviewed, and the decision about the kin most closely involved would be made by the patient. While there was no intention to negate the experience of other kin, friends or support people it was necessary to draw a boundary somewhere for the purposes of managing the data and limiting the findings.

With the 'known dying' that allowed time to reflect, dying was related to a disease process and not to age or accident. The person would therefore be engaged with the health-illness system in some way, for both acute and on-going care. However, it was judged that those working in the acute system, including the consultant for the disease involved, were of peripheral importance to dying in this particular study.

The palliative care nurse, with her or his context of episodic continuity⁷ (Christensen, 1990) had a part in the lived experience of the patient that was potentially significant on several levels. For the nurse the patient is both an individual person and a member of the population of 'patients' for whom she cares in a lifetime of nursing practice. In this way the patient has both generic and specific qualities. Issues of relationship, communication and influence among all these participants would be of interest in the study.

Individual issues

Individuals die in their own way, as they have lived in their own way. Unlike childbirth, there is no evidence that when it is all over, this way or that way proves better. Those who are not facing death in the foreseeable future can talk relatively easily of such concepts of transition from life to after life; moving from life to being dead; going to heaven; not existing in any form and so on. When death is a probability it seems that it becomes more difficult to grasp, yet this is a time when kin see death as coming closer. The observations and reflections of those actually in the experience would be of central importance in the study, particularly when examined alongside existing philosophical understandings.

Moving from the general and theoretical to the specific and real paradoxically makes the experience more fluid and less certain. For example, Lewis' text in *The*

⁷ Episodic continuity describes the situation where nurses provide continuous care for patients in a series of encounters of shorter duration, punctuated by other duties and activities (Christensen, 1990).

Problem of Pain (1940) appears more confident than the writing in his later book *A Grief Observed* (1976). The earlier book was written from an educated and deeply thoughtful position whereas the second was written following the death of his wife and is more painful, more personal and more pathetic or feeling. It seems that being engaged in a life event is radically different from contemplating it from the safety of 'not-yet'. This study had the potential to open the engaged world of terminally ill patients to view and understand.

Dying is a very individual experience in which there is little predictability from one person's illness experience to another, and even for individual patients a good deal of uncertainty about the quality of the days to come. Issues such as how people cope with the fluctuations of well being; the place hope has in this constant adjustment; the expectations of kin of the whole trajectory, and how they manage the 'ups and downs' of the patient are all part of the personal context. A terminal illness also brings the knowledge that the relationship is now finite which affects the interpersonal context of patient and kin. How do people cope with outside enquiries when it is known that the person has a terminal illness? Perhaps there are similarities between this experience and others, for example, waiting for the transition into life that is birth.

All of the individuals who have a role, greater or lesser, in the patient's terminal illness come with existing knowledge. Literature, media, culture, religion, family traditions and life itself all contribute to familiarity with death and dying. The health professionals working in this field have had specific education to provide care for dying people. They also carry with them the knowledge that comes from practice, a situated knowledge that comes from shared experiences. Some individuals and kin have limited prior knowledge of death, as they may never have had anyone close to them die and may not have thought about dying or about death at all. Some general practitioners have limited experience in palliative care and an outdated idea of management. What influence do these situations have on the dying passage? And yet for all involved, but most particularly the patient, this is a once-only experience. The inability to review, edit or change the events of dying may exert a subtle pressure on kin and other caregivers to focus only on the patient's experiences and make them as good as possible. Exploring any possible presence of a moral imperative to make the

experience perfect, where it was found, could identify concerns of power and dominant beliefs.

As the person approaches death existential and spiritual issues are perhaps considered more than at other times. Exploration could find out if this was the case, and what related concerns were important to the patient and kin. At the same time I was aware of the possibility that people who agreed to be participants in the study may have reached, or be working toward, resolution of significant spiritual concerns. Equally, people may have agreed to participate in order to have an opportunity to reflect on these areas.

In terminal illness and the transition towards death the changes in mind, body, time and space perception, and in social issues are potentially and actually more acute and significant than at any other time. Drugs and disease processes affect mind, body, perception and relationships. Medication used to treat cancer is, of necessity, highly toxic and side effects are common and expected. Two frequently used drugs are vincristine and methotrexate, with side effects of peripheral neuropathy⁸ and increased sensitivity to sunlight respectively (Paterson, Rees, Czarniak, Reiss, & Evans, 1993). Further, the negative effects of illness are cumulative, as for example the decrease in self-esteem that follows when a body becomes disease-ravaged. Cerebral secondary tumours, by occupying space within the brain, or by infiltrating tissue, may cause delay in comprehension, or inaccurate word use, affecting social relationships. Both singly and in relationship with each other these issues were relevant for the terminally ill patient and thus questions for the study.

Assumptions

The discussion above, exploring issues that would be likely to be relevant in the study, reveals some assumptions, personal and social, that were part of the background in which the study took place. Assumptions include both what the individual expects from society and what society expects from the individual. In the context of this study the following assumptions were the taken-for-granted background of living with a terminal illness in contemporary New Zealand society:

⁸ Peripheral neuropathy refers to the loss of sensitivity in the body extremities of toes and fingers.

- that dying of cancer is somehow worse than dying of 'old age';
- that dying prematurely is more tragic than dying in late life;
- that cancer is difficult to treat and is highly likely to be fatal;
- that treatment for cancer, particularly chemotherapy, is an awful experience;
- that cancer is generally not blameworthy, and following from these:
 - that terminally ill people deserve special care and treatment;
 - that appropriate treatment will be available, and that immediate access will be ensured.

Society has assumptions of the patient and kin:

- the patient will wish to be treated, and will co-operate with treatment regimes;
- if the patient declines treatment social acceptance of this decision will depend on the severity of the condition and the age of the patient. That is, older people with more difficult to treat disease may be more readily excused not wanting treatment.
- the patient's central focus of life after a diagnosis of cancer will be the process and experience of dying;
- the kin will provide support and care for the patient.

Within the study I acknowledged the assumption that the participants would be open and indeed willing to share their experiences. Some assumptions held personally at the beginning of the study became apparent only during the process, for example the belief that the ideal place to die is in the individual's home. While superficially I acknowledged that people die in the place that is best for them, I was able to observe in myself a wish to promote dying at home, which surprised me, as I had believed I was open in this respect. I also entered the study with an assumption that the accounts participants offered would be relatively consistent individually – though I was ready for interpersonal variations. I found the degree of inconsistency within each person's several

narratives surprising, and found I had to re-examine the relevance of consistency.

The assumptions, both recognised and unrecognised, influence the language used, and the terms, set out below, reveal more of both the personal and contemporary context that is the milieu of the study.

Terms and language used in the thesis

Participants: those who provided their life experience as the material for this study were more involved than the term 'subjects' allows. At the same time, they were not 'co-researchers', as they did not assist in the interpretation of text or data beyond their individual making sense of their own lives in day to day living. Participants included the set of patient-kin-nurse who were formally interviewed.

Patient: the term 'patient' was the one used by the terminally ill person and his kin, and the health care service, so it is used in this work in preference to 'client' or any other possible term.

Caregiver: the term caregiver is used to denote any person, whether professional, volunteer or family member who provided care, or was ready to provide care for the patient. In addition to this generic use various caregivers are also separately identified.

Kin: the original term 'family caregiver' was challenged during the study as the first participant in this position was not strictly family. Kin seemed better to describe the close and significant relationship that could include groups with family ties and also those with no formal or legal relationships.

Palliative care nurse: refers to the nurse providing palliative care. For some this was their only work and for others it was a part of a more varied work load. Palliative care nurses worked in hospitals, hospices, clinics and the community and were employed in a number of different services.

Palliative care: this is care that is focused on alleviation of symptoms rather than cure of disease. It is further discussed as a care specialty in chapter 2.

Dying and death: are terms used interchangeably by participants, other writers, and in this text. In addition they may be separated, and overlap. Dying may refer to any time between diagnosis and death, and death may refer to both the actual time of demise and the time immediately preceding this. I have also varied the order of the words in the text to try to limit their being seen as a single concept.

Terminally ill: denotes people whose disease process is not amenable to curative treatment. The natural and expected outcome of the illness is death within a relatively short period of time, and the cause of death will be the particular disease process. In this study patients and kin were aware that they were terminally ill, but the way they experienced and understood this differed.

Hospice: hospice refers both to an institution and a service. The institution offers in-patient care for terminally ill patients and their kin and the service offers the same care for people in the community.

Gender: where discussion requires that the patients become 'everypatient' I have used the male pronoun consistently rather than other options such as alternating he/she. Likewise 'everynurse' is referred to as she/her for simplicity. Where 'everyone' or other plural pronouns are used this is followed appropriately by 'he' instead of he/she or they. I have made this choice to avoid awkwardness and aid reading and hope the pronoun he/his will be seen as neutral rather than gendered.

Tense: for the most part I have used the present tense with the intention of keeping the experiences, interpretations and questions alive.

Personal pronoun: I have made a conscious choice to avoid the use of 'I', 'my' and 'me' as much as possible after this introductory chapter. This is not done to comply with academic tradition, but so that the reader may engage with the text and not the writer.

Overview of the chapters

The preliminary chapters, 1 through 4, provide the theoretical and practical basis for the study. Chapter 2 examines the literature which provides part of the intellectual background for the study, enlarging on issues introduced above. The

body of literature is enormous and complex and is necessarily reduced to a slice of relevant material.

Chapter 3 returns to the philosophical issues begun above and argues the methodological approach appropriate for the study. This discussion begins with phenomenology, moves through hermeneutics to narrative and back to hermeneutics, debating the strength and value of each in relation to both the participant experience and the data. The chapter concludes by introducing relevant work of Anthony Giddens whose philosophical constructs assisted interpretation of the texts.

Chapter 4 outlines the study itself, with a general description of processes and issues. Specific challenges and concerns are discussed. The intention of the chapter is to permit audit of the process of data gathering and the overall integrity of the study, data collection and researcher behaviours. The chapter also introduces the participants by providing a short sketch, sufficient to allow the reader to build a picture of the people whose experiences follow.

The middle group of chapters, 5 through 8, are collectively the 'data' chapters. Chapter 5, *Fateful moments*, deals with the participants' early experiences and how they make sense of their lives with a terminal illness. Issues of crisis, an unreliable body and ontological security are relevant at this stage. A sense of the very personal nature of the experience is perceptible also, as the relevance of expert interpretation is challenged. Individual strength is apparent in the participant accounts, and confirmed by kin.

Chapter 6, *Living in suspended time*, includes many of the tasks of simply getting along with being terminally ill, such as beginning morphine and other tribulations. Relationships with others are reviewed, as the patient re-negotiates roles, duties and responsibilities, all of which become more or less fluid. While there is a sense of time standing still, this is parallel to an inexorable progress and the strength glimpsed in chapter 5 seems to become more visible as a clear resolve.

Chapter 7, *Handing over*, identifies the processes by which the patient makes sense of his life as it moves towards new experiences. There is a feeling of relinquishing of previous concerns, and for the most part this is done actively,

maintaining a sense of personal agency. Both narrative theory and the concepts of Giddens assist the explication of a series of dichotomies that are evident in the patient text.

Chapter 8, *Enduring work*, moves the discussion from the individual experience of the participants to a more generic level, providing an interpretation that, while rooted in the participants' narratives, brings it to a more abstract level. This philosophical exploration includes ontological challenges, questions of agency and some issues related to time. It also argues that the strength, resolve and sense of personhood, increasingly evident throughout the experience, coalesce to a perception of enduring self.

Chapter 9, *Discussion*, with chapter 8, addresses the significance of the study. The limitations of the study are acknowledged, and the findings related to current literature and practice. It is argued that the key findings, the centrality of the patient experience, readiness for change and a sense of endurance, while not entirely new, are here re-interpreted in ways that have the potential to improve both practice and the quality of this significant life event for those approaching death.

Conclusion

This introductory chapter has opened up many issues related to the central question of the lived experience of dying, and those of literature and methodology require more exploration before the study itself can be described and the outcomes presented. Chapter 2, in exploration of writing in relation to death and dying, opens the context more widely than the outline presented above.

Chapter two – a review of literature related to death and dying

The study, and the lives of the participants, take place in a context of particular knowledge and of a defined time and place. Unlike most other groups described in nursing research, for example Wenneberg & Ahlström's (2000) study with post-polio sufferers, their experience is not bounded by disease, or age, or situation. Death is our common fate, and most people die with some knowledge of impending death, so that the experience of looking forward to a dying time and one's death are in the probable futures of the majority of people. Knowledge of post-polio syndrome dates back only a hundred years, but knowledge of death goes back as far as time. It is not only our recent knowledge of death that is important in the context of dying in modern society, but our past understandings of death are the basis for present knowledge. The wisdom, practices and customs of the past remain with us in recognised and unrecognised forms. Indeed they are still present, and able to influence us, as we interact with older forms of art, literature, film, poetry, sculpture and oral tradition. The mystery of death, including how to die, is not simply addressed, but must be met by each generation and each person within his own reality. Thus a review of the context in which the study takes place must offer a brief historical overview, showing the themes and pattern of knowledge of the past, as these roots have growing branches in our present.

The context is not just the context of the experience of people dying, but also includes such areas as what dying is, what the particular physical, social, emotional and spiritual experiences may be, how best to care for people who are dying, and the experience of those who are helping, both kin and professionals. All of these accounts are part of the context of the present study because they all influence what people believe, know and do. In addition, dying overlaps with

other events or experiences, quite properly, and produces specialised as well as general knowledge.

Thus, while the literature is potentially vast, the content of this chapter is restricted to providing the theoretical and contemporary background in which the lived experience towards death of these people took place and in which it is understood. While qualitative studies do not require justification by literature review there is still an imperative to both set the study in a particular context, and to make a case for carrying out the study by identifying some deficiency in present knowledge. The text below clarifies these issues.

The chapter opens with a discussion of the theoretical understandings of academic writers and the less formal personal accounts of patients and kin who have experienced the diagnosis of a terminal illness and the passage of life that followed toward death. It includes a brief historical overview of the evolution of attitudes towards death and dying in Western culture, discussing significant shifts. The influence of advances in the disciplines of medicine, psychiatry, psychology, and sociology is reviewed with reference to selected literature to illustrate the shifts and changes that have occurred over time. Autobiographical and non-academic writing includes a discussion on how the popular media influence attitudes toward dying. Nursing literature in the field of death and dying is increasing rapidly and shows diverse areas of exploration. The range offered in this chapter is illustrative and relevant to the type of experience the study would explore.

Historical overview

The central societal and philosophical influences on the context in which people die in New Zealand are those of the so-called Western world. The strongest influence on beliefs about dying and death comes from the Judeo-Christian tradition, and though society is now more secular, practices such as funeral rites retain discernible links to this past.

Aries' (1974) useful review of dying and death practices in the Western world shows clearly how practices of the past persist in the present, and also how patterns develop, fade and re-emerge. This French historian-philosopher suggests that for much of history, death was seen as social, something

experienced by a whole community. Donne's (1572 - 1631) meditations on his mortality, when feeling as we might say today 'like death' as he languished in a churchyard with fever, show such a social connectedness with all life and death.

No man is an island, entire of itself; every man is a piece of the continent, a part of the main. If a clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as if a manor of thy friend's or of thy own were: any man's death diminishes me, because I am involved in mankind, and therefore never send to know for whom the bell tolls; it tolls for thee.

(Donne, 1959, p. 109)

Aries (1974) goes on to describe a phase occurring between the 16th and 18th centuries, which saw Death personified as a sudden intruder, sometimes violent and sometimes seductive. When Death is viewed as having the capacity to come by stealth or force it can interrupt the individual's proper preparation for eternal life and is more to be feared. Aries describes this shift as one that moved death from a concern of society to a personal issue. What followed next, Aries claims, was a romanticising of death, with ritual and emotion. The claim is supported by literature of the period. For example the poetry of Emily Dickinson (1830 - 1886) explores death and dying from many angles but it is not a situation of blame, even when sorrow and regret are present.

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It's coming - the postponeless Creature -
It gains the Block - and now - it gains the Door -
Chooses its latch, from all the other fastenings -
Enters - with a "You know Me - Sir"?

Simple Salute and certain Recognition -
Bold - were it Enemy - Brief - were it friend -
Dresses each House in Crape, and Icicle -
And carries one - out of it - to God -

(Dickinson, 1970)

Other contemporary poetry such as that of Tennyson and Keats confirms this sentimental attitude which was also apparent in art, music, literature and even architecture. Keats, who died in 1821, was aware of the fatal nature of his tuberculosis when he wrote the following:

Darkling I listen; and, for many a time
I have been half in love with easeful Death,
Called him soft names in many a mused rhyme,
To take into the air my quiet breath;
Now more than ever seems it rich to die,
To cease upon the midnight with no pain.

(Keats, 1991)
Ode to a Nightingale

Keats seems unafraid of death, seeking out death's acquaintance and welcoming the relief from suffering. Yet more than this, he is communicating his ease with death to his audience, including them in his experience and reflection. Aries (1974) interprets this trend to explore death, in poetry and other literature, as demonstrating a return to the question of the relationship between society and the individual at the time of the individual's death. With death as more of a social concern again an increased focus on the moral issues of caring was evident.

Who should care for dying people is an issue to which every societal group has a particular response - the caring practices of health professionals and kin in the study developed from their historical backgrounds. In Europe in the 19th century care of needy people, such as the poor, the sick and the dying, was an important Christian duty for those who lived their faith. Munro (1996) notes that in 19th century France the expectation was that this duty would be fulfilled by the ordinary citizen giving money to the church which would then make its own decisions about using the resource. Women who insisted on helping directly were viewed as somewhat of a nuisance and a potential threat to order. Up to the early decades of the twentieth century people died at home, cared for by kin and aided if necessary by voluntary or charity workers, such as those in religious orders or other church organisations. If people had no kin and could not afford to pay for care, they could be cared for in institutions such as the English workhouses or their local equivalent. Hospices, as the modern equivalent of morally driven care are described later in this chapter. In addition, medical, scientific and social developments have all influenced questions of how and where to care for dying people.

Today people do not expect a death-sentence with a diagnosis of tuberculosis or pneumonia, and correspondingly, when they are diagnosed with cancer they ask questions about forms of treatment. The context has changed. Callahan (1993) suggests that the development of medicine as an effective science has shifted society's attitude towards death from seeing death as a social evil to viewing death as a moral evil. He argues that around 150 years ago, death was a social loss or negative event, but that as science began to cure disease and stave off death people started to expect that medicine would continue to improve these skills in cheating death. Mortality statistics for New Zealand illustrate this improvement, showing female life expectancy as 61 in 1901; by 1950 it had reached 70, and in 1996 was 80. For males it changed from 57, to 67 and 72 respectively (New Zealand, 2000). Media articles revealing discoveries that will extend people's lives even further contribute to this unexpressed belief that we ought not to die. Litigation against doctors sparked by a seeming anger at medical science, particularly in the United States, confirms that people frequently believe that something *ought* to have been done to prevent death. Death has become a blameworthy event, rather than an event beyond anyone's control. Aries (1974), in his final claim that in Western society, particularly in North America, death is denied, would support Callahan's view.

This overview sketches the historical background upon which the subsequent developments took place. It also illustrates the traditions from which the knowledge of the participants in relation to dying and to death would be likely to come.

Developments of the last half-century

The complexity of developments related to knowledge and theory of death and dying during the last five or six decades makes recent evolution of thanatology difficult to map with clarity. Knowledge emerged from academic areas via an increasing number of disciplines, and from lay and consumer movement groups. The purposes of each group were diverse, ranging from acquiring greater knowledge, through practice and resource issues to the moral concerns of how to die. Generally the sequence of the evolution of present-day understandings of death and dying is as follows, though such a format is artificial and does not fully illustrate the myriad of influences or convey its complexity.

Around the time of the world conflict of 1939-1945, and in the decade that followed, there was a sudden increase in medical science's ability to respond to many life-threatening conditions, mainly by chemotherapeutic means, but also by improved surgical procedures. People who could not be treated were an embarrassment, leading to a general unwillingness to address the issues of death. In reaction to this denial of death the hospice movement began to gather strength and increase its influence (Cassidy, 1994). The work of Kübler-Ross (b 1926), published in 1969, added weight to the re-emergence of dying as an issue that could be openly discussed. At the same time there was a burgeoning, in a number of disciplines, of research into death and dying that continues to the present day. One outcome of the move to bring death and dying back into a normal social environment was a return to the notion of romantic death, and this had two quite opposite responses; one was the 'good death' perspective and the other the euthanasia movement. The present co-operative practice structure of multi-disciplinary care teams reflects cross-disciplinary collections of writing, joint research and conferences (Corless, Germino, & Pittman, 1994; Hallam, Hockey, & Howarth, 1999; Holmes & Purdy, 1992; Parker & Aranda, 1998). Throughout this recent history the repeating nature of concealment and recognition of death that Aries (1974) described can be seen, (Gorer, 1955/1965; Nuland, 1993) but its pattern is not clear-cut. Like a barber-shop quartet, the song's repetitions overlap, so we have concealment of death and recognition of death at the same time.

The ambivalent attitude toward death evident in everyday media and formal studies would be a part of the generic knowledge environment for patient, kin and health professional, and thus a factor to consider in the study. How people deal with opposing world views when put into a real-life dilemma could be quite different from any more theoretical understandings.

The next section is separated - though the separation is a little awkward because of a constant overlap - into the moral and practical issues (romantic death, good death, euthanasia, hospice and palliative care and ambivalence toward death) and academic, discipline-centred research that has a more theoretical output.

Moral and practical issues in the death and dying field

The term 'good death' is interesting in that, when seen as two words, it contrasts a desired and a non-desired item, suggesting that it is possible for something good to be found in something intrinsically bad. Yet as a discrete term it has developed further meanings.

Bradbury (1999) has addressed good death in two studies, identifying a range of key factors from absence of suffering, not dying alone, a timely death, to sudden death. The range of factors even included both being aware of a fatal diagnosis and being ignorant of it. Survivors had a wider acceptable range of 'good death' than professionals, most of whom judged minimisation of distress, having time to make any wishes known and the presence of family as key features. Bradbury cites her earlier (1996) study in which she proposed three theoretical constructs: the sacred good death, the medical good death and the natural good death. Walter (1996), in categorising types of death, is also evaluating the good death aspect, though this is not his primary intention. There is some congruence between Walter's types of death and Bradbury's constructs. Her sacred good death has parallels with Walter's traditional death, in which the dominant discourse is theology. Bradbury's medical good death seems to fit with Walter's modern death with a dominant discourse of medicine. Walter's third type of death, postmodern death, while offering a dominant discourse of psychology, focuses on the self and self-determination, and thus fits quite well with Bradbury's natural good death, which was categorised as free of extreme medical interference.

Five studies of nurses' views of good death were reviewed by Wilkes, identifying common themes of peace, symptom control without over-medicalisation, acceptance, preparation and completion, presence of family and hope. However the most significant factor was the variations in the manifestations of good death. The following comment sums up her position:

If this (such a wide variation) be the case, prescribed death, a death of compliance, death as a symptom of illness to be controlled, cannot be allowed to happen. The patient's and the family's ideas, feelings and expectations must be incorporated into any care given in preparation for the inevitable and unknown.

(Wilkes, 1998, p. 123)

The notion of achievement, inner resolution and peaceful death is evident as a thread in nearly all writing on the subject in which the person who is dying is more than an object. The subtitle of Callahan's (1993) book, *'In search of a peaceful death'*, and the expression of nursing goals in many nursing theories to include 'a peaceful death' show this stance. An early nurse theorist, Virginia Henderson (1897 - 1996) refers to death in her definition of nursing.

The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge.

(Henderson, 1966, p. 71)

A further response to the attitude of concealing death was the publishing of professional literature and research in the popular media and subsequent enlargement of common knowledge about death. The best-known theorist in this category is the Swiss-American psychiatrist Elisabeth Kübler-Ross. Her stage theory will be discussed below, but the subtle influence of her concept of 'acceptance' has also been far-reaching. One critic notes:

'On Death and Dying' depicts acceptance as a return to a peaceful, oceanic, womb-like state, a near ecstatic freedom from pain and suffering, similar to religious experience of mystical transcendence. The appeal of the book is undoubtedly linked to the sanctification of peak experiences, achieved through drugs, meditation or sexual abandon, in the American counterculture of the late 1960's.

(Seale, 1998, p. 30)

The return of the romantic pattern of death shows a new aspect here, seeing death as some kind of transcendent experience. This sentimentalism draws a blunt response from Nuland, (1993) who says that he has never seen a 'good death'. He describes a variety of dying and death scenes in clinical terms and makes a strong case for euthanasia. Many other supporters of euthanasia also deny the romantic death. An attempt to demythologize the process of dying is made by Nuland as he describes biological events and, with stories to illustrate, shows death and dying as painful, prolonged and distressing to patient, kin and professional. However it should be noted that his work is a reflection on his

practice life and does not claim to be an objective or academic work. His case studies support his view and his own evaluation of each situation is dominant, but his work is published in the public arena, reaches many people and thus influences people's perception of what dying is like.

The hospice movement, initially a response to the question of how we should care for dying people now that society recognises their presence and need to be cared for with dignity, has evolved into the specialisation of palliative care. From palliative care the specialisation of palliative medicine has developed, giving rise to concerns that over-medicalisation of palliative care may move hospice focus from care to treatment. While the patients in the study were probably not aware of this debate, the nurses were certainly concerned that funding for hospice care could be diverted into therapies and away from human care. Acknowledging the debate was important to create sensitivity to any subtle influence on decision-making by health professionals.

The cross fertilisation of academic and popular literature and the development of some writing that bridged both groups, meant that more formal knowledge than that provided by such media as art, film, poetry and television was influencing the ordinary member of society. For example the books of Kübler-Ross (1969), Callahan (1993) and Nuland (1993) are available at regular bookstores and are written in very accessible form, making their ideas and opinions part of common knowledge and therefore part of the context of this study.

Formal academic writing

Interest in the field of death and dying as a life experience to be investigated seemed to quicken and gain momentum during the sixties. In North America Glaser and Strauss began their studies in hospitals leading to the publication of their *Awareness of Dying* (1965) and *Time for Dying* (1968). These significant studies influenced subsequent developments, though modern critique (Seale, 1998) shows the limitations of the study imposed by unrecognised contemporary ideologies. Seale points out that the focus of the two works is the context in which dying takes place, the relationships among those involved, and the expected structure which is prevalent and which subtly directs actions and choices. He identifies the dominant discourse as that of the health professionals and the work of the institution. The institutional discourse is the yardstick for the

patient and kin experience which are evaluated as fitting or not fitting with the standard account of events. While such dominant discourses are more easily recognised in retrospect, Seale does remind us that there are always power balances in interpretation. These questions and issues would be of importance in the study, as health professionals' language commonly includes such terms as 'compliant' (and 'non-compliant'); co-operative (and 'non-co-operative'); and supportive (and 'non-supportive') when describing patients and kin. The health professionals have personal and institutional standards to evaluate these power-related terms, and experience shows that patients are often aware of them.

British work in the death and dying field in sociology has been relatively sparse to the last decade of the century but more recent writing (Seale, 1998; Clark, 1993; Walter, 1993; Howarth, 1996; Hallam, 1999) provides scholarly thinking which challenges current thinking and practice in a very useful way. British sociology uses modern academic paradigms such as deconstructionism, narrative and gender to critique death and dying theory, whereas the North American work (Glaser & Strauss, 1965; Kalish, 1979; Wass & Neimeyer, 1995) is richer in cross-disciplinary experience and the qualitative approach.

Walter (1993 p. 36) offers a number of alternative theses that provide ways of comprehending the complexity of changing attitudes and practices towards death. Significant in his work is the use of 'frames' to view and understand modern dying and death. Such frames influence attitude, language, outcomes and what is regarded as important. Within a hospital environment Walter names such frames as the practical, the biomedical, the lay and the semi-psychiatric, though he notes that there is no particular relationship among them. Other frames identified are the theological and the funeral frames, and the psychological frame for grief. He claims that such fragmentation in the way different groups interpret the same phenomenon is typical of the post-modern era.

Clearly the participants in the study would have both individual and shared frames through which they viewed the world, but the significance of frames on actual lives, and the constancy of frames would only emerge during data collection and interpretation.

Theories and models

In the last half-century knowledge about life's passages have commonly been organised into theories and models which are linear in structure. Often they are portrayed in chronological sequence and their influence is so strong that they are often seen as the norm beside which life is measured. Of course life as a series of stages is not new, as shown by Shakespeare's seven ages: *one man in his time plays many parts; His acts being seven ages* (As You Like It, act 2, sc 7, Cambridge ed.), yet there is a sense in which stages are now somewhat prescriptive. Both the expectation of stages and the influence of any specific model were part of the context of both patients, kin and professionals in the study.

The influence of psychology and psychiatry on theories of death and dying, following the work of Freud (1856 - 1939) and of Kübler-Ross (b 1926), remains very powerful. Models based on these disciplines fit into the semi-psychiatric frames described by Walter (1993), as they emerge from the discipline but are transformed for multi-discipline and lay use. Psychological stages are also seen in grief work, which is not surprising, given the contact between Kübler-Ross and Parkes and Bowlby described by Parkes (1997) as they worked on loss issues in the middle 1960's.

Kübler-Ross's well-known stages of denial, anger, bargaining, depression and acceptance have been applied as a prescription which the patient is expected to achieve. Though she did not claim that dying people would follow a rigid progression, her work has been used as though it were a gold standard. Anecdotal stories of well-meaning people trying to force dying people into this framework have led to some discomfort with the theory. The attractiveness of her theory lies firstly in the familiarity of a stage process. Our lives are lived in sequences, events follow events, many of which are predictable in short and long time frames. Humans search for patterns and predictability, and this theory offers some structure. Secondly, the various stages have been observed, whether in Kübler-Ross's sequence or not, so there is a recognisable truth about them. Her theory focuses more on the psychosocial issues relating to death and appears to assume that if these are resolved, other attendant concerns will not be problematic.

As the limitations of Kübler-Ross's work were recognised more models were proposed in attempts to encompass the complexity of the dying experience. Glaser and Strauss (1968) describe the patient's life as death approaches as a trajectory, implying the person would have a strong focus on an inevitable and relatively predictable outcome. The term trajectory also gives the impression that an undeviating progress towards the time of death is expected.

Pattison (1977) builds on the notion of trajectory work, arguing that there is a definable passage from diagnosis to death with tasks to achieve, and an effective and ineffective resolution. Devised at a time when the pattern of being terminally ill was more predictable, this model does not take into account periods of relative wellness that patients now experience.

Buckman (1993) proposed a three stage model that is both simpler and more comprehensive than Kübler-Ross' five stages, and it is argued, more accurately reflects the patients' experience. The model begins with the initial stage of facing the threat, moves into the chronic stage and then to the final stage of acceptance. As the trajectories of many conditions, particularly cancers, now include a period of chronicity, this model fits better with what people currently experience.

The longer disease prognosis of modern cancer experience is also reflected in newer interpretations of the living/dying phase common to many models. The patient experience during this phase was described by Buckman (1993) as being 'integrated dying' or 'dis-integrated dying', meaning that the patient was able, or not able, to integrate both living and dying successfully into his everyday life. Copp (1998) proposes that the living-dying phase may now include both integrated and disintegrated dying. Tasks of dying, first proposed by Kalish (1979), re-appear in work by Corr (1992), who suggests four main areas in which there are tasks to meet. These four areas are physical, psychosocial, social and spiritual. Copp's (1998) nursing study examined the experience of individuals dying in a hospice setting in relation to impending death. She proposes a 'readiness to die' model, in which the individual achieves a congruence of both body and person ready to die. Seale (1998), a sociologist, also allows for both social and biological death.

Other contemporary writing critiques the use of models, particularly in the grief field, for problematising or medicalising events that are part of natural life

(Bradbury, 1999). Reflecting on extant theories is important in this study because, as they are published in academic and popular writing, it is common for both professionals and lay people to know of them and use them. Their continued evolution suggests that they do not yet fit the dying experience, though that, in turn, brings up the question of using a model outside of the societal and temporal context in which it was developed.

Multi-disciplinary writing

Collections of thanatological writing during the last decade bring together significant cross discipline studies and reflections for those working in the field. For example Wass and Neimeyer's (1995) *Dying: Facing the facts* offers chapters covering historical and cultural aspects, writing from psychology, sociology, nursing, medicine, political, philosophical and counselling. Parkes, Laungani and Young's (1997) *Death and Bereavement Across Cultures* necessarily includes much on practices related to dying and the existential aspects of death itself. *Dying, Death and Bereavement* (Corless, Germino & Pittman, 1994) is another such collection, again bringing together significant workers in the field of thanatology from many disciplines.

An illustration of the contradiction raised by the denial of death and the inevitability of death, is the placement of terminally ill people in intensive care where they experience extreme measures that are futile. A North American study (Muzzin, Anderson, Figueredo, & Gudelis, 1994) explored how individuals and families seek to normalise life while living with cancer. The authors proposed that the reasons why there was such a low level of access by these families to appropriate community services and networks may be because the illness is heavily stigmatised and medicalised. While the problem of terminally ill people dying in intensive care units is not yet common in New Zealand, it is still something that patients and kin fear, influenced by North American film, television and drama.

Although this study began from a nursing focus, and most of the literature reviewed is thus health-illness related, literature from other fields is also part of the intellectual context for both patients, kin and professionals. Such books are purposely written, by appropriately qualified professionals, for both professionals and lay people. From the social psychology-counselling area, for

instance, is *The Art of Dying* (Weenolsen, 1996). *Light from the Dark Valley* (Cassidy, 1994) provides a combination of theological-medical reflections.

The increasing movement of the medical profession into palliative care as noted above, has led to a number of texts such as that of Dunlop (1998) and Woodruff (1999). These texts are guides to good medical practice, and also useful for the nurse. However, their content remains strongly medical and physically oriented, with small sections on spiritual, cultural, social or alternative approaches. Attitudes towards patients are kindly but given from the expert point of view. This approach is not necessarily out of place, though it does bring up questions about whose experience is significant in the dying period.

Some clear points arise from the reviews above. Over history people have sought to understand the nature of dying and of death. That human kind has failed in this endeavour is shown by continuing research, philosophical reflection and writing. The theological interpretations were superseded by more secular biological explanations, and overlapping with this, sociological accounts. None are adequate, and a contemporary move to acknowledging the mystery in human life may indicate that the unknown is regaining a place in the dying and death experience. At the same time the struggle between the human reluctance to die, supported by ever-more effective medical science, and the inevitability of death remains a strong element of the context, producing degrees of ambivalence for all participants. These issues are part of the collective and individual contexts of the people in this study.

Nursing literature

Nursing literature focuses on nursing work - caring for patients and their families at times when nursing knowledge and actions can support them. The context of nursing knowledge particularly in relation to the field of dying was relevant to explore and become familiar with before interviewing. The issue of situating personal experience within the literature was important, too, to note where assumptions about good practice were supported (or not supported) by formal investigation and wider knowledge. A wide scoping and investigation of areas that were likely to be met, such as concepts of hope and suffering, terms commonly used in the experiences around dying, was also judged necessary. While it could be argued that such reading might limit the process of

interpretation to a previously decided list – and this risk was taken into account – the purpose was to provide a sensitising to common experience in all its presentations so that it could be recognised in many forms.

The amount of nursing literature related to the field of dying and death has increased enormously in the last decade, building on the early work of nurse scholars in the area such as Quint⁹ (1967) and Samarel (1991, 1995). Nursing literature reviewed for this study has been grouped into four sections: general studies on dying, nursing practice in palliative and terminal care, specific issues of the dying experience, and studies on kin experience in caring for dying family members.

General studies on dying

Nurses' writing on dying as a field of knowledge is found in collections mentioned above. Benoliel's early work is based on early sociological research with Glaser and facilitated the entry of nurses to this potentially difficult, yet appropriate field of enquiry (Benoliel, 1994). Observation and interviewing were explored as means of data collection, and the learning gained from process and outcomes provided a basis for studies that followed. The influence of this scholar continues to the present; her major works guide present studies and she is still writing, researching and offering papers in the field. Her work is highly respected by many disciplines and adds credibility to subsequent nursing studies.

Samarel's (1991) study researched nurses' experience of providing care for people who were facing both life and death in a combined acute and terminal care ward. She also gained insight into the patient and kin experiences by her observations and discussions with participants. This study confirms the suitability of an open stance to data gathering such as that found in qualitative methods. Copp (1998) offers a meta-analysis of current theories of death and dying, and includes the outcomes of her own 1996 study. A meta-analysis of literature related to chronic illness (Dluhy, 1995) identifies themes common to a number of relevant studies as demands and challenges; emotional and cognitive responses; day-to-day tasks; illness in a 'healthy' society; changing patterns of

⁹ This writer used the name Quint in 1967; later she was to use Quint-Benoliel; she is currently writing under Benoliel.

social interaction and potential outcomes. As it can be argued that terminal cancer has many of the attributes of chronic illness – on-going-ness, ever-present symptoms and no likelihood of cure – it seems appropriate to include the findings from some chronic illness studies. These studies confirm the complexity of dying, the need to value the social context and the importance of avoiding categorisation of patient or family into an ill-fitting theory.

Review of this group of literature has helped identify the general range and content of nursing enquiry at a macro-level. The fact that there are fewer studies at this level is likely to be related to the size, and therefore the cost, of such large scale work.

Nursing practice in palliative and terminal care

The following literature, written in the main by nurses, contributes to knowledge about the care provided for patients by health services for terminally ill people, and that of the general quality and approach of nursing care.

Nursing research and reports relating to nursing practice in palliative and terminal care include reports about palliative care services in hospice settings (Ogden, 1994); hospital and community (Irvine, 1993) and rural community (Knepfer, 1994). These reports document the development of the services offered and the work of the nurses employed in them. As many hospices and hospice services are partially charitably funded in the UK, Australia and New Zealand, the articles also address the support needed to maintain them. In addition these reports argue that nurses need particular skills and knowledge to work successfully in the area, and that special support needs to be provided by the services for their staff.

Collections of writing about palliative care nursing are beginning to appear and provide both philosophical discussions and the findings of studies for practitioners to reflect upon. Parker and Aranda's 1998 volume covers such issues as care for children, the dying experiences of residents of rest homes, palliative care for people with dementia, as well as resource concerns and ethical problems. The overall tenor of such collections is that palliative care is a right of all people; that it deserves resourcing; that it is a specialist area and that it demands much of those who work in the field. These Australian assumptions

show parallels with those identified in chapter 1 for the New Zealand context. The political as well as the care focus of these collections is echoed in New Zealand in the biennial Haematology-Oncology Nurses' Conference. The papers offered here provide a snapshot of contemporary issues, and provide a forum for nurses to debate current problems. Though the papers are not published in collected form to date, the oral tradition allows a sharing of knowledge. The nurse participants in this study showed evidence of knowledge gained from this and similar conferences.

Nursing studies address diverse issues such as culturally appropriate care for dying people and their families (Becker, 1999; Boyle, 1997; Kanitsaki, 1998) arguing generally that the cultural beliefs and practices of the 'other' are very important at this time. Concerns relating to deaths in acute or intensive care (Manias, 1998; Pierce, 1999) are also studied, showing that the institution's belief systems tend to dominate the patient/family needs. Effective communication was found to be an issue, though this is hardly new and the reader is left wondering why these actions are not being carried out. Perhaps it is related to the concerns raised above which suggest that dying competes with the institution's focus on life-saving interventions. While these items refer to situations outside of New Zealand, media articles suggest that patients and families here, too, experience communication problems, in spite of apparently well-educated health professionals. The information coming from the study could help provide good evidence about this topic.

Another study whose outcome affirmed accepted wisdom was that of Rasmussen and Sandman (1998) which showed that most nursing interaction was based on 'doing' rather than 'being', in spite of the knowledge that the combination of being and doing reflects good nursing care of the dying. Nursing activity was also studied by Bottorff, Gogag and Engelberg-Lotzkar (1995) and May (1995) who identified some of the strategies nurses develop and use in their care of terminally ill people. An awareness of such strategies would help recognise their use in the study, and also encourage an openness to other possible strategies that nurses use in New Zealand.

Specific issues of the dying experience

In most literature on issues relating to oncology, terminal illness, dying and death there are terms or concepts that are in constant use. These include suffering, comfort, grief, hope, transcendence, dignity, altruism, and finding meaning. Such commonly used concepts often contain much personal and familiar meaning, and may consequently lose some of their usefulness, so an examination of current understanding and use was an important early step. The section below provides a window into such work in order to raise issues that were likely to arise in the study. This group of writing finishes with a review of some other issues of real concern to nurses working in this field: medication, especially narcotics, and meeting the spiritual needs of patients and kin.

Daly (1995) investigated the lived experience of suffering using Parse's 1981 Man-Living-Health model to guide interpretation. His findings were that suffering was paradoxical, multi-dimensional unfolding and co-created and co-constituted - that is, that it is complex beyond the linear sequential understandings of previous studies. A later study by Fagerström, Eriksson and Engberg (1998) explored the ways in which patients communicate their suffering as caring needs. It found that nurses who attended to the experience of comfort were able to relieve suffering, and also suggests that nurses who include knowledge of the existential/spiritual dimension of human beings will enlarge their understanding of patients' caring needs.

The concept of comfort has been explored extensively by Morse (1994; 1995; 1998). One study (Morse, Bottorff & Hutchinson, 1994), identifies nine themes relating to comfort, which they see as achieved in a balance of living without being dominated by the ill or injured body. A further study (Morse & Carter, 1995) shows the relationship between comfort, suffering and enduring. In this study nursing actions which were perceived as comforting reduced suffering and enhanced the patient's ability to endure.

A concept analysis of grief by Cowles and Rodgers (1991) explored the knowledge of a number of disciplines related to grief, finding a general vagueness and ambiguity. Their work defined the following attributes of grief: that grief is dynamic, a process, individualized, pervasive and normative. There is more work to be done, they suggest. A later concept analysis study (Jacob,

1993) works towards a comprehensive definition of grief, identifying antecedents, attributes, referents and intervening variables. This structure is helpful, though the ambiguity remains, resulting from the professional use of words which also have common meanings.

Hope is common theme in care of the dying, and identified as important in many studies, including Kübler-Ross (1969), Samarel (1995) and Glaser & Strauss (1965). Hope is the sole topic of a study by Benzein, Norberg and Saveman (1998) who isolate hope away from the health/illness variable in their study of hope in a Christian group. For this group, their hope was founded in God. A study by Cutcliffe and McKenna (1999) of hope in critically ill patients found that hope was greatly therapeutic in these patients' recovery progress. The inter-relationship between the patient's hope and the nurse's hope is described in an account of a patient making an unexpected recovery from a malignant melanoma with widespread secondaries (Douville, 1994).

The concept of hope was the subject of a meta-analysis reviewing 46 articles from 1975 to 1993 (Kylma & Vehvilainen-Julkunen, 1997). This work identifies a lack of precision in the descriptions, noting that hope may be described as an emotion, an experience, or need. A distinction is made between generalised and particularised hope. In the dynamics of hope the most important dimension is the dialectic between hope and despair. These authors identify the need for further work to clarify the concept, suggesting qualitative longitudinal study, and work with healthy people at different stages of their life cycles.

The phenomenon of transcendence was explored in doctoral study by Williams (1995). The researcher proposed a tentative definition of transcendence that included wisdom, connectedness and a sense of peace, and sought to contribute to the understanding and description of the phenomenon by examining the experience of three participants who were evaluated by experienced nurses as having reached this state. This study confirms the complexity of life experience during dying, showing that hoping for life while facing death elicits a variety of degrees of attention to preparation for death.

Further examples of concepts related to the experiences of the terminally ill include a clarification of dignity (Haddock, 1996) and altruism (Smith, 1995). Though the context of these two studies was not the experience of dying people,

the concepts of dignity and altruism are used often in care of the terminally ill. Altruism is present in the care provided by kin, and mentioned as a sub-concept in several of the studies already cited. An Australian study (Hudson & Richmond, 1994) examining the hopes and expectations of elderly in rest homes, found that dignity was a key desired feature of their dying.

Creating meaning from life experience is a precursor to many of the concepts described above. Coward (1997) reviewed nursing research and psycho-social theories, and undertook observation to attempt to understand how people construct meaning from the experience of cancer. The conclusion is that there are turning points within the cancer trajectory when choices made by persons with cancer and their families may have far-reaching consequences in terms of new goals to pursue and new sources of meaning to create. A further study into the search for meaning in illness crisis is that of Dirksen (1995) who believes it is important for nurses to discover what meaning people attribute to their cancer in order to provide appropriate care. Finding meaning in suffering may offer some insights to finding meaning in cancer experience. The nurses in a phenomenological study on suffering assisted their patients to find meaning as they responded to a 'call to care' by listening, being present, providing hope, calling forth a voice and being a guide (Eifried, 1998).

Studies related to providing care for terminally ill patients

A pilot study by Edwards, Herman, Wallace, Pavy and Harrison-Pavy (1991) compared patient-controlled and nurse-controlled anti-emetic therapy during chemotherapy and is an example of quantitative studies examining specific symptoms and experiences in a controlled way. This study confirmed the findings of other studies (Snell, Fothergill-Bourbonnais, & Durocher-Hendriks, 1997; Pellino & Ward, 1998) that the patient who controlled the administration of his own medication used less medication for the same or better analgesic or anti-emetic effect.

Despite decades of education, concerns relating to the use of opioid¹⁰ and opiate¹¹ analgesics remain present for nurses and kin. Fears of addiction, side effects and the significance of increased pain are among concerns raised by

¹⁰ synthetic narcotic with opiate-like activities.

¹¹ narcotic containing opium or any of its derivatives.

Ward, Berry and Misiewicz (1996). McCaffery, a nurse who has been researching pain and its management for many years, in a study with Ferrell, suggests that the misconceptions brought by nurses into their education may be carried into their practice unless they are directly addressed (McCaffery & Ferrell, 1996).

Spiritual aspects of chronic and terminal illness are explored in studies such as that by Narayanasamy (1996) who argues that nurses can and should provide spiritual care. However there are those who argue that nurses have no place in providing, or even assessing the need for, spiritual care. For example Behi (1997), argues that in a secular society such work is best left to specific professionals. A further concern is how decisions are made and communicated when treatment is not effective. The issue of transition from cure to palliation is confronted by Panek-Hudson (1998) as she writes of the dilemmas faced by nurses in their attempt to provide optimal levels of care when they recognise the futility of treatment. Such recognition may be in advance of the patient, family or medical practitioner. She notes further that "nurses are required to work daily with the competing interests and perspectives of all involved and it can be enormously frustrating when attempts to meet the comfort and care needs of the patient are thwarted by a continued focus on cure" (p. 255).

Specific symptoms may also be the subject of enquiry, as their management in the terminally ill patient will often produce different challenges than those seen in the patient who is not dying. For example, an assessment of the instruments available to measure dyspnoea¹² by van der Molen (1995) showed that no single existing instrument takes into account the complexity and multi-dimensional nature of this symptom. It makes sense, then, to tailor symptom research to a particular context and not to assume a generality of assessment modes. While nurses and consultants were specialists in palliative care, it was important not to assume that the care they prescribed would necessarily be focused on the patient's situation, and studies such as this provided a reminder of the complexity of care needed.

¹² Dyspnoea refers to any difficulty in breathing, including breathlessness and laboured breathing.

Patient and kin experience

Academic studies of patient and kin experience have the advantage of greater objectivity, defined boundaries, and a specific research process. They will thus produce more reliably applicable results than the personal accounts that follow the section below. With the study interviewing kin as well as patients a review of relevant literature related to their experience was vital.

The whole cancer experience, including that of chemotherapy, is stressful for family as well as for the patient. A study of men's lives while their wives were having treatment for breast cancer showed many sources of stress resulting in substantial emotional distress, worse at times of uncertainty, but almost always present (Wilson, 1991). Part of the stress came from needing to damp down personal stress in order to support a wife undertaking chemotherapy. Schumacher (1996) proposes that family care-giving is re-conceptualised to Family-Based Illness Care which takes this stress into account. The fatigue experienced by cancer patients is a prevalent symptom, and difficult to understand fully and treat. A phenomenological study (Pearce & Richardson, 1994) identified five essential factors: the nature of fatigue; the causes of fatigue; the consequences of fatigue; coping strategies; and the constant presence of fatigue.

Related studies also recognise kin stress and concerns. Research addresses such issues as the extent of support perceived and received (Robinson & Austin, 1998); the effects of terminal illness on patients and their caregivers (Davis, Cowley, & Ryland, 1996); family and friends' needs at the dying of a loved one (Berns & Colvin, 1998); the need for information and support (Yates & Stetz, 1999); how community care was negotiated (Aranda & Kelso, 1998); how professionals could help kin both during (Hegedus, 1999) and after terminal illness (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998); and how decisions about end of life care are made (Sicola & Hall, 1997).

The experience of the patient himself is also the subject of research and the outcomes of such studies formed part of the background of knowledge in which the study took place. An extensive study of suffering in the cancer experience highlights the complexity of the losses of terminally ill people. The tension between the expected and the actual experience is shown in the loss of faith and

trust in the medical system, the failure of treatment, the death of other patients, the dismissal of symptoms by physicians and the false reassurance that 'cancer can be beaten' (Gregory, 1994). The effect of the culture of medicine as cure is seen as influential in a study looking at end of life decisions for the elderly, and open communication once again seen as essential in reaching good outcomes (Basile, 1997).

Nursing research and academic writing in this field of the terminally ill patient is increasing and addresses a wide range of issues, specific and general, from a variety of approaches. It shows respect for patients and families and commonly demonstrates a pause before interpretation. Exploring and clarifying concepts is an important area of nursing research as concepts can contain a wealth of complex meaning which investigation shows may not be shared. Present research-based knowledge is thin in several areas: there is room for more patient and kin involvement in the direction and interpretation of dying narratives; using narrative from several people in a kind of constellation around the primary participant does not appear widely used, if at all; and investigation into recognised and unrecognised concepts is not yet adequate.

Writing directed at practitioners is the subject of both research and theoretical-philosophical writing, and is increasing in amount as interest in the area continues. No less plentiful is writing directed at other participants involved in the experience of terminal illness.

Non-academic writing and writing for the patient and lay caregiver

The primary participant in this study is the patient, and the accounts of patient and kin are key data. It is important, therefore, to examine what currently exists in writing by and for these people. What is known already and the availability of such information for the lay reader is relevant here. That dying was once a non-medicalised event is evident in the profusion of writing for the patient, lay carer and support people. There are accounts from the central figure, from kin, from support people and from professionally educated people writing for these groups.

Personal accounts

Patient accounts give a personal insight into the experiences of being terminally ill, and are usually from the 'triumph over adversity' genre, or the 'living with adversity' genre (Warburg, 1988). It is possible that the person who has another frame on the experience, such as anger, or denial, puts energy into attacks against the system, maintaining the barrier against the outside threat, or, in the process of writing, comes to terms with what is happening. Sometimes these writers call themselves 'patient', 'sufferer' or 'victim', though this is no guide to the actual attitude expressed. Mostly they do not label themselves, and some discuss this saying, for example, that the disease process is only a small part of who they are. Madden's focus is on life as he notes that "the joy of living need not be dampened by thoughts of death, but death should be seen only as a part of, and an affirmation of life. . . These days bring new challenges and new excitement" (1993, p. 54).

Some are more personal accounts, such as French's *A Season in Hell* (1998), which traces her life from an awareness that something was wrong, through treatment to recovery. She is clear about the agony of her travail through illness, and the huge cost to her to stay alive. Her philosophical reflections are searching and beautifully written and demonstrate an uncommon courage and determination. Some accounts of non-academic writings are personal journals which family have edited and produced after the person's death, and may form part of the grief work of these families. Certainly the significance of an encounter with a life-threatening condition such as cancer is such that individual accounts are frequently written, and, Sheehy notes (1995), form a large number of unsolicited manuscripts to publishers. She suggests further that mastering a major life transition may produce wisdom, and equates such a painful passage as a secular 'conversion' experience.

Collections of personal accounts are produced to assist others in a similar situation to understand some of the ways the experience may be lived through and managed. *Cancer Through the Eyes of Ten Women* (Dunker & Wilson, 1996) offers a variety of accounts, of different women, from different backgrounds and with different experiences. It seems that personal stories communicate very effectively with people who are then able to make their own parallels with the

stories of others. Such publications are often produced by organisations such as the Cancer Society.

Some authors write specifically to enable others, both patient and kin, to cope with diagnosis, treatment and the possibility of death. Examples of this group are Madden's *Carpe Diem* (1993) and the very popular *Letting Go: Reflections on Living while Dying* written by Schwartz (1996). This type of book, especially when written by a competent author, provides a reflective guide for those new to the events, and comforts, coaches and reassures them.

The professional account of the patient experience

Professional writing in this group is often from counsellors, particularly grief counsellors, for example *Comfort and Care in a Final Illness* (Kolf, 1999). Kolf is a director of bereavement and a hospice volunteer co-ordinator: her book is simply written and addresses the reader directly as the person experiencing the events. There is no doubt that professional writing is useful for the patient and lay-person, and for those who have access to them and use them, they are informative and comforting. Most, however, are focused on the North American health, illness and dying model, which is frequently an aggressive fight against death in comparison with the New Zealand norm.

Exceptions are those from England and Europe, and their audience is more likely to include professionals. Cassidy (1994) offers a theological perspective, based on her personal practice as a palliative care physician and woman of faith and Kearney (1996) writes on dealing with the intractable pain he calls 'soul pain'.

Publishers group many of these books under the heading of Self Help, which seems to work well, as both patient and kin often have a desire to know more of what to expect and to maintain independence and autonomy. On the whole their purpose is either cathartic or educational, but both may strike chords with patients or kin, and provide welcome information.

The place of popular media, such as film, print media and television is another large area of influence. It is difficult to assess because of its volatility, size and range, and the number of factors which would need examination. To what extent do people trust what they read in the press or hear on the television, and even when they are skeptical, what subtle influence is exerted? For example Johnston

(2000b) reviews a book about beating prostate and breast cancer that was written by a geo-chemist researching the links between the environment and health. The writer, Plant, had a personal experience with breast cancer, and, attributing her survival to avoiding dairy food, sought support for this position in the literature. However experts invited to comment on her stance note that it is not based on clinical trials, and various issues that could seriously affect her findings are not adequately factored in. Some of these critics express concern that avoiding dairy products to complement cancer treatment could introduce other problems. Nevertheless the general public appreciates personal survival accounts, and Plant's influence, strengthened by her professional status, may well influence women with breast cancer, or a personal or family history of breast cancer.

A brief evaluation of media articles related to cancer shows a heavy use of metaphor related to battle, for example *beat this cancer, win this fight, not going to let it beat me, triumph over it, last battle, fought courageously* and so on. The influence this has on individuals is not known, especially the potential for self blame when death is inevitable, and the person wonders if he hasn't *fought* hard enough. The headline given to a story of a media personality who recently disclosed a diagnosis of prostate cancer is "I am going to beat this cancer for my children" (Holmes, 2000). Such an active response is common to the point of being expected, making it difficult for the newly diagnosed cancer patient to espouse a different reaction.

The World-Wide Web

A good deal of information is easily accessible via the world-wide web and includes material ranging from the most recent scientific studies of diseases, through alternative treatments to personal web-sites established by people experiencing particular illnesses and conditions. It is not difficult to access such information and refine a search for a particular topic. Those web-sites that provide details on the number of 'hits' or contacts made, reveal that large numbers of people do use this avenue for information gathering. Through sites people can access libraries, research, support groups, treatment options and basic disease knowledge in accessible language. The range and amount of information available, coupled with inexperience in evaluating such data can produce confusion. Research on the effect of this mass of information on patients and families is not presently available, but the freedom to research information for

themselves appears beneficial for patients. The question that arose for the study from internet information was not only its use by patients and/or kin, but what influence did the ability to access information directly have on them.

A second significant issue is that of the interventions called variously *alternative, adjunctive, natural* or *non-medical*. Though writing about them is usually non-academic and not subject to objective scrutiny, there is no doubt about their influence when listening to public debate or hearing of appeals for funding patients to undertake these 'treatments'. The presence of both the internet as a source of information, and alternative treatments is problematic as their informal aspects make evaluation of their effect difficult. Nevertheless, they are a part of the knowledge and practice context of the study, and it is important to recognise the place that such influences may have on the knowledge and expectations of those encountering terminal illness either as individuals or as companion to another.

That there is a dissonance between the perceived understanding of dying experience and the actual patient life is shown in the proliferation of patient accounts. Their need to have their narratives heard may be in part an individual work to make sense of their experience, but it is often accompanied by an almost desperate need to communicate what dying is like to others. Professional or formal accounts may be expressed in language that is inaccessible to patients, and while these studies may not be written for the patient, professionals will use the terms developed in them when providing care. In this study specific attention is paid to the patient and kin voice, and to interpreting their narratives in language that portrays their stories accurately, clearly and plainly.

The place of literature in the present study

Literature related to dying and death is continually growing, perhaps because it does not yet convey the experience of terminal illness adequately or meet the needs of those involved. Suggested shortcomings identified in the literature in both approach and interpretation are set out below.

Much work up to this time has been philosophical exploration, with a more recent emphasis on psychological interpretation of events observed by a professional. Patient narratives, either to supplement observations, or on their

own, have been more common in the last 50 years, and have enriched professional understanding. However, when patient narratives are included in academic studies, they are usually interpreted solely by professionals, and may be influenced by the professional lens of the academic who is doing the analysis. Such bias is probably inevitable, but it does argue for multi-disciplinary studies and cross-discipline education.

The dominance of the expert voice is clear in the formal studies and philosophical explorations on dying and death and its rejection shown in the patient responses by providing their own accounts. This suggests that we should hear the voice of the patients, but also, perhaps more importantly, that we need to recognise the gulf between the two interpretations.

One reason for a seeming inadequacy of understandings of dying and death is the shifting context in which life is played out. Prior experience and knowledge to date impinge on both the present life of individuals who may be dying, and on the practice of those caring for them. Each subsequent experience is thus altered, changing the fit between the new knowledge and developing experience. The context is also continuously revised in terms of health care provision and the societal obligations placed on the caregivers – these in turn affect the dying experience.

Increased chronicity of cancer with a longer dying time, interspersed with periods of being quite well, changes the experience, and this needs to be reflected in more up-to-date understandings. Relationships among patient, kin and caregivers change with a longer illness and such issues as prolonged dependence also need to be a part of new interpretations.

Using narratives of two or more key participants in a life experience is not evident in studies readily available for examination, yet life is lived – and died – in relationship with others. Suspending outsider/observer interpretation until the narrator has had a chance to make his own sense of his individual narrative is also not evident in the literature, though it is likely that research reports would not have this level of detail in them.

Conclusion

This review of the literature that influences the study has followed several important themes. The historical influence, both in knowledge of and attitudes towards dying remains significant today. It is the basis on which everyday perceptions, academic writing and health care practice is developed. History also provides a mirror to reflect modern experience, and a yardstick against which newer practices are measured. The developments of the twentieth century in the way dying is regarded and managed show that earlier patterns of concealment/recognition of dying recur, though in a new environment some of the reasons for the particular stance may have changed. The review of current research, most of it practice-based, is driven by a desire to better meet the needs of dying people and their families, but often shows an academic take-over of the patient or kin experience. Research is more likely to involve similar sets of people, such as all patients, or all kin, or all nurses, rather than the arrangement of the present study. Patient and kin accounts of their experience offer knowledge to others going through the same ordeals, and to professionals, and this too, is part of the rich background of knowledge to the present research.

Having set the research question in its intellectual and temporal context, the issues of guiding philosophy for the study can be explored before turning to the account of undertaking the actual data collection.

Chapter three – philosophy and method

The participants in the study, patient, kin and nurse, were going through the very experiences the research sought to understand. It is via the intellectual processes of philosophy that their experience is moved from personal encounters with life-events to articulated knowledge available in a new way for others to understand.

The place and extent of a discussion on philosophy must always be somewhat problematic in a work whose focus is on practical matters. While it is useful to establish the general paradigms in which understanding and interpretation are placed and by which these processes are guided, extensive philosophical debate is not the purpose of the thesis. The following discussion, therefore, seeks to provide the intellectual context of the ways in which knowledge is constructed, apprehended and explicated. It attends to what is relevant to the study and its intellectual processes but not to the adequacy of philosophy in general for other application.

The particular character of the philosophical approach that emerges in this chapter is influenced by professional, temporal, personal and contextual factors. The profession of nursing values the human-to-human relationship highly, and philosophical stances and research approaches that promote and respect this attitude are both popular and respected. Likewise, contemporary western society is moving from a high confidence in pure science to a more median point that is sensitive to humanity and quality of life. Personal values, while reflecting the professional and contemporary contexts above, also include a pragmatic orientation and a respect for the individual within his community. A fourth influencing factor, and this permeated the others, was the moral imperative to work within a philosophy and research methods that suited the lives of the people in the study. Suiting their lives meant not only in the way the people were approached, but also the way in which data were gathered, analysed and

interpreted. The end product had to be meaningful to them, or others who were their heirs to the experience of being terminally ill.

The chapter opens with a brief discussion on philosophy as the discipline that studies knowledge, and moves to examine qualitative research as a means of uncovering knowledge. A digression into phenomenology shows that early engagement with this approach, though not maintained as a central method, provided values that persisted and remained congruent throughout. Hermeneutics, as a process that assists in the examination of text, is introduced from an historical and general view, linking to the next section, narrative. Although narrative is recognised as an emerging method, it is clear that analysis of story for meaning is an old way of gaining useful knowledge about human events, and the chapter's discussion, as it re-engages with hermeneutics, confirms this established relationship. The introduction to the work of Anthony Giddens (b 1938), the philosopher whose work assists interpretation in this study, is the final section of the chapter. Giddens' field is sociology and social philosophy, and one of his central tenets is that humans exist in relationships with one another, making sense of these interrelated lives by providing self-acceptable narratives. The key material of the chapter may be summed up as examining the knowledge relating to how humans account for their lives in a social world, in order to examine how a small group of humans account for their lives when faced with leaving their social world.

Philosophy – what the discipline offers the study

The place and influence of philosophy in the study is complex, as it entails issues of philosophy as the study of knowledge, including both the process, construction and the material of knowledge. In addition, a common topic of philosophy is the challenge of death's place in life, and philosophy, in its branch of moral philosophy, also refers to an individual's personal values and beliefs and those of society. Because these are important concerns in the study, the exploration of philosophy begins with a wide discussion.

Philosophical debate and reasoning is a common way to explore the great existential questions, used from Aristotle (384 - 322 BCE) to Descartes (1596 - 1650) to Heidegger (1889 - 1976) and to modern philosophers such as Richard Rorty and Charles Taylor. Campbell (1984) claims that while science is based on

observation, experiment and scientific reasoning, the work of philosophy is in the fields of logic, the analysis of concepts and studies of the bases of knowledge. He also notes the complementarity of the two disciplines, as each builds on the other and contributes both new understandings and challenges. The philosopher takes the widest possible perspective in scrutinizing scientific and common-sense material, Campbell (1984) notes, and in this inclusion of non-scientific information the philosopher acknowledges the dynamic context of the philosophical endeavour. Philosophers' belief systems have always guided their logic, and while today these include faith in the knowledge produced by sound scientific research, in the past their belief systems have included prevailing theological understanding. The approaches taken toward what was beyond the philosopher's ability to explain - the unknown - show the influence of previously developed knowledge. The Homeric view had nature and divinity intertwined, and this view of creation dominated the understandings and explanations of early philosophers for the phenomena of both worlds (Tarnas, 1991). The uncertain nature of the gods was seen as the common cause of phenomena whose nature did not fit recognised patterns. By the early 17th century God was seen by philosophers as less fickle, though elements of mystery remained. Both Campbell (1984) and Macrone (1995), for example, claim that Descartes believed an omnipotent God could reconcile the contradictions he (Descartes) recognised but could not explain. Modern philosophical enterprises have reduced the place of theology and divine influence, and increased the authority of the empirical sciences. They are thus equally dependent on the prevailing logic underpinning contemporary philosophical reasoning, and seem just as sure in the positions they develop (Rorty, 1989).

Contemporary philosophical discussions about the proper ways to die and how death should be interpreted, influence personal understandings, whether in ancient Greek times or modern times. Consequently the historical and current state of the discipline of philosophy in relation to these topics is a part of this study.

An essential tool in philosophy is logical argument and structuring. The issue of the extent to which the present study should rely on logical processes, and the extent to which it should depend on intuitive processes was an early concern that remained active to the end of the research and writing up. Logic and reasoning

are used to establish a form of truth, or confidence in something, and are built on more or less reliable premises. How intricately the proof of each premise should be developed leads us into the hard science end of the continuum of reliability. However, according to Russell (1998) sooner or later the debater reaches self-evident truths. At this level, there are, he explains, general principles and self-evident truths derived from sensation (perception) and memory. There is a point, then, where things just *are*, and to provide proof by evidence or increasingly complex logic undermines the credibility of the argument. The 'reliable' premises of logic and established fact become less reliable the further in time they extend from their initial description.

The pre-eminence and authority of logical reasoning is also challenged by feminist thinking. Since Gilligan's (1982) investigation into gendered moral decision making the notion that women operate from an 'engaged' position has developed, taking into account the contexts and people in any situation. This is more than casuistry, which also argues for contextual solutions that are not necessarily precedent-setting, because it asks as well that the values, opinions and relationships of those involved are taken into account (Sherwin, 1992). Logic requires a formal trail of reasoning, where each premise is sound and able to be proven, and where connections among them are equally clear and unassailable. There is an assumption of consistency that would prevail in similar situations, and feminist thought argues that this stifles the presence and development of knowledge reached by other routes (Purdy, 1992). The engaged stance that feminist philosophy argues fits well with the lives of the participants in this study, whose living with disease and approaching death was a social, societal and historical experience.

Like other disciplines philosophy is developed within an historical context of social, moral, religious, cultural and scientific evolution. What is accepted truth for one generation is often challenged by the next, and may be undone by the generation following. Sometimes its language renders it no longer accessible, sometimes the context changes so that it is no longer relevant, sometimes it is shown by further evolution of knowledge to be actually wrong. These ideas are enlarged below.

One of the challenges of philosophy is that some of its work, for example in existential and post-modern discussion, uses very specialised language, and

both in the shared understanding of all participants of what death was about, and in the interpretation of the data from the study.

Rorty (1989) claims that all philosophers work in their own context, with the language and metaphor of their time, dependent as are poets, upon the work of their predecessors. Perhaps a self evident truth, he makes the point to show the limitations of philosophical knowledge, and the narrowness of application for any given theory. Rorty also points out that the metaphysical philosophers work from the premise that their way of being in the world, and making sense of it, will be universally applicable. This intriguing variation of ethnocentrism is partly true, in that arguments are frequently based on the proposer's 'givens' in order to proceed with the case being made, and partly not true for the metaphysicist who argues that each individual apprehends his own world in his own 'truth'.

The progression of philosophical discussion from the study of knowledge, to the structures of knowledge, to the ways knowledge is apprehended, to how humans exist, to why humans exist, shows a development from general to specific knowledge. These overlap in the work of many philosophers. The work of Heidegger (1962) and of Wittgenstein (Pears, 1971) , for example, plots a personal path of discovery that offers illumination to others as it may be relevant, but at the end it is their travail, driven by their uncertainties, which leads to their individual understanding. Each person must find his own meaning, guided as it may be by the work of others. In this study, too, participants worked on their own personal paths, finding their own meaning, assisted by the wisdom of their predecessors, and leaving understanding for those who would follow. The patterns of personal experience, enriched by singular histories leading to expressed knowledge are part of both a philosophical process and the lives of these participants.

Such valuing of individual lives and development calls into question again any sole reliance on logical structuring in philosophical reasoning. Good reasoning which includes emotion may be very rational or reasonable, but it may not be possible to structure such a process with solid premises and logical progression. The outcome may still be good and true.

Clearly abstract philosophical reasoning on its own will not be adequate to explore the lived experience of a series of individuals as a means of

understanding what this time of their lives is like. Nevertheless philosophy as a general way of exploring and structuring knowledge, and particularly in the area of the study, has much to contribute to the present study, and will be brought in as appropriate. Within the major discipline of philosophy a field that would not rely solely on abstract reasoning, logical structuring or an objective position would be more suited to the study.

Researching human experience – qualitative research and phenomenology

Knowledge gained via empirical means such as observation, and even experimentation are useful for dying experiences in general, but when the question asks about the lived experience of *individuals*, a qualitative approach is required. Qualitative - or interpretive - methods have arisen in the social sciences as a response to the inability of purely objective methods to apprehend the complexities of the human condition (Denzin & Lincoln, 1995). Quantitative methods' limitations in grasping the 'whole' in a meaningful way, because of the reductionist focus, and the inability to deal with the present but ephemeral matters of such concerns as emotion and perception, significantly reduce their application in areas of human living. This study required a methodology that could perceive, hear, appreciate, take into account and record the fluid, personal and intense nature of human experience. As qualitative research uses a more engaged or situated position with the participants and the data, and because it provides more of a general understanding than a specific answer, it was more appropriate for this study.

Phenomenology

Phenomenology fits within the values of the interpretive paradigms and, though more philosophy than method, is commonly used as both. Because of phenomenology's attention to phenomena it is useful for questions of human experience and has become increasingly used in nursing research as studies of the last two decades show (Benner, 1984; Benner & Wrubel, 1989; Diekelmann, 1983; Diekelmann, 1992; Smythe, 1998; Spence, 1999).

Debates about the type of phenomenology that should be used are part of the context of using the methodology in nursing research. Debate includes claims that Husserl's notion of bracketing was unrealistic (Cohen, 1987); a counter from

Crotty (1996) that Husserlian phenomenology is more true to the original intents of the movement; and the risks of a subtle fascist influence in using Heidegger (Holmes, 1996). Fundamentalist views are also apparent in the application of phenomenology, or indeed any method, with arguments against any mixing of philosophy, methodology, methods, analysis and interpretation (Geanellos, 1998a; Lawler, 1998). The result is often a heavy focus on one aspect of a study, which although laudable in itself, unbalances the whole (Geanellos, 1998b). Such narrow views seem to have an inconsistency with the focus on the phenomena itself that is demanded by phenomenology: it seems logical that analysis and interpretation should arise from what is true in the phenomenon.

This study was guided by the core values of phenomenology as set out below. As any values are barren when simply articulated, and bear fruit when they are matched with reality, so too these values become rich and complex when they are employed with the participants. Used in another context, with other people, they would produce different knowledge. This difference and complexity is in its way an illustration of the value of focus on the phenomenon itself and allows the phenomenon to be seen and to guide the process.

Approaching phenomenology as a philosophy, the underlying belief is that we can begin to *know* something by a thorough examination of the phenomenon itself (Husserl, 1973). The *way* phenomenology deems it proper to investigate phenomena is by seeking description via observation, data gathering, reasoning and logical arguments (Spiegelberg, 1994). The main tool is the human intellect, and there is no experimentation and little use of equipment. The acceptable *field* of interest for phenomenology is the human condition and how we, as humans, are in the world (Van Manen, 1990).

The particular *views* that are acceptable to phenomenology include the notion that not-knowing has a significant place in the development of understanding and new knowledge (Madjar & Walton, 1999). Examining the place of knowledge means in part that the influence of prior knowledge on the process of seeking new knowledge is legitimately examined. It means also that not knowing precedes knowing, and continues along with the knowing uncovered, and remains, in part, at the end. Phenomenology seeks to examine the hidden parts of a phenomenon, and to be always aware of the existence and potential influence of not knowing. Because of this stance, proof of knowledge is not

essential nor is it a core impetus to study. Rather, confirmation is arrived at through intuitive congruence and logical structuring of concepts. The key purpose for phenomenological research is understanding. Van Manen (1990) describes the object of phenomenology as to 'bring the mystery more fully into our presence'.

For the phenomenologist, what it means to be human can be established through investigation of the lived experience of a phenomenon and elucidating the meaning of this experiential knowledge. Because the phenomenon is studied in a systematic, coherent and reflective way, which leads to a rich description, it is possible to provide an explication of the phenomenon (Van Manen, 1990). The emphasis is on beginning with and focusing on the phenomenon, so the primacy of the phenomenon influences the process. The lived experience is diverse and complex, and from it essential meanings may be drawn to provide a common base for comparison. If what is important is the human state, and how humans are in the world, then a genuine respect for those beings logically follows. This research and thesis is based on a care for the other, and moral and practical considerations must be taken into account. To be human involves making intellectual sense of the life lived. These points all fit well with the fact that the participants would be living complex lives, with the phenomenon to be studied embedded in their social and physical existences.

Such complex life experience is the 'lived experience' of phenomenology. In a way the term 'lived experience' seems tautologous as experience connotes being in, being involved and participating. Yet we also qualify some experience as vicarious, recognising that there is an at-length knowing which informs us. In the main, however, the aspects of experience that are part of the term lived experience are those of involvement, being in and becoming familiar, which lead to the second important connotation in the word, that of knowing through this process of being in. If our living through life events is not subject to reflection, comparison with other events and analysis, then it does not become experience. A simple behaviour-response level of unconsidered activity is not experience unless it includes the critical element of processing information so that experience can help the human respond in new situations.

Lived experience is thus a human and a conscious activity in which meaning is found. This is congruent with Gadamer's (1994) view, which holds that the

central concept in experience is reflection which contributes to understanding. It is also confirmed by Giddens (1991) who says that a person with a reasonably stable sense of self-identity has a feeling of biographical continuity which she is able to grasp reflexively and, to a greater or lesser degree, communicate to other people (p. 54). What it means to be human, then, includes this conscious and reflective aspect of experience.

Hermeneutics

A kind of text, or perhaps a story or account, is created by such conscious reflection on personal life and thus allows further reflection. Hermeneutics, as a process to examine texts, whether individual or public, spoken, written or pictorial, holds that texts should be considered in the environment in which they were created - *context* being the apposite word. In addition, influencing factors, including contributory texts, are assessed to understand the ways in which they have shaped the primary text. Individual words and phrases may be examined for contemporary meaning to determine if current use is similar or whether it has developed differently. Changes in social patterns and mores expressed in text are identified and elements such as customs and laws are questioned. The process creates a further text that bridges the primary text and the contributing ones. It, too, becomes an object for examination.

Hermeneutics is often seen as originating in theology as a means of exegesis of biblical texts, yet is present within the Bible itself as scholars debate and examine the meaning of previous writing. For example, in the parable of the Samaritan (Luke 10:25-27) Jesus and a lawyer discuss the meaning of 'neighbour' referring back to Leviticus 19:18, bringing in contributory concepts as needed, and in this process creating a further text. During the Middle Ages theologians used four 'senses', literal, moral, allegorical and eschatological, to study biblical work (Croatto, 1984) and this has parallels today in the use of literal, psychological, metaphorical and existential examination of text.

The move of hermeneutic process from theology to a more general use is attributed to a German theologian, Schleiermacher, stemming from a set of lectures he delivered in 1819 (Abrams, 1981). The wider application was further developed by Dilthey at the end of the same century who proposed that hermeneutics could serve as a science of interpretation for the human sciences of

literature, humanities and social sciences (Dilthey, 1961). The purpose of the new approach would be understanding rather than the explanations that the natural sciences sought. Dilthey named Schleiermacher's process the hermeneutic circle, and developed it further by exploration and explication. The hermeneutic circle affirms the integrity of the whole: "Traditionally the paradigm for the hermeneutic circle is the reading of a text, where the parts cannot be interpreted without an understanding of the whole, but the whole cannot be grasped without an understanding of the parts" (Hoy, 1993 p. 172).

The accuracy of Dilthey's prediction about the usefulness of the hermeneutic process is shown by its use in diverse disciplines such as psychology, nursing, social practice, philosophy and medicine. Rather than the balanced interpretation of the Middle Ages described by Croatto (1984), however, each discipline now seems to focus more on one avenue to meaning. For example counselling focuses more on psychology (Monk, Winslade, Crocket, & Epston, 1997) and nursing on existentialism (Diekelmann, 1992). Any such focus has the potential to diminish the thoroughness of a study and the practicality of application of the findings. The differing developmental paths also create difficulties for disciplines recognising, and accepting as adequate, hermeneutics in other fields.

In nursing research and writing, hermeneutics is used as guiding philosophy (Allen, 1996), as process (Benner, 1994), and as interpretation (Baker & Diekelmann, 1994). Allen's (Allen, 1996) use seems more methodological than philosophical, and his clear statements and assertions both invite and allow critique and challenge. Benner (Benner, 1994) differentiates between the mechanistic recognition of codes that are the quantitative end of text analysis, and the hermeneutic engagement and reflection that fit with the hermeneutic processes. Diekelmann (1992) proposes a team approach for coding and supports the use of a computer programme to aid analysis. What is common is the circular process of engagement, reflection and understanding; re-engagement with new insight, further reflection and a deepening of understanding.

The issue that seemed significant for this study was whether hermeneutics should be viewed as a philosophy or as a process. While accepting that there are questions of meaning that are important to hermeneutics, there is no evidence of a well-structured and tested philosophical account of knowledge about how

humans are in the world. The values that guide the hermeneutic process are those which shape the road to understanding rather than explaining the parts or the whole of the text. The specific hermeneutic beliefs that were important in this study were that a process of engagement with text could lead to understanding; that both text and context in which the text is created are important; and that the researcher – and later the reader – enlarges the meaning of both the primary text and the texts of meaning subsequently developed.

Croatto (1984) supports this last point particularly in his statement that there are three important aspects of the hermeneutic process. He claims that the primary purpose of the process is the interpretation of texts; that the context of the person who is interpreting is significant in the creation of meaning; and he is clear that the interpreter has a goal of taking the text to greater meaning. This last point is more tacit in other writing, but for Croatto (1984) it seems more than an assumption: it is a primary duty. Such a position moves interpretation from an academic activity to a moral concern, and this stance seemed to fit well with the deep commitment made to participants in the present study to re-tell their stories for others to use and learn from.

Personal texts are created as narratives, a discursive account of events in a person's life. The examination of narratives is developing a place of its own in academic research.

Narrative analysis

Narratives as stories to communicate information are as old as history: indeed they are history. At the most basic level stories are a coherent account of some events, arranged in a particular sequence, for some purpose. Richardson (1990) writes that narrative is the primary way through which humans organize their experiences into temporally meaningful episodes, adding that narrative is both a mode of reasoning and a mode of representation.

Interviewing the participants for this study resulted in a series of narratives about the experience of living with terminal illness and in order to respect these accounts as singular constructions some knowledge of narrative theory was important. The following discussion outlines key issues in narrative theory and

presents some of the areas and questions that were used to explore the participant narratives.

Berger (1997) traces the history and development of narrative examination, identifying the major theorists. Aristotle's explanation of narrative was that it was the imitation of life, and the elements for analysis were therefore the medium of imitation, the objects imitated and the mode of imitation (Berger, 1997). While the word imitation currently carries connotations of tawdriness and mockery, Aristotle's use suggests more a sense of capturing or crystallising something transitory so that it can be appreciated by others, much as an artist captures a scene. It also recognises that the telling, or painting, is not the reality, and has been firstly edited, and then interpreted by the narrator or artist. Plot, characters and dialogue were important aspects of the text to Aristotle, and these continue to be important to narrative theorists. Propp's 1928 work on Russian fairy tales shows a structure for this genre with limited components and limited variations (Berger, 1997), though Berger argues that to suggest that all human narratives can be fit into this structure of heroes, villains, good and evil, may be unrealistic. It is also limiting for both listener and narrator who may hear only what fits, or shape what is heard to fit a 'type'.

Structural analysis continued with the further exploration and definition of the elements of character, function, sequence and type (Manning & Cullum-Swan, 1995). Burke's work (as cited in (Manning & Cullum-Swan, 1995) relating to the basic terms of act, scene, agent, agency and purpose added further detail to structural development. A study of community psychiatric nurses found these terms helpful in examining the empowerment of people with enduring psychiatric disorders (Tilley, Pollock, & Tait, 1999), showing the link between narrative theory and explication of practice. The notion of binary opposites, good/wicked, safety/danger is developed by Berger (1997), based, he acknowledges, on the earlier work of Saussure and Levi-Strauss (as cited in Berger, 1997). Berger argues that the analyst can establish meaning from these oppositions in a clearer way than by plot analysis. It seemed that the actions of contrasting one state with another had the potential to fit better with lived human experience. For most of us the notion of plot is not a day-to-day issue, but whether something is OK or not OK is a more immediate concern, and tells us more about the significance of the experience.

Narratives thus have an expected form, that may be partly dependent on the context in which the narrative is actually told. Brenneis' (1996) work on conflict narratives suggests that narratives are linked through the circumstances of a particular telling, and they are further intertwined with a particular web of narrator, audience, purpose and expectations.

The narrative is modified in this way by the audience, and it is notable that the patient giving a history to the admitting doctor will offer a different narrative from that he offers to the patient in the next bed, and these will be different from what he tells his wife, and from what he tells his work-mates. It is fair to suggest that the audience will affect the language, the emphasis, the detail and the manner of telling. Examining these aspects may help us to understand the layers of relationship the patient has with each person, and identify the purposes of the narrative.

Narrative may also be reviewed in terms of sequence, layers (or sub-stories) and genre. The chronology of a story is seen by Brody (1987) as "a narrative of events arranged in a time sequence" (p. 10). However Berger (1997) challenges the idea that events are necessarily related in a time sequence. While he accepts that time is relevant, he says that the primary order is imposed by the events, and they may not be in a chronological sequence. This is true for health narratives where the patient may provide the key events of an illness experience initially, then provide more detail, and later recount the social or family events of the time. Identifying the sequence as recounted by the narrator can reveal what is important to the narrator suggests Sandelowski (1996). She also notes that the listener needs to be aware of his own notions of what he expects to hear as these can influence what is heard, recorded, believed, and seen as important.

While discussion in relation to genre, for example the classic comedy/romance/tragedy/satire group (Abrams, 1981), has a firmer place in literary analysis than in human narrative, the notion of genre does acknowledge that there is a convention to stories. Such convention, which is influenced by both author and listener/reader, guides the format and keeps the narrative within certain confines. This was another aspect of narrative that could be present in the participants' stories, and its presence needed to be observed for during data collection and analysis.

Also important to consider for this study is the evaluation of the intent/s of the narrative. While the reason for communicating may be overt, more subtle messages and intents may also be present. Foucaultian discourse analysis focuses on identifying power relation in an interaction (Foucault, 1973). Words, phrases and general content are deconstructed to lay bare the hidden meaning that influences transactions and in turn affects our whole attitude toward the phenomenon. Narratives about cancer, for example, contain much reference to *battle, fighting* and *winning*, and the analyst might discuss the potential effects on one who by failing to respond to treatment, is then seen as not fighting hard enough, and thus expected to take personal responsibility for his cancer. Evaluating health related texts for specific discourse is seen in Wood's (1996) analysis of a media campaign in the late nineteenth and early twentieth century. Her analysis differentiated between the overt discourse of the provision of health care for children, and the covert discourse of stimulating a humanitarian response in the citizens.

Narrative as therapy is used to identify the prevailing story which guides the person's life, and the therapist and counseled person can then work together to re-write an alternative that is more functional (Monk, Winslade, Crocket & Epston, 1997). This field also includes grief counseling where the person gradually develops a personal narrative that allows that the dead person is departed and that the bereaved will continue his life without them (Harvey, 1996). The notion of re-writing a story that is no longer appropriate is clearly part of managing living with a terminal illness, and though the partnership that guided such change was not a specifically therapeutic one, to ask questions of the text about mutual influences would be of interest in this study.

Another common form of text analysis is literary evaluation particularly of words, choice of words, emphasis and arrangement of words, and also in literary devices (Abrams, 1981). Some of these, such as epiphany and metaphor are present in many disciplines with their own variation of meaning, and are commonly present in personal narratives. Culbertson, (2000) discusses the limitations and the possibility of metaphor, observing that old metaphors have the capacity to restrict our understanding, but that new and creative metaphors can lift us beyond the obvious. At the same time it should be noted that metaphors are abstractions, and for people who think more concretely they may

be less used or useful. Occasionally narratives contain older stories, perhaps from the patient's family history, and here the concept of allegory may help the interpreter understand the significance of what is being told.

In summary, then, narrative theory has much to offer the process of understanding the personal narratives of the participants in this study. Narratives do have discernible form, characteristics and functions. These elements can be studied and interpreted, and meaning can be derived from them. Areas significant for this study would be the purpose, perceived and concealed; the audience and the content of the account itself. Narratives also embody the self, opening a personal world to the listener. The individual portrays himself through narrative, showing his self to the listener and also to himself. The reflective nature of narrative allows transformation, offering the narrator a chance to 're-story' himself to a different self. The audience is a mirror for the narrator, but not necessarily a passive mirror. Responses and non-responses have the capacity to influence the form of the emerging narrative, and future narratives. Finally there are many narratives that influence an individual's own story, and these may be parallel, contributing, complementary or contradictory.

Narrative and hermeneutics

There is a close and natural relationship between hermeneutics and narrative. The hermeneutic process is what allows us to understand narratives. It also allows analysis to precede interpretation in a general sense, as the question of 'what is present here?' is asked before 'what does it mean?' Yet the sense of seeking hidden meaning is present in every engagement with text or narrative, and this links well to the phenomenological value of closely examining the phenomenon while simultaneously being aware of higher levels of meaning. Van Manen (1990) describes this as seeking the 'nature or essence' of an experience (p. 10), showing that such a search goes beyond what is immediately apparent. Such self-awareness on the part of the researcher allows a place for intuition to signal possibilities that may emerge. The respect for the text, or narrative, is congruent with the valuing of the human and his story, important in this study and the approaches outlined.

Both hermeneutic and narrative methods see the text as being within a context, yet retaining sufficient elements of separateness to be examined aside from the

context. Using the hermeneutic circle process allows engagement and retreat from a narrative, so that the new text that is created in this process may stand separate from the original, able to contribute to its understanding, but not altered by unconscious editing. At the same time, identifying the context in which the text was created for the terminally ill person and his kin created a further text, which in turn influenced the primary text and the texts of developing understandings. The larger contexts of the health systems and the disease course and prognosis were also part of the background for events. Additionally, the life experience of the participants, some discussed openly and some identified in silence, were influences on the primary text.

Narrative theory works with a text that is more fluid and self interpreting than the apparently static and depersonalised texts of historical hermeneutics, yet living narrative is not ruled out in hermeneutics. For the participants in this study, particularly the patients, events demanded constant revision of the personal account, so the narratives evolved as time went on. Narrative theory permits a developing meaning, one that is always only potentially true, not necessarily constant, but with integrity in its context of time and place.

Analysis and interpretation

Analysis and interpretation are frequently used interchangeably, and the meaning and order of each is variable. Is it possible to see or hear without attributing meaning? Yet if we see meaning it is because we have internal concepts and structures – perhaps so automatic they are unrecognised – on which to base our assumptions of meaning. The attitude taken to the debate in this written work is that analysis is a process of ‘the division of a physical or abstract whole into its constituent parts to examine or determine their relationship’ (Hanks, 1990). Interpretation follows analysis, and is the abstraction of meaning from the discoveries of analysis. While the processes are used simultaneously, in that as soon as one engages with a text one is seeking meaning, and it is not possible to analyse without a conceptual understanding, some separation is also useful. To make a conscious putting aside of interpretation in order to examine the components of the text, to ask the narrative questions, and to allow the hidden to emerge permits an openness to possibility that is congruent with a hermeneutic process. Such putting aside involves recognising tentative interpretations and suspending them to return to the

primary data or text. The process of suspending emerging possibilities does not mean that they are ignored. Rather it allows them to be articulated so that their existence has boundaries, and so that their influence on the overall patterns may be discerned. Suspending emerging possibilities acknowledges the interrelated nature of analysis-interpretation, and ensures that there is space for due and measured consideration of all elements.

Just as analysis is aided by process, so interpretation is facilitated by the use of a framework of appropriate understandings. It is common for researchers to work within such a framework from the outset, though this does immediately colour perception and interpretation. For this study the initial thinking was that Heideggerian (1889 - 1976) philosophy would guide understanding of the participants' worlds and experience. There were two key reasons why this did not work: firstly Heideggerian interpretations did not fit comfortably with the participants' stories, and secondly the principle of the meaning arising from the data seemed to be confused by beginning data analysis and interpretation with a set of prior understandings.

Giddens' views of humans in society

The social philosopher Anthony Giddens (1979; 1991) holds that humans exist in relationships with one another, and these relationships are how they know, prove, negotiate and develop a personal sense of self. He explains that humans self-interpret by providing a personally acceptable narrative that is continuously created and modified. Potential crisis is normally filtered out by a 'protective cocoon' that prevents looming fear of possible disaster interfering with normal day-to-day living. On the whole, people are optimistic, and cope with life events by integrating them into their lives via narrative processes. Giddens argues that individuals in this 'late modern age' are active in adapting to and controlling their social environment, and not passive objects in fast-paced modern life. These ideas fit well with the evolving narratives of the participants and suggested a structure of explanation for their experiences. Giddens' ideas will be presented in more detail in the data chapters, including his notions of 'dilemmas of the self' where he proposes a set of paradoxes by which people are able to manage the challenges of living in an increasingly complex and rapidly changing world.

That Giddens' ideas fit well with the people of the 'late modern age' is not surprising, given his engagement in the social, economic and governing systems of the current age. Giddens is director of the London School of Economics, advisor to the British prime minister, Tony Blair, 1999 Reith lecturer, among many other distinguished posts and awards. However his objective is to understand those who function competently, rather than the focus on pathology seen in psychology or the quest for life's meaning of philosophers. For Giddens meaning comes from studying a life that is adequate. He also writes with a cautious optimism about humankind and human society, challenging the romantic retrospective view, and offering a very practical and engaged construction of present and future society. These characteristics add to the applicability of his philosophy to the participants' lives, as they were people who were coping well, and yet as individuals very differently, with the experiences of living with terminal illness.

Conclusion

There is a sense in which the described philosophy in any study is a synthesis of externally articulated philosophical writing and the developed and developing understandings of the writer. Yet the data themselves, and in this case the participants as well, modify and shape the beliefs, constructions, values, analysis and interpretation of the process and outcome. The words and reflections of the participants contribute to the integrity of the study both materially and morally. In this way the work is true to both the values of the methodologies outlined and the lives of those involved. How this came about is the material of chapter 4.

Chapter four – undertaking the study

This chapter, in turning to the actual study, moves from the abstract to the practical. It begins with the background to the process of data gathering, defending the decisions made about the best ways to proceed. A brief account of the approval procedures and the security of data during the study is provided to show conformity to the ethical concerns of human research. The description of data collection focuses on the challenges that inevitably emerged while working with individuals and families living in stressful times. The next section of the chapter outlines the intellectual management of data – the processes of analysis and interpretation. Finally the participants are introduced with small sketches carefully constructed to maintain privacy but allowing a sense of genuine human experience to remain. The participants and the challenges brought up by the interactions with them and their lives introduce a more specific and personal nature to the text from this point.

Beginning the study

The first ideas, outlined in chapter one, were to work with people who were living with terminal illness, or accompanying someone during that time, in order to discover more about this life experience for these participants. The number of sets (patient-kin-nurse), the number of interviews and the timing of beginning data collection were the subject of some deliberation.

While a reasonable amount of data would be obtained from four sets of people it seemed prudent to use six sets, in order to allow for any premature conclusion to the interviewing processes caused by illness progression. Miles and Huberman's (1994) statement that qualitative researchers usually work with *small* samples of people nested in their context and studied in-depth provided confirmation of the proposed size of the study. Benner (1994) reminds us that repeated interviews increase the text, and therefore the work of analysis.

Timing the interviews was the subject of further deliberation. Reflecting on literature, personal observation and experience, and discussion with others it seemed the best time would be when the patient had realised that he had moved from treatment to palliation. Palliative care nurses noted that this was often a gradual process and need not be parallel to the health professional's assessment of his disease progression. The observation that practitioners knew the existence of and recognised the transition in real life as part of their practice knowledge suggests that the area would be suitable for future research to comprehend the phenomenon.

Tentatively, it seemed that two substantial interviews, following an introductory session and then a concluding session, would be appropriate. The need to balance the volume of data with the intrusion into people's lives at a critical time influenced this thinking. Miles and Huberman (1994) note that such decisions about how much interviewing is adequate tend to be made gradually, as familiarity with the information and situation increases, yet there was a need to provide a boundary to the scope of the study at the time of seeking ethics approval.

In a discussion on the common characteristics of qualitative research Streubert and Carpenter (1999) note that the enquiry needs to be conducted in a way that limits disruption of the natural context of the phenomenon of interest, and this value guided thinking about the manner of interviewing. The principle of respect for the situation and the participants' expert knowledge about it was also important, so hearing their complete story was essential. Experience, judgement and advice suggested that the number of interviews proposed would allow the parties to finish their narratives. It seemed that the participants actually achieved this, as the interviews changed in their content and urgency when the narrative appeared complete. It was common for participants who had reached this point to repeat previous information with little or no variation. Sometimes they would communicate that there was nothing more to add to what they had already shared; other times they might simply find it difficult to make conversation about their present lives, but would be happy to chat about unrelated issues.

The issue of saturation as the repetition of discovered information was considered here. While it is usually taken to refer to information from the whole sample becoming repetitive or confirming (Streubert & Carpenter, 1999) it also

provides a guide to the researcher that the participant has completed the task to their satisfaction. Morse (1989) recommends that the researcher is the only person in a position to decide that data is sufficient, and it is familiarity with the people and their information that allows this.

The plan was not to take the patient and kin to the end; dying is hard work, and there would be no energy to put into reflecting on the process. That time is family time, and experience indicates that it is usually a quiet time. A researcher would be in the way.

Approval processes

The proposal was drafted, redrafted and eventually ready for submission to the various bodies which would examine it. Originally written for a Masters thesis, it was later expanded for doctoral study. Advice from the Research Committee of the Department of Nursing & Midwifery was incorporated before the proposal was sent to the Human Subjects Ethics Committee at Massey University. Concerns raised by the university committee related to intrusion to people's lives at a crisis period. Perhaps the non-health professional members of the committee did not fully understand that terminally ill people are not constantly critically ill, and this brought up the possibility that the study might increase knowledge generally in this area.

The proposal, further amended, was presented to the appropriate area Health Ethics Committee whose meeting was attended in person, so that questions could be responded to. These related mostly to whether persons whose primary language was not English would be interviewed. The committee was assured that only those who were confident and comfortable in English would be included. It was explained that to use an interpreter could easily erect a barrier to the nuances of communication that were important to the study. In addition culture was not to be the central issue of the study. Given that culture is expressed and embedded in language (Cole, 1979), it seemed best to avoid this complication.

Finally the proposal was evaluated by the institution in which it was planned it would take place. This group were concerned whether there would be any unreasonable demand on staff time. They also commented that the study would be emotionally challenging for the researcher. Such a human touch in an

institution that provides health care was heartening. Before data collection began the proposal was amended to meet the requirements of doctoral study, and the area Health Ethics Committee approved this change. Further approval was sought, and gained, when the re-structuring of health services made access to patients via a nurse-run clinic problematic.

The passage of the proposal through four approval processes was of concern in that each group gave approval for the study to proceed in the form which met their own criteria. The proposal was then further amended by the subsequent group. The entire complex approval process was documented and presented as a paper at a New Zealand bio-ethics summer seminar in February 1996, to the interest of members of the Combined Health Ethics Committees who were attending (Niven, 1996). The paper supported a proposal to streamline ethics approval processes. The experience was again shared at a meeting of the chairs of Health Research Council accredited committees in 1997 when the streamlining proposal was in danger of being dropped. Relating how complex the course through approval could be provided the members with evidence to continue with the development of a common approval process.

To meet the requirements of the approving bodies, arrangements were made to keep the audio tapes, the transcripts and the computer material secure. Patients, kin and nurses were asked to select a pseudonym. Participants shared their stories in the knowledge that they would be used, but trusted that the final accounts would not contain unnecessary detail.

Data collection

Participants were approached via a palliative care service at a large metropolitan hospital, with the co-operation of the nurse who operated the outpatient clinic. A discussion on suitable patients and how to go about inviting them into the study was held. The agreed process was that she would introduce the study to potential participants by offering information sheets and ask if they would be willing to discuss participation by telephone. If they agreed, contact was made and an appointment set up to meet them. Preference was to meet people in their own homes, mostly because they were not well, but also because working in their own territory kept a sense of control in their hands, and helped maintain

their role as person rather than patient. This 'natural setting' also reduces distraction from other life events (Streubert & Carpenter, 1999).

Issues of potential harm had to be kept in mind while planning the whole interview processes as the sensitivity of the situation meant that this group belonged in the category of vulnerable populations. Both their physical and emotional well being would need to be monitored carefully, with an ever-present willingness to interrupt the interview. Streubert and Carpenter (1999) also note that the researcher is more vulnerable in this type of situation. There are a number of potential issues here - harming the participants in any way would reflect negatively on the researcher and the study, as well as the health and educational institutions; the data may be limited by the researcher's subconscious avoiding of sensitive areas; the researcher may be under closer scrutiny and more critique than in other studies; there may be problems with difficult situations revealed in interview; and the researcher may carry an emotional load from the stress of hearing tragic narratives. The greater number of concerns listed were met by the thorough planning processes, regular academic supervision and attention to detail throughout data collection. The last concern was recognised, and professional supervision arranged to meet personal emotional challenges.

The issue of getting kin agreement to participate was considered to be potentially problematic, as there was a possibility of the patient subtly or perhaps not subtly pressuring them to participate. Time and care were therefore taken to negotiate this consent to reach confidence that it was freely given. In fact in all situations, the kin was glad to have an opportunity to talk as a person separate from the patient. The issue of who cares for the caregiver has been addressed in studies by both social workers and nurses (Davis, Cowley & Ryland, 1996; Pitkeathley, 1989). The specific problems in the situation of the terminally ill patient relate to the common need for the caregiver to be present for much of the time; their need to continue their lives; the probable short time frame; the tension between certainty and uncertainty; and the fact that they have made a commitment, and see caring for themselves as departing from that situation. As the chronicity of cancer increases the issue of the effect on kin as caregiver will need further study.

Another concern was whether kin should be present during the patient interview, and patient present during interview with kin. Kin are protective of

patients and could want to guard the energy of the patient; patients often like to know everything that is going on and may become uncomfortable if there are conversations about them at which they are not present. At initial meetings people were assured that these choices were theirs, and there was no requirement of the research in relation to who was present during any interview. What tended to happen was that the initial interview engendered confidence in each other, the interviewer and the process, so that subsequent interviews were usually characterised by an apparently relaxed attitude to who was present. Interviews with the close family members, however, were shorter and more focused than those with the patients.

The term 'close family member' had always felt a little awkward, but the options of 'significant other', 'partner', or 'friend' were too limiting. In November 1997 at Nursing Research Conference the term 'kin' in relation to family was used by an Icelandic nurse (Fridfrinnsdottir, 1997). It was a good reminder of the strength of this word in connotations of commitment and that also that it transcends blood relationships. It was decided to use the term for the 'close family member' particularly as in some cases they were not relatives.

Challenges of data collection

The first challenge of data collection was observing the agreed structure that the initial meeting would have more of a social focus than a research project focus. The university's Ethics Committee had emphasised that consent was to be gained following, not during, this visit to allow appropriate time for reflection. However at first meeting the patient was keen to provide the account of his illness experience. In spite of requests to delay this information until the next visit the conversation kept returning to what was clearly the most important issue in his life at this time. At the second visit the participant was often impatient if asked to review stories that had already been told, and the accounts became summarised, with the detail that signaled fruitful avenues for exploration often missing. The solution was to trial using the microphone, with the tape running, at the first interview. A week after this interview telephone contact was made to seek agreement for participation in the study. If the person did not wish to continue the tape would be destroyed; if he agreed to continue permission to use the first tape would be sought at the second visit.

Creating an environment for this style of communication was challenging, as participants were more accustomed to providing information to meet the needs of an interviewer, such as medical interviews. They were not used to being able to present all the detail that they wanted to, and often had to be reminded that if something occurred to them, it was probably because it had some significance. Preparing for interviews was guided by consulting writing about unstructured interviews from a variety of sources (May, 1991; Streubert & Carpenter, 1999; Van Manen, 1990 and others). Generally their ideas were similar, and those that were significant in this study are summarised below.

The principle of an unstructured interview is that the interviewee is not guided by the prior ideas of the interviewer. There is no list of questions, though the interviewer may have general issues that she believes will be discussed. Any pre-understandings and experience are carefully subordinated to the informant's perspective (May, 1991). However Van Manen (1990) cautions about being too unfocused, and this was particularly important as participants were likely to be tired, and to get off track would not be respectful of their contribution. It was planned to open the interview with a statement such as: *"I am interested in hearing about what life is like for you at the moment. Could you tell me how this is for you."* The participant would be supported to continue by the use of non-verbal and minimal encouragers, for example the use of nodding and saying: *uh-huh* and *hmm*. The temptation to persuade the participant to follow a particular topic needed to be delayed until he was ready to do so in his own judgement. Silences needed to be allowed, and in this study it was clear that the participants used the silences to reflect on an issue, as they would often resume the conversation in a thoughtful, considering way, offering something that was specially important to them.

A further important issue was maintaining confidence that the participant was the person who knew best what it was that should be told. On several occasions, for example, the significance of a topic was not apparent until much later in the interview. Once or twice the implications became clear as late as during the transcribing of the tape to computer records. Specific issues were followed when a reasonable pause appeared in the conversation. As the data gathering progressed it was possible to gain more sense of what was significant for the participants and to recognise and even seek information related to common

experience. At the same time it was important to remain open for the unexpected. In a way expected, yet often surprising, was the frequency with which the participant – and this was particularly true for the patient – would have a differing viewpoint on an important issue from that expressed at a previous session. Interviewing was always a learning process, and it was important to maintain an attitude of willingness to learn to be prepared for new ideas.

The first interview was therefore very important in the way of setting the pattern for the forthcoming sessions. What was apparent was that the person had much to share from the beginning. Mostly he had been accustomed to beginning an interaction with his 'health narrative'. As he was listened to, and experienced no attempt to re-interpret his account, he seemed to become the chief narrator. In addition, it seemed he was often observing the response to himself, measuring how his story would be accepted, and deciding whether to offer trust. The intuitive assessment of the audience listening to his narrative also influences the story that he believes will be acceptable. The interactive nature of the story, acknowledged by Harvey (1996) is something an interviewer must be constantly aware of, as any unconscious responses may subtly guide the participant.

Communication

Among the challenges that were foreseen were possible communication issues among patient, family, nurse and other health professionals; treatment issues and confidentiality. These usually overlapped. Sometimes the patient requested that particular things were not transcribed and this request was honoured. It was also taken to include all the conversation on that particular topic, even if the request was made earlier or later. If a kin or patient said something which could be personal, for example:

Have you got any pain? And you know she is lying through her teeth when she says: oh, no, it's all right (F3p3).

The understanding was that this was said in the expectation that it would not be directly shared with the other, but could be recorded and used. Often the other would be aware of the concern, noting perhaps:

They are just trying to keep the pain under control, but you don't see that, you see the morphine is going up (F4p2).

The plan to share the transcripts with the participants was amended, for two reasons. Firstly, transcription took longer than expected, and secondly, the prospect of presenting patients and families with 20 or 25 pages of verbatim work to read and comment on at crisis time seemed to be an unnecessary burden. With their consent, the tapes were listened to several times, and a summary made of what they had said, which was used as the basis for the subsequent interview. At the final interview it was possible to tell them what general impressions had been gained from them, and the kind of themes that seemed to be emerging at that stage. Their agreement with these tentative findings was a validation of the directions the data was taking.

Ethical challenges during data collection

Sometimes extended family or friends were puzzled by the participation in 'research', and commented to the effect that people should be left alone at this time of life. One participant explained how she responded to such comments: "*I told her we were working on a thesis.*" This challenge illustrates the dilemma of working with unquestionably vulnerable people, where the potential for harm is high, and the ability to redress any harm done is extremely limited. Research has a poor press generally, yet people are amazingly willing to assist in its processes. These participants saw a potential personal benefit in being able to talk freely about their experiences to someone who was not pivotal in the amount or quality of care they received. They also commonly expressed a satisfaction that through the process of this study they may be able to contribute to better experiences for others. These comments are affirmed in Salakys' (2000) work, where she notes that patient narratives present familiar protest against the impersonality and standardization that inevitably accompany a highly regulated health care system influenced by social norms, scientific paradigms and principles of efficiency and economy.

Studies by West, by Conway and by Frank (cited by Salakys, 2000) also identify that the actions of patients intended to achieve change for others are morally driven. The principle of autonomy, so highly valued in present society, seemed to override concerns about intrusion, and kin accepted the individual's right to self-determination. It is also likely that families, wanting what was best for the patient during terminal illness, perceived that the talking-out of problems would be beneficial.

Treatment issues, potentially a real concern, did not provide any insurmountable challenges. Sometimes a change in the patient's condition was noted which the nurse had not indicated that she was aware of. In those situations the patient would be advised to discuss the new symptoms with the nurse. Permission would also be sought to discuss these concerns with the nurse personally if she was contacted, as usually happened after an interview. In one situation the patient was so sleepy there was no confidence he would remember to call his nurse and discuss his sore throat, so permission was asked and received to contact the nurse directly.

In another instance the patient was very uncomfortable and fearful that he would need to be admitted to the hospital, as he had a belief that if he went into hospital again he would not get home. His nurse was away, and he did not wish to use any other services. On assessing the situation it was discovered that he had stopped taking his laxatives¹³ as he reasoned he was eating 'virtually nothing' and could not possibly get constipated. He followed the suggested pattern of laxatives and reported later that everything had returned to normal.

The dilemma to be resolved here is where the role of nurse and researcher overlap. The guiding value was that the patient's well-being over-rode other issues, such as the interview process or the completion of patterns emerging in the data. It was the nurse-experience that allowed an expert assessment. In the first situation it was experience that recognised the severity and significance of the sore throat, and also understood that medication and disease process would hinder the ability to remember to call the nurse. If the principle of patient autonomy were used as the primary value here it could have led to an undesirable outcome.

The example of the patient who had stopped his laxative medication probably had a higher potential for a bad outcome because of its particular context, and the nurse-role taken was greater. The situation was assessed, the prescriptions and doses interpreted, and specific actions encouraged. These actions fall very much into the professional sphere, and are, on the surface, beyond those of a researcher. Seeing this issue as simply one of resolving competing roles avoids the more important concern - that of the safety of a vulnerable participant. The

¹³ Morphine has a constipating effect, and a laxative regime will be prescribed.

focus here is on the individual relationship of care, not a retreat into the safety of generic rules.

On one occasion there was a great deal of concern to find a patient in a very wrought up state related to an interaction with the usual doctor's locum that had gone poorly a week earlier. By the time of the research visit and interview, the regular doctor had returned, and had responded to the family's complaint. If some action had not been taken there would have been a moral duty to act. This action would have been to seek consent to discuss it with the palliative care nurse. As the situation was passed, the harm done and the risk of further harm to this patient minimal, it could be argued that a researcher had no need to act further. However professional duty demands a response in a sense of a nurse's accountability to society, and the personal, human-to-human commitment also demands action. These principles over-ride others in such situations.

Ending the relationship when interviewing was over had the potential to become an ethical issue. Usual processes in such interviews would be to terminate the relationship clearly when data gathering was complete, and in most cases this was simply done. With one set of patient/kin, however, the relationship was reduced more gradually as that was judged to be more appropriate than a sharp cut off.

These decisions reflect the use of contextual or situational ethics (Rogers & Niven, 1996) where the best decision is guided by the contextual reality of those within the field of concern. Traditional values, such as autonomy, veracity and professionalism are used, but priority is determined by the human relationships and the welfare of the central participants. This is not to indicate a necessarily teleological¹⁴ stance, as the ideal outcome may be modified by the processes of achieving it. Neither is it particularly deontological¹⁵, though the primary duty to the patient is high, as there may be competing duties, with variable priority. Research situations carry a higher moral duty than treatment-only situations, as in treatment the primary beneficiary is the patient, but in research it is the researcher who is gaining from the patient. Yet the patient potentially carries the risk, so is conferring a significant favour on the researcher. These concerns are

¹⁴ Where the ethical nature of a situation is determined by examining the outcomes.

¹⁵ Where the ethical nature of a situation is determined by examining the actions and duties of those involved.

recognised by other researchers such as Clandinin and Connelly (1995) who note that, as personal experience researchers, we owe the research participants a duty of care, and that our responsibility to is to be constantly aware of how our research texts change their lives.

The participants expressed great trust that the process would allow their stories to be told, and conveyed confidence that it would be done with integrity. Both the responsibility to do this, and their trust, is acknowledged. The next challenge was in doing just this - in examining the data closely and identifying the meaning within it.

Working with the data

This section deals with the pragmatic matters of data management and the processes of working with the data to find meaning. The primary method of data collection was audio tape. Tapes were transcribed as soon as possible. Transcripts were thus produced in three forms: printed transcripts, a file on the hard drive of the computer, and copies on floppy disks. Once all transcripts were word processed, all these data were copied to a backup super-disk. Further data were generated by reflection on the interview process, and additional field notes from listening to the tapes. Written workings and reflections from journals, notebooks and print-outs from word-processing created yet more material. When analysis had begun formally more notebooks and computer files of work added to the data collection. Audiotapes, printed material and disks were kept securely in a locked filing cabinet and information on the computer's hard-drive was password protected.

Data analysis and interpretation

The position taken in this work on analysis and interpretation, as described in chapter 3, is that while to some extent both are used simultaneously, there is also an advantage in regarding them separately. The process of recording and reflection outlined above shows a continuous engagement with and withdrawal from the data. At this early stage the focus of attention was the immediate data, in order to avoid premature interpretation of the complete experience.

The questions of meaning were noted as they intruded on analysis, but deliberation came later. This process was not seen so much as a suspension or

attempt to bracket out prior understanding and emergent interpretation as more of a stance of heightened awareness of unconscious and parallel processes.

A summary of the processes of a number of phenomenological researchers and theorists (Van Kamm, Giorgi, Paterson & Zderad, Colazzi, van Manen, Streubert, 1991) offered by Streubert & Carpenter (1999) shows a common movement from immersion in data to identifying structure to explanation. Such a summary supports the analysis to interpretation progression outlined above.

Some preliminary analysis and interpretation was done with one set of transcripts in preparation for a conference paper, and this allowed an introductory skirmish with the data. The exercise confirmed that the data contained material of significance. Presenting these tentative findings confirmed that the experience of the participant had been interpreted in a way that was 'real' for those in the audience who had clinical or life experience in the field. It also showed complexity of the transcripts and the challenge of extracting the essence of the narrative.

The formal analysis process

The first part of analysis was reading around various material to establish exactly what processes would best suit the data. The original proposal stated that the methodological stance taken during the study would be more existential than hermeneutic. It also proposed a simple thematic analysis of data, and left open the issue of interpretation. While a number of methods for undertaking analysis exist, such as those summarised by Streubert and Carpenter (1999) above, other writers advise caution in following specific plans. Van Manen (1990) offers general stages rather than specific steps, and Crotty (1998) recommends that as researchers, we have to "devise for ourselves a research process that serves our purpose best, one that helps us more than any other to answer our research questions" (p. 216).

During the study these general approaches have developed into more specific stances. This has come about because of expanded reading on methodology, more focused reading on analysis and an effort to provide a space between analysis and interpretation. The data themselves kept intruding on notions of order being imposed from outside of the narratives, and this also prevented the use of analysis methods which demanded splitting up the story of the narrative

without regard for its integrity. The notion that the data themselves direct the analysis and interpretation was a central theme to these processes (Van Manen, 1997)

During the long process of completing the transcriptions, there was regular reflection on what seemed to be the current issues, and frequent records made of this. This collection of ideas has strong links with the themes which emerged later during more formal analysis. For example on January 21, 1998:
Pacing may be a key issue.

And on May 25, 1998:

If we embody ourselves through our narratives, then how do our narratives prepare us for our own and for other's death? (disembodiment)

on May 31, 1998:

How do all the narratives work together to make sense for the patient?
(personal notes)

When print-outs of all transcripts were done, the major work with the patient interviews began. This brought up the question of how to group the sets: as sets of patient-kin-nurse, or groups of all patients, all kin and all nurse. It seemed that there were advantages to both, and the decision to work first with the patient scripts as a group was influenced by a desire not to flow into case study issues. Some degree of case study lay-out is inevitable with such a small number of participants in an in-depth study, but it was felt that to use too much of the format would lead to questions about why the whole study did not use case study methods.

Summaries of the transcripts were created to reduce the material being worked with. The summaries were then further concentrated into a précis. All the material was read and re-read to gain a sense of satisfaction that the précis accurately reflected the primary data, and that the essential points appeared well linked through all formats. Deep reflection about the material and the emerging ideas, in the light of the constant reading of both academic writing and personal accounts was both a continuous and a deliberate process. There was also reflection on how the ideas that seemed to be emerging as important fitted with life experience and nursing practice. Any mis-matches provoked a return to the primary data with questions. The major issues listed which had emerged from

the précis were listed and consideration was given to how they fitted together and within the study. It seemed that the imposition of an arbitrary division or shape upon the data was not useful at this stage, though it was conceded that knowledge of these shapes was now part of the data, and could influence what was eventually used. Confidence grew that the data themselves not only *could* but also *should* direct both the last stages of analysis and the interpretation of the findings.

From this familiarity with the data meaning began to emerge more clearly and the tentative findings were compared with the primary narratives. Patterns among the meanings were seen and a possible structure developed. Although early themes had been discussed with the participants, it was at this stage too late to verify the subsequent themes with them. However the themes were validated by other patients, other kin, and other nurses. A thorough process of re-visiting the data for confirmation and logic continued during this time.

Focus on the patient experience

During the process of data analysis and reflection it became clear that the early, and perhaps unrecognised, assumption that three distinct narratives would create a three-dimensional form to understand living with terminal illness was not supported by the patterns emerging from the data. It was gradually apparent that kin and nurse narratives were complementary to the central patient narrative. The patient narrative was detailed and rich, whereas the kin and nurse narratives were economical in description. Some kin narratives were sparse, though even these added another dimension to the patient experience. More of a challenge was the realisation that the patient narrative was dominant and rich, containing what appeared to be as-yet poorly recognised aspects of living with terminal illness. To devote equal attention to kin and nurse narratives would risk over-shadowing what was emerging as the primary narrative. The kin and nurse narratives suggested that they supported the patient's experiences and their texts show a complementary rather than an individual stance. From this point the patient narrative was recognised as dominant and therefore primary.

Interpretation

Chapter 3 has introduced the work of Anthony Giddens (1991) as the philosophy through which the themes of this work are interpreted, and subsequent chapters

will elaborate on this. Movement of the participant experience from its own individual meanings to meanings that were relatively common to the group of participants required intellectual engagement with the data and the potential for subtle change was always present. The moral duty to keep as close as possible to the personal narrative in order to keep integrity of the data and keep faith with the people was a key issue, and at the front of consciousness during this time. Creating transcendent meaning required stepping away from the engagement with the participant group's experiences and looking for wider significance. While it was necessary to do this in order to have the deeper significance of participant experiences revealed in ways that would allow insight, it was also vital to keep the reality of their lives and contributions close. Such higher level interpretation demands courage, integrity and a sense of openness and lightness which conveys the provisional nature of the interpretations. Giddens' work, then, is just one possible means to understand the experience of these participants; the reader will have others which, if the data permits, will convey new understandings to him.

Introducing the participants

The ethical question of maintaining privacy even when using pseudonyms provided some challenge. The following chapters rely on the coherence provided by individual accounts, yet the need for detail is not great. In order to achieve privacy beyond the anonymity of pseudonyms much personal detail has been omitted. Actual diagnoses are not necessary, nor the ages, occupations, nationality and so on. Family details have been blurred by providing general rather than specific statements, for example 'children' rather than 'four sons and three daughters'.

One participant's data is not included. This person had progressed to a stage where tiredness was overwhelming when interviewing commenced. Although several congenial visits were made, as the patient and family were keen to contribute to the study, fatigue limited questioning. This person's experience confirmed that of the others, adding strength to the findings and affirming the value of his contribution.

'Abby'

Abby was a woman in her late fifties.

I'll tell you one thing that I did one night. When I had to go into hospital, I was having terrible trouble going to sleep one night and I was trying to think of pleasant and wonderful things that have happened in my life, and there have been a lot. So I thought, I know what I will do, I'll count my blessings. I got to 69. It was really wonderful. I felt so completely different. Actually it was people. My blessings are in the form of people (B3p5).

Abby lived with her husband in a well-set up house. Their children had left home, and some were married, with children. Her very elderly parents were both still alive, and moved into sheltered care at the time Abby became ill. Abby's roles as wife and mother had been uneventful in terms of health-related events so she had no close experience of severe illness or death.

Disquieting symptoms had been present for a little time before Abby visited her doctor. Treatment for possible infection did not alleviate the discomforts, and her doctor investigated further, resulting in a fairly rapid diagnosis of cancer. Treatment of chemotherapy was undertaken with hope but not a great expectation of success. Abby and her family worked to make the best of the time left to them.

Care was provided in the home setting, with short hospital admissions for treatment and for a chest infection. Hospice and Cancer Society nurses visited, though Abby's strongest relationships were with the hospital and the Palliative Care nurse there.

The key issues for Abby were coping with her illness and impending death. Her ability to maintain control over events seemed fragile, as she balanced hope and realism, knowing and not-knowing, and coping and chaos.

'Florence'

Florence was in her eighties.

Well, of course, when you get news like that, it is rather devastating. And then I thought, well, I have had 80-odd years, and I have done most things people would want to do. So, therefore I have got so much to be happy about. (. . .) lovely children, and grandchildren, and great grandchildren. What more could anybody ask. Therefore it is a circle. We are born, and we know we have to die. So, we really know. I can't see any point in fighting it (E1p1).

Florence had lived alone until her illness, when she had come to live with her daughter. She was familiar and comfortable in this environment, with her own furniture and possessions about her.

Florence enjoyed living, and valued her family very dearly. She had many friends and cared very much for them. Her main focus was normally on 'other' rather than herself in a natural and loving way.

Some years earlier Florence had had surgery for cancer, followed by many years without symptoms. A recurrence of symptoms was not recognised by her general practitioner until an acute situation arose. Curative surgery was not possible and Florence was given a short prognosis.

Care was undertaken at home by her daughter, with the support of the Oncology District Nursing Service, which had by this time been set up. Florence engaged a new general practitioner in her daughter's suburb. He was excellent at palliative care, and cared for Florence with dignity and respect, something she had not experienced previously from the medical profession.

Florence expressed that coping is learned day by day, that families support each other in many different ways, and that caring is mutual and reciprocal.

'Ivan'

Ivan was in his mid sixties.

I believe that all of us are born with not just the sense, but the obligation to create. Whatever we create, whether it is crime, or passion, or monuments or just individual happiness around us, we are bound to create something. Even the most barbaric, the most unintelligent, even the most primitive human can't help but create something in his own life time.

So I live my life in that respect, and it is very, very hard for me to just sit down and accept anything final. And say: I have got no further obligation, no further reason to do anything (D1p4).

Ivan had emigrated to New Zealand about thirty years earlier. He lived alone, as his wife had died from cancer about a decade earlier, and his children were grown up.

Ivan had surmounted many severe tribulations in his life, including being condemned to death and being sent to prison camps, both for political reasons. He was a survivor, fiercely independent and with many strong views.

A persistent cough and increasing shortness of breath were attributed by his general practitioner to infection, in spite of a history of a lifetime of heavy smoking, and no treatment was feasible by the time he was diagnosed. For Ivan and his children the short prognosis was a shock and difficult to cope with.

Care was provided for Ivan by his general practitioner, the community nursing team and the hospice as needed. He also used the acute care service when needed, and the palliative care nurse at the main hospital. Ivan found it difficult to discover who was 'in charge' of co-ordinating all this care, as he found the team approach confusing. He remained at home until about four days before he died.

Ivan conveyed clearly that living toward death is singular; that there is one chance to do it right; and it is a sentence against which there is no appeal.

'Jan'

Jan was in her late fifties.

I think it becomes a realisation. I am on steroids at the moment. And it is a little bit of a false hope. Because they make you feel so well, your body has had it, but the steroids make you feel quite well. And you think: you can do anything. But in actual fact, your body is failing you. and it gives you that sort of – oh, I will be able to fight again. Then you think – oh, hang on, it is just (the steroids). So your body is falling round you, but you think how can I possibly be dying because I feel all right (F1p1).

Jan and her husband had an apartment attached to her son's house, where most care was provided by her daughter-in-law, Lee.

Jan was a feisty and independent woman, who was accustomed to caring for an extended family and those who were her patients in her nursing work.

By the time Jan's cancer was diagnosed it had begun to move throughout her body, making any form of therapy palliative. She had some secondary deposits of cancer in her bones which made them fragile, and she used a wheel chair to get around.

Jan's home care, provided by Lee, was closely supported by the Hospice Community Team and the Oncology District Nursing Service, working harmoniously and effectively together for this family.

The most significant issue for Jan seemed to be what she called 'the letting go thing'. She described this as hard work, that you have to do every day.

'Annie'

Annie was in her early sixties:

I am a bit radical in my views about death, you know. It sounds a bit funny, but I don't believe in all this participation, where you have landed up in hospital and they've sent for everybody. I don't believe in people sitting there and being so sad (A1p1).

When you are sitting down with cancer you feel all tired. As if you have been running a long, long way. You know, if I were me, I should be sitting up straight, but instead I am just slouched, and it is just comfortable, being slouched. And really you should sit up straight (A7p38).

Annie had stopped work because of her illness, and lived in a comfortable, modern unit with her lifelong friend, Nell. She was very independent and liked to know about her illness and treatment.

Annie had had symptoms for some time before she could persuade her general practitioner to investigate them. She found this delay frustrating, so the diagnosis was a relief as well as a shock. Treatment for her cancer prolonged her life beyond initial expectations. Annie had chemotherapy first, and later some radiotherapy.

Both Annie and Nell were keen that she stay at home as long as possible, though they declined care from the community nursing team. Annie's palliative care specialist nurse was able to visit her and co-ordinate care at that time, which suited these women well.

Annie conveyed a sharp sense that the whole world had changed irrevocably from the moment of diagnosis. Nothing would be the same again.

Conclusion

These people, then, with their kin and nurses, are the *Dramatis Personae* of the research experience which investigates their passage toward death. They have made sense of their lived experience as they have lived it and narrated it as individuals. Considering these singular accounts both separately and together, and using the work of scholars to aid interpretation, further understanding is possible. Such a deeper knowledge would transcend the personal and allow a reader insight into the experience of other people in a similar life stage. The next chapters provide interpretation of these experiences.

Chapter five – the fateful moment

The next three chapters present the data obtained through interviewing the key participants, Abby, Florence, Ivan, Jan and Annie, and their kin and nurses. Chapter five focuses on occurrences and experiences of participants in the early times of their illness; chapter six describes the significant findings of the middle period, a kind of suspension of progress toward death; and chapter seven recounts the participants' actions and reflections as death came closer.

This chapter, with its focus on early events, begins with the participants' accounts of the shock of diagnosis, and how they and their kin managed this ordeal. The middle section of the chapter deals with the responses to diagnosis and disease on the patient's body, discussing relationships between the body and self and the body and other. The final part of the chapter continues the theme of shock-response by examining how the participants coped with their new situation through narrative work.

The significance of diagnosis

Diagnosis of a terminal illness sets the patient apart from his kin, and from this point the patient narrative becomes primary and the kin and nurse accounts are secondary and contributory. The bad news of a cancer diagnosis is recalled with great clarity by all participants, though the actual details might differ a good deal among patient, kin and nurse. It is clearly a turning point, and often stimulates existential issues, though perhaps less than might be imagined. Diagnosis was the point from which most participants began their accounts, as it was the time at which their whole worlds changed. For those in this study, the news did not come 'out of the blue', as all had been experiencing symptoms of illness, though it was still a shock for many of them. First responses varied, as individuals developed differing priorities.

Annie experienced increasing pain and disability, and could no longer work, but she was frustrated that her general practitioner did not seem to realise how unwell she was. Eventually the doctor agreed to investigate the symptoms.

I had an x-ray. I was so bad, I couldn't get out of bed, and I had an x-ray at the hospital. I went to Dr C and I said to Dr C "if you don't send me up for an x-ray I am going to pay for one because I am rolling out of bed, and it can't be . . ." She (had) said it was osteo-arthritis around the neck (A1P6).

I think she was very, very nervous, because she stood at the door, you know, and she let us sit here, "you sit there," because she stood at the door, and she took me in and she said, "your x-ray - you've got cancer. You've got cancer all down here," she said, "and you've got it here, and you've got to go to the hospital immediately."

Well, that was when they said it was terminal. They said, "oh, you haven't got very long - it's terminal." And so she (general practitioner) was very uptight. Because she said it was osteo-arthritis. I think if I hadn't insisted on going for that x-ray I probably would have died with it. So I changed doctors (A1p7).

You know when they do that 'colopsy'¹⁶ thing, and they put that thing down I heard the man say, "oh, this is inoperable." He said, "this is inoperable, because the tumour is underneath the heart. It is on the wall of the heart, so this is terminal." So I mean, I heard the guy say it as plain as anything (A1p8).

It was a bit of a shock when I found out I had cancer, of course, but when the doctor said to me, "oh, it's terminal," I really wasn't that worried, strangely enough. I thought, "oh well, if it's terminal, it's terminal." And we were rushing around, trying to get funerals done, and I arranged things, and the insurance, and everything like that because I thought when the doctor said it was terminal it was just a matter of time. I thought, I've only got a few days (A1p2).

Annie communicates her concerns as anxiety at persisting symptoms and offers a picture of a doctor experiencing guilt at not following them up. She has clearly lost trust in this woman, but seems very matter-of-fact when she reports changing doctors. While her personal understandings of anatomy are difficult to follow, what is essential to her is not. She understands that she is terminally ill, and knows what she must do.

¹⁶ Taken to mean an examination of the upper respiratory tract with a fiber-optic scope.

Initial response to diagnosis

The factors that trigger particular responses may differ from person to person, though it seems likely for these participants that the words *cancer*, *terminally ill* and perhaps *inoperable* are highly significant. Annie related how the term *terminally ill* had connotations of immediacy and urgency for her. She seemed to be delaying dealing with any existential significance of the news while she got the practical issues under control, these practical issues being influenced by her particular understanding of *terminally ill*. Once she had arranged for disposal of her body, ensured that everything would be exactly as she wished, and paid for it all, she was able to allow the concept of death for herself to come closer. She says:

It's strange. I've accepted it, and I know I am going to die. So, if I die, I die. As the doctor says, it's terminal; but I don't know for how long (A1, p2).

This action of putting some information aside, in order to deal with what seemed to be more important issues, was seen with other participants and kin. Exploration of possible treatment is a common and appropriate response for many. It may be a way of exploring the gravity of the diagnosis while delaying focus on its prognosis. Jan's kin was typical of those who wonder if acceptance without exploring conventional and alternative therapies could be 'giving up too soon'. Lee notes:

The first thing I thought was: "Right! Lets see what we can do and try to help her cure it." A friend of mine works for the Cancer Society, so I rang her. And she got hold of some names for me, and some books for me to read. One of them was about a guy who had got cancer and he did this New Age healing. Probably things like carrot juice and all that kind of stuff. He went to Melbourne and did something over there, and now he is cured. That was a really good book. And there was a guy that actually did the course himself, whom she knew, and he has been cured. He has been in remission now for five years. I thought: "mighty! We have got all this info'." I found out the people we had to talk to and how much it was going to cost to send her overseas.

But she wasn't really interested. She just said: "oh, look we'll let the - - " Probably being a nurse . . . and because her mother had been through bowel cancer, and she had tried this alternative therapy. So I thought:

"Righti-ho! I am not going to push it, I will just leave it until she is ready" (F3p1).

She elaborates this later:

Really, that's the thing that got to me, lots of people were very pessimistic about it, like: Cancer – that's it! Might as well put a big X next to your name. So that's why I really got into 'let's find something, let's do it'. So I was a bit . . . and she hasn't, she didn't even show any more interest in it. Which annoyed me a bit, because I thought: "well, why don't you get in there and give it a go." You are not going to lose anything. But she just didn't seem to want to. So I left it. And as the prognosis got worse and worse and worse I kept thinking: "well, it might not have got worse if we had tried that way back then. But." (F3p1).

(So when did you move from that 'let's try and cure it' to, another way of viewing it?)

To just accepting it and now we are making her comfortable? I think when she came home at Christmas and was really bad. They didn't think she would last. Time to throw those books away. So that's all gone now (F3p2).

Lee's account shows that her first response was to do everything possible to defeat the cancer, and her disappointment in Jan's reluctance to enter this pathway is clear. Also clear is her respect for Jan's autonomy and greater life experience, and though she says she accepts the situation there may be a tinge of regret still. Such careful exploration of the boundaries between the kin's opinion of how the patient should respond to diagnosis and the patient's actual wishes was seen with other participants. However, the patient's self-determination normally took precedence over the kin's notions of the best response.

Coping by creating space

Jan found the initial diagnosis devastating and a shock. She too, made space between the information and herself.

I made jokes to divorce myself from it. I suppose I was in denial (F2p1).

Jan is reflecting on her behaviour and offering an interpretation of the meaning of it when she suggests she was 'in denial'. This psychological term was sometimes offered by kin, though the nurses were more cautious with it,

recognising that such labelling could limit an individual assessment. It can be a narrow concept, and is not always recognised as a temporary coping mechanism. Patients can experience it as judgmental, which may account for Jan's *supposing* she was in denial.

It was three months after first diagnosis that the tumours appeared in Jan's knee. She realised then that her prognosis would be 'poor'. As a nurse she knew that poor means no recovery, but did she use the term with her family, who may not have recognised the meaning beneath the euphemism?

During this time Jan had chemotherapy which she hoped would help her situation, though she did not really expect the treatment to cure it. This suggests another approach, that of focus on treatment to delay beginning the dying time. Whether treatment was therapeutic¹⁷ or palliative¹⁸, patients and kin often had higher hopes than were objectively warranted. Their hopes were partly supported by the health team's attitudes of not shutting out hope knowing from experience that every now and then surprising things happen, and that patients with hope live more satisfying lives to the end. However, mostly the patients hid their hopes from the medical and nursing team, perhaps because they knew they were not realistic. This apparently ambiguous approach seemed to allow a choice of possible futures, and prevented the patient being committed solely to the path toward death.

Cancer diagnosis as a small death

The transcription excerpts above show that diagnosis is a shock which is followed by a period of striving to understand both the diagnosis and the prognosis. But is this shock different from other diagnoses? Any diagnosis from influenza through diabetes to untreatable cancer has the potential to influence a person's life. It is the significance of this diagnosis that makes it different, as it promises a change which is the most radical that a human can experience. The patient is moved, in what is experienced as a peremptory fashion, from a living human to a dying human; where thoughtless comments about 'we're all dying in some way' are so radically wrong that the sense of dislocation is increased. His

¹⁷ Treatment with the aim of cure.

¹⁸ Treatment with the aim of alleviating symptoms, reducing tumours or prolonging life with the intention to improve or maintain quality of life.

responses show that a life-shattering event, a small death, has occurred and outsiders may feel that it is a place where only those with this news can go. One way of gaining insight into the experience of diagnosis shock is through the words of participants and others. Splitting the experience into two facets allows the discussion to focus more, and permits illumination via the work of relevant philosophical understandings. Julia Keegan noted that when she was diagnosed with a tumour in her brain she was “hit with shock of course. But it failed to make any impact immediately that an untimely death was possible” (Cardy, 1997). Two facets of the experience, like two sides of one coin, are *facing the possibility of losing life* and *facing the possibility of dying*.

Facing the possibility of losing life

Facing the possibility of losing life is a momentous experience. These times stand out from inconsequential, every day life and as such are described by Giddens as “fateful moments”. He writes:

Sometimes, however, a particular situation or episode may be both highly consequential and problematic: it is these episodes that form fateful moments. Fateful moments are times when events come together in such a way that an individual stands, as it were, at a cross-roads in his existence; or where a person learns of information with fateful consequences.

(Giddens, 1991, p. 113)

Giddens discusses both elements of risk and of fortune in relation to fateful moments, and they are evident in the accounts of the participants. Risk, which society and individuals seek to minimise and control, has gone wild. The risks that present with a life-threatening illness are unknown, potentially numerous and may not be able to be controlled. There seems to be a chance element in the presence of cancer. While the causes of some cancers are now understood, and the contributing factors for others are being explored, many cancers seem to develop silently and unrelated to lifestyle or genetics. Some patients (see below) experienced their tumours as alien, invaders, or ‘other’. The element of chance, “fortuna” for Giddens (p. 110), suggests a random quality to the events which does not relate to desert (deservingness) or consequence, and which is beyond the individual’s control or influence. Alongside this sense of dislocation, there is usually a need to make decisions at fateful moments.

These decisions, Giddens says (1991), are usually almost by definition difficult to take because of the mixture of the problematic and the consequential that characterises them. Thus, experts are consulted at fateful moments. However, in the case of a cancer diagnosis, these same experts have often precipitated the fateful moment by their very expertise, and this may lead to a sense of distrust. Because the consequences arising from decisions are so significant, and perhaps may be difficult or impossible to reverse, individuals may consult other experts. However, rather than easing the situation, second opinions may make it even less clear. If the situation were more predictable, it would not be a fateful moment. In addition, the scale or enormity of the consequences adds to the significance of the decisions.

In making decisions about treatment, those diagnosed with life-threatening illness need to consider risks of any treatments. However, in developing cancer, the patient has moved from facing a theoretical, known and therefore supposedly manageable risk, to falling into danger, becoming a victim. Risk is no longer general, but personal, and has become real. Expert advice about risk probability related to treatment is given in the previously trusted language of numbers, factors and percentages which have the function of cloaking risks to populations, not people. Now those statistics cannot be trusted, and as Giddens (1991) points out, the higher the risk, the greater the element of chance. Risk involves future events, but now that death is the prognosis of the illness, the future is not open, it is *toward death*.

Ontological security

Fateful moments challenge the “protective cocoon”¹⁹ which guards the individual’s “ontological security”.²⁰ A person’s sense of self includes confidence in his being and place in the world (Giddens, 1991). Ontological security begins as the human resolves the trust/mistrust dilemma of babyhood described first by Erikson (1963) and in doing so begins to differentiate between self and other. The elements of ontological security are time, space, continuity and identity and trust in them is built and confirmed by the practical experience of engaging in life and

¹⁹ Protective cocoon: the defensive protection which filters out potential dangers impinging from the external world and which is founded psychologically upon basic trust (Giddens, 1991, p.244).

²⁰ Ontological security: a sense of continuity and order in events, including those not directly within the perceptual environment of the individual (Giddens, 1991, p.243).

accumulating knowledge and confidence. This security provides a bulwark against generalised anxieties which might otherwise be overwhelming. The reflexive nature of learning about trust leads to a sense of self identity which depends in part on the ability to predict, manage and control potential chaos.

Achieving ontological security depends to some extent on being able to bracket out both the potential for disorganisation in the world, and anxiety about the reality of things and people. Giddens (1991) suggests that the individual is aware of the enormous potential for things going wrong in day-to-day life, and also aware of the fragility of his and others' constructions of the perceived world of things and people. Ontological security is in the ability to live 'as if' this chaos were not there, and 'as if' people and things will carry on as they always have. Taken for granted, he says, are "time, space, continuity and identity. The protective cocoon, created by ontological security, allows the individual to get along with his day-to-day life" (p. 53).

The diagnosis of cancer has threatened the protective cocoon by showing evidence that the identity which has been carefully nurtured is not as it has always appeared. Chaos crowds the protective cocoon. Continuity becomes unpredictable and time changes its structure and rate. The place the individual occupies may be vacated. Everything that was taken for granted must now be questioned.

The place of experience

Fateful moments also present moral and existential dilemmas. That is, they are presented both in being laid out before the person, and present in their proximity in time. Existential questions of dying, death and beyond are indistinct when they are far off. Difficult to examine because they contain many as-yet-unknown factors they may appear problematic, and projections are speculative. In modern society it is common to have little experience of these end-of-life events, with smaller, distanced families and the medicalisation of death. While Giddens (1991) suggests that the vicarious learning of mediated experience (film, literature, drama and art) allows insight into events as yet beyond the personal, the participants in this study did not overtly recognise this influence on themselves.

Glimpsing chaos and death

Existential questions related to death come close with the knowledge of a life-threatening illness. It seems that in their new proximity, these issues lose some of their unfamiliarity and become less fearsome. The question of 'if' becomes 'when' and the question of 'how long' becomes 'how soon'. Death has moved from a possible event to a certain event. While it will often shift again to be a little further away, it will rarely return to the unknown distance it had before diagnosis. The glimpse of chaos caused by the gap in the protective cocoon is both frightening and re-assuring. To do nothing with the breach in security risks being overwhelmed by chaos.

However, the patient has glimpsed chaos, and recognises that his destination and his progress towards it separate him from both who he was before diagnosis, and other people. New concerns about approaching death and the process of dying itself may enter his consciousness.

Ivan describes how this experience was for him:

Ah, you see, there's a very, very deep divide between the healthy and the dying. We have to bring that issue up again. Nobody, but nobody, can see the world with the same perspective as we see it.

When you are alive, there's always a tomorrow, and the issues, however much they hurt, can be avoided. Circumvented. Abandoned. You can move from one country to another. You can change political views. You can change jobs, professions. You can marry another man, another woman. But when death comes along you have got no alternative.

And a lot of things become very, very finite. Infinitely final. There's no other way you can go about it (D4 p14).

It seems there are two distinct messages here from Ivan. In the first place he is clear that this experience is singular, widely different from previous experience and absolutely, personally finite. Secondly he is telling us that those who are not terminally ill cannot understand what it is like, and by implication, should not presume to either describe it or direct it.

Does this mean that the experiences of the terminally ill should not be tentatively interpreted by one who is not terminally ill? Just as Ivan used metaphor, life

experience, literature and the wisdom of others to help understand his life with a terminal illness as he moved toward death, so a careful practitioner can seek to throw light on this final stage of life using accumulated knowledge, and avoiding generalisation of the experience. What he is warning against is prescribing his course for him, or failing to listen to him, or not taking account of his reality.

Facing the possibility of death

Being-towards-death is examined by Heidegger (1962) as he explores the relationship between Dasein (Being) and the end of Dasein. He expresses this as an apparent paradox: "Death is the possibility of the absolute impossibility of Dasein" (p. 294). Death is possible from the moment of existence; to exist is to have the potential to die. Indeed, death is certain as history tells us. Yet our own death while certain, has a not-yet uncertainty about it which keeps it in the possible. This not-yet quality shows a space between Dasein and not-Being. Heidegger points out that this gap is not closed simply by completing the course to the end, but also includes a potential for fulfillment which is a constitutive element of Dasein. Fulfillment, which seems to be an authentic grasp of Dasein, may or may not be achieved.

Because death is known only as an 'out there' event, happening to others, it is not able to be grasped in the same way as other phenomena. Heidegger (1962) discusses the 'they' who are the public mind and voice, accepting death and talking of it in a general way, depersonalising it and keeping it away from the sphere of any specific individual. 'They' continue to use the same talk to the dying person to prevent him bringing death into his immediate comprehension. People do accept that all will die, but are not imminently threatened by it. He sees this approach as allowing the concealment of death and argues that this concealment at the same time acknowledges its existence.

Dying, Heidegger (1962) says (sections 47 - 53), is not an event: it is a phenomenon to be understood existentially. It is not clear here whether he uses 'dying' as referring to that part of life lived after a person is given to understand that they are terminally ill, or the act of passing from human existence, or being dead as compared with being not-dead. Later he seems to separate these into dying, demise and death, though there remains some unclarity, probably as his focus is the existential rather than the living of that existence. His comment that a

psychology of 'dying' gives information about the 'living' of the person who is 'dying', rather than about dying itself, seems to concede this.

Modern views

Exploring the possibility of death helps throw light on the complex and ambivalent relationship of living with dying. While we are living we have an acknowledged potential to reach the end of that life, but both personally and societally we have developed the ability to hold this knowledge as impersonal and far-off. In modern society this is increased by the seeming endless ability of medical science to treat all manner of conditions, giving rise to responses such as Callahan's (1993) comment that death is now a moral evil. The individual is able to hold to a 'yes, but not now' stance toward death supported by society's depersonalisation of death. The potential for death may be examined as Heidegger's exploration shows so well, but unless the person has an actual and personal diagnosis of a reasonably imminent terminal illness there is, those who have moved to this place indicate, an inauthenticity about it. Lewis identifies the gap neatly:

Yet H. herself, dying of it, and well knowing the fact, said that she had lost a great deal of her old horror at it. When the reality came, the name and the idea were in some degree disarmed. And up to a point I very nearly understood.

(Lewis, 1976, p. 29)

The shock is abrupt and numbing, as the person is wrenched from an open-ended future to one with a completion event defined and a time-frame estimated. It seems to be the intense contrast of open future/closed future that contributes to the impact of the news. The sense of shock continued for the key participants, even as they recounted how they had coped and continued to cope.

Late modernity views

A more complex and modern interpretation of the self than that developed by the existential philosophers of the first half of the twentieth century is offered by Giddens (1991). His construction allows for a more relational, externally influenced being who is intersubjectively created and normally ontologically secure. His claim that Heidegger's philosophy is premised on a view that death is the end, is supported by Macquarrie (1955). Macquarrie, writing as a

theologian, interprets, rather than translates Heidegger's work, and questions Heidegger's claim that we need to grasp death fully in its ontological character before we ask what is after death. Macquarrie asks how we can hope to arrive at a full existential concept of death, as this requires a phenomenological approach, which necessarily cannot be completed. Giddens (1991 p. 49) cites Kierkegaard's remarks about the individual necessarily being excluded from knowing his own death as he cannot come near enough to death to experience it without actually going through it.

Existential concerns are mediated by the individual's work on his ontological security, as Giddens notes also that the human skill in filtering the multiple possibilities of life situations enables the practical mastery of everyday life.

Practical consciousness, together with the day-to-day routines reproduced by it, help bracket such anxieties not only, or even primarily, because of the social stability that they imply, but because of their constitutive role in organising an 'as if' environment in relation to existential issues.

(Giddens, 1991, p. 37)

It was this practical 'as if' response to events which characterised the lives of the participants, providing a pragmatic solution to the myriad of uncertainties which presented. They recognised that they were continuing to live, in spite of the ever-present risks, and this helped them turn away from the uncertainties unless they intruded into day-to-day life. Though they were *toward death*, they were living. Giddens's (1991, p. 37) comment that "To investigate such matters on the level of abstract philosophical discussion, is of course, quite different from actually *living* them" (emphasis in original) seems wryly apt for the participants.

The body in crisis

An early effect of diagnosis is to force attention on the body, as the body has forced its attention on the individual. This section of the chapter begins with crisis and change and adaptation to change and then discusses how the changing body affects the two key modes of the body, that of the body-for-itself and the body-for -others. The section ends with a summary of this body de-stabilisation.

Florence notes that her body is no longer working in its usual way.

They said I wouldn't be able to go back and live on my own and that they could relieve the symptoms for the present time. But there was nothing more they could do. it was very, very – ah, very invasive. And that was very hard to believe, because I had been playing bowls about a month before that. (I was) feeling tired most days. I said to the girls: "I just get so tired." I think: well, I will go out into the garden, and I am out there about twenty minutes and I think: oh, my goodness, I can't do any more of this. But I didn't think about that horrible thing taking all my energy away.

(How do you picture it?)

It's a weird picture. I think there is something there, and it's getting on with what it wants to do, and I have got to fight and say, well, you are not going to do that. But that's probably an impossibility. However that's how I feel I can deal with it. It doesn't feel part of me. I think: away with you! Whether it will is a different story.

I am sure most people would think: how could this happen. And you still sort of continue, as I thought, very normally. It has crept up on me, but I had no idea there was something doing it, did I?

That's what I think is so strange. Nature is so wonderful in so many ways. When you think that there had been a little – perhaps there was a little something, but you don't recognise it.

I have thought for years: what a wonderful mechanism it (the body) is. The way you eat and sleep and drink, walk and talk and think. And we really don't take a lot of notice of it, do we? Until something happens. And then we are brought up with a round turn (E3 p2-3).

In this reflection, almost a dialogue with her body, Florence is listening to her body's communication with her. She is focusing on experiencing her body and looking back on a life of taken-for-granted embodiment. She notes that it has always been there, but when she is shocked by its failure to continue to function she is 'brought up with a round turn' to face it.

Crisis draws attention to the body

The body in crisis, especially in death, suggest Hallam, Hockey & Howarth (1999), forms a site at which self and social identity are highlighted. Confidence in the body is challenged as threat of death or dysfunction are reminders of frailty, vulnerability and mortality. The body has continued to function

independent of the individual's volition, as humans do not need to remember to breathe, or to initiate digestion. The body communicates its needs in hunger, thirst or thermal sensation, and the needs are met. A relationship is formed which is so integrated it is imperceptible. It becomes the norm, and the boundaries for its function are accepted. Illness and threat of death destabilise those boundaries, opening up the possibility of an unknown area. Comments from Van Manen confirm the awareness of the body when disease strikes:

Serious illness changes everything: our sense of time and priorities, our experience of space, our felt relations with others, and our sense of self and the body. At the moment when our wellness is disturbed, then we discover, as it were, our own body. We might say the body reflects on itself as body. We discover the object-like nature of our body when the unity of our existence in the world is broken.

(Van Manen, 1998, p. 12)

Questioning the body's reliability

Until the time of diagnosis the patient had not thought very much about his body in terms of what his body meant to him. Diagnosis changed this, as he became aware of his body in a new way. The presence and activity of cancer within his body seemed to lead to a sense of alienation and 'other-ness' of body which is perhaps the beginning of the separation of embodiment. The feeling of betrayal, invasion and an unknown body was recognised as he reflected on the body-person relationship. In addition, he had to cope with the effects of treatment on his body which was becoming somewhat alien, and develop a new kind of relationship with it.

What is the place of the body, and what is the relationship between the self and the body? How is it possible to understand the experience of people who are dying in relation to their body-as-entity?

It seems somewhat obvious to say that we live embodied lives, yet it is the taken for granted nature of this aspect of life that is newly presented at a time of crisis. We need our bodies to move and communicate: we need our bodies to demonstrate that we exist in our world. Our bodies are so much part of our being that we see our being as integral with them - coexistent. While any illness or injury may cause reflection on the reliability of the body, a terminal illness has a

more significant effect because of the potential for complete body disengagement.

Accepting the body-as-it-is

Facticity is used Heidegger (1962) and other existential philosophers including Sartre (1956) to encompass the notion that every way of being includes a factual aspect and a situated aspect. Just as there are a large number of things that cannot be controlled in the way humans are placed into the existence they have, there are many uncontrollable aspects to the body in which they exist, and the nature of the decay of that biological body. The Heideggerian view is that the being must face up to its facticity and all that it means in order to become all that it could become (Heidegger, 1962; Hoy, 1993). The quest for the authentic life is seen as the chief purpose of life by existentialists, although it is not clear from this account of Florence's that it was the over-riding goal for her. How does she accept the fate of this particular body when its flaws become apparent? It seems that there is a time of some awareness of signs "*I was feeling tired most days*" but the cause of this fatigue is not apparent to her. Is this because she has an in-authentic response? As she reflects she wonders if age (she is over 80) and weather were significant factors in the tiredness, but does not recall her previous history with cancer. She acknowledges that "*perhaps there was a little something, but you don't recognise it*" (E3 p2-3).

A gradual disclosure of change

Rather than 'authentic' or 'in-authentic' responses to the signs which in retrospect collect together in a pattern of significance, it may be that Florence both recognises and hides her growing frailty. She acknowledges dis-ease, but puts away the thought of disease. Her focus is on the body's experience at first, then, perhaps reluctantly, moves to the body as object. She seems more able to cope with the symptoms when both the body and the tumour are moved to 'object' -- *it doesn't feel part of me* (E3 p2-3).

The place of the body is also discussed by Sartre (1956). He offers an approach which includes reflection on the body-for-itself, and reflection on the body-for-others. Giddens (1991) discusses the grasping of reality via day-to-day praxis, and developing as a competent agent in the world. Being a competent agent involves such things as bodily control, and knowing how the body presents.

These ideas suggests it would be useful to examine the body-for-itself in terms of the body as known via its own experiences and the body known as object. There is overlap and merging between the body-for-itself and the body-for-others, but to explore each in turn allows a better understanding of the experiences facing the patients in the study.

The body-for-itself

The sensations which are received from the physical body to the conscious mind convey messages about the body and confirm the existence of that body. People who experience interruption in sensations caused by such events as nerve damage or stroke may fairly quickly lose cognisance of the affected part, and even fail to recognise the existence of the part. In his account of a climbing accident and subsequent surgery Sacks tells how his leg became alien to him as he lost sensation. He describes how, after the operation to re-attach the torn muscle, he examines his leg:

. . . I touched nothing at all. The flesh beneath my fingers no longer seemed like flesh. It no longer seemed like material or matter. It no longer resembled anything. The more I gazed at it, and handled it, the less it was 'there', the more it became Nothing - and Nowhere. Unalive, unreal, it was no part of me - no part of my body, or anything else.

(Sacks, 1984, p. 48-9)

Without sensations there is gross interference in perception of the body. People seek to know their bodies via sensation, and will try to make themselves more alert to such experience.

Florence is seeking to know the tumour as it dwells in her body and so she projects her awareness towards it.

Well, I feel it is down here and I don't like the look of it. I think I can see it. I think it looks really ugly. And dark. Other than that - I don't know whether I understand, but I think I heard that there were two. So whether they are fighting each other . . . I think that they could be.

When the pain has got bad, I have thought: oh, goodness, do you have to perform like that. I have thought that, but I haven't said anything to it. Maybe I should get more vocal (E6p7).

Florence recounts experiences of pain and of a visual nature that signal a bodily presence which she cannot ignore. As she listens to it she begins to speculate about the meaning of the sensations she receives. Abby, too, is aware of pain and its significance. She says:

But I know when I am getting worse and its just been a progressive thing.

(So you are able to observe yourself?)

Oh, you can tell. It's . . . I have got friends who – refuse to think of me having cancer so I am a bit . . . I have only to listen to this 'cat' inside me – to know that I have cancer (B1p8).

Abby is aware of her body, listens to it and does not hide from the reality, though her friends would wish her to do so. Like Florence, she transforms the sensations of pain to a visual conception. She seems to recognise the temptation to hide from the cancer, but hears the scratching and clawing in her chest which does not let her forget.

As long as we remember, the body is there, always there, and there as the instrument of the self. The body is taken for granted, and its presence is regarded as permanent. The body makes itself known, that is, moves from silent and reliable presence to impinge upon consciousness through the medium of sensation or function. Part of the body as taken for granted includes its physical appearance, and in this way the body is viewed as an object. It is a personal view, and will include experience, but the main means of acquiring information is by visual observation, which turns the body into object.

Annie reflects on her changed appearance.

It (my head and face) was bad enough last time (during previous treatment) when I lost my hair, but it seems to be a bit more swollen. When they said I was going to lose my hair, the day I came out I went and cut it all off. I thought: well, if I am going to lose my hair, I'd sooner lose it at my pace than theirs. So I sat in front of that mirror and I just cut the lot off. And another thing, I just about grew a moustache here. I said to Nell: I am changing sex. . . . I shaved it. . . . What lady wants it on the chin?(A2 p15).

There are a number of issues to examine here. Firstly, the body has a known and accepted form and shape. Annie knows what she normally looks like. She knows what she looks like after chemotherapy-induced hair loss. She compares those two pictures with what she sees today.

The importance of the fit with socially defined body shape and image is argued as increasingly important in 'high modernity' - the beliefs of the late twentieth century. External referents of dieting and fitness industries and fashion and health have a large influence on the acceptable appearance, demeanour and function of the body in modern society according to Giddens (1991). The influence of phrases such as 'you are what you eat' and 'image is everything' indicate a pervasiveness of conformity to a young, fit, healthy and attractive image. Annie finds her loss of hair and a swollen face do not fit with this image. She is also uncomfortable with facial hair, and using the term 'lady' suggests that her femininity is important to her. It is likely that the loss of hair and thickening body shape are compromising her culturally molded picture of female.

The person has normally come to terms with their particular fit with this image, and even with a slow movement from the 'ideal' with ageing. However, a rapid movement from their picture of themselves and how they fit with the standard they use for measurement, particularly when accompanied by the threat of further deterioration, can precipitate disjunction between the inner self and the image of the body (Hallam, Hockey & Howarth, 1999).

Jan recounts part of her experience with cancer.

Well, I went to theatre²¹ seven times last year. It started off in January, when I had a hysterectomy, and they found that I had cancer. And then I had radiation that did all the damage. Then, in the March, my femur broke. Gradually. And they found I had a tumour in the knee (F1 p1).

More surgery followed with repeated attempts to stabilise her body, which just kept going wrong. Eventually things became relatively secure and Jan was able to go home.

. . . so that's . . . I don't want any more. I have a daughter who is not very good about it. She can't see why people can't fix it. And I just say: well, I don't want it fixed. (she thinks) everyone else is to blame, why

²¹ The surgical operating room.

did they do this or that. And why can't they fix it. I don't want to go through anything else. I couldn't go back into hospital and have another operation (F1 p1).

In this text a move from the personal to impersonal can be seen, as Jan first says *my femur*, but in the next sentence begins the de-personalisation of her body by saying *the knee*. The seven visits to theatre show Jan both how unreliable her body has become, and how she has to hand it over to the care of others to be fixed. Seeing her body as object seems to assist in this process. However, the notion that the body is an object that can be fixed by experts stands in the way of her daughter's acceptance of the situation. Jan has to explain that *she* doesn't want to go through anything else, admitting that it would be *her* that had to go back into hospital and have another operation, not just the body. The issue of handing over of the body to others is explored by Lawler (1991) who asserts that the dying patient is encouraged to keep control for as long as possible, and that this process is set by the nurse rather than the patient. It is possible that the setting for her study, hospital rather than the community setting of this study, may have influenced this opinion. For the patients in this study their wish to maintain control often outstripped the nurse's judgement of what was prudent.

Hallam, Hockey and Howarth (1999) explain that for aged people the issue is the extent to which their deteriorating body is an accurate representation of themselves as they see themselves, as they wish others to see them, or even as their bodies objectively *are*. It is clear that this is an area of tension for terminally ill people, just as it is for aged people. For Jan this tension is heightened by the obtrusive nature of her deteriorating body. Her responses show that she is both affected by the acceptable/unacceptable body discourse which she perceives and imagines, and that she resists the discourse as well as she is able.

Giving over of the objectified body to caregivers may be total when surgery is undertaken, but in the home situation there seems to be more of a partnership. In the text below it is Jan who is interacting with the nurses, not *the body*

I was amazed how much I had come to depend on her, and when they reduced the visits to only three times a week, I got quite a shock. It surprised me that I had actually come to rely on her so much. And I still do rely on her.

(what is so special?)

They seem to have all the answers. If you have a problem you can ask them and they will always seem to know the right answer, and if they don't, they will go away and find out for you. And she always fixes what is wrong. She is the main one, I think. As I said to her, if I have any problems, I will tell you. Sometimes the others come and they haven't seen me, and they might pick up on a problem, and they might be aghast . . . they might get a bit freaky. But if I am worried I tell her (F4 p2).

As the body is 'handed over' to others for treatment (repair) there is a sense of dislocation, aggravated by the thought that others (outsiders) know the body better, more intimately, than the person himself. The body has information not available directly to the 'owner'; the owner must rely on an outsider to share information about his very dwelling place. The body has moved to 'other'. Confidence in how the body will be in the future, even the immediate future is undermined.

The body as a means of physically being in the world includes the practical aspects of mobility and independent functioning. These are threatened by increasing illness. Annie knows her legs are weak, but wants to remain independent.

The thing is, it's made my legs very weak. At this critical stage of your life, your legs are most important, because if you can't put the weight on your legs, then you can't get round how you'd like to (A2 p18).

Her vision becomes distorted.

I don't want to get worse. I am looking through a glass jug; I am not steady, I am not straight when I walk. There's no way I could defend myself if anyone came near to attack me (A3 p 5).

Yet she insists on getting up at night without waking Nell.

Nell: I say to her: wake me up because you might faint. What I get anxious about, Annie, is perhaps you might fall.

Annie: the exercise is good for you. because you'll stiffen yourself up.(if you don't exercise) If you feel you've got to get up, you should get up (A4 p4).

She notes that this weakness may be temporary, reflecting later:

Annie: I am better now. I was wobbling, and I could hardly walk. In fact, half the time Nell had to help me go to the toilet. And now I could walk, I could walk to get the mail or anything (A4 p8).

But she is aware that this period of mobility will not last:

Annie: You are (I am) going to get worse. The fact of the matter is – I will know. I am going to start having jolts of pain constantly, waking up, trying to get out of bed, and sooner or later, Nell, I feel that with my back, when you really have to help, sooner or later I am not going to be able to go on that toilet because the knees will give way. And so, you see.

Nell: what happens then?

Annie: You are (I am) becoming worse of a burden. A burden, a burden, a burden (A4 p 11).

The body as a reliable conveyance is taken for granted. One wills walking and it happens without coherent planning. The person forms an intention to do a task, and the actions of getting up, moving and assembling the tools are not consciously ordered or planned. Only when a person is incapacitated in some way does he actually plan how to arise from a chair, how to walk downstairs, and how to fill a glass of water. This mobility, intentionality, the instrumentality of the body is another taken for granted aspect that has now become uncertain.

Change in the body-for-itself further influences the body-for-others. The person can no longer fulfill the hitherto expected commitments in a relationship and foresees a time when this will change even more radically. As Annie notes, she will be worse of a burden.

The body-for-others

As well as being for itself, the body is for others. In this, the body is the instrument of relationships, and becomes seen anew by the embodied self as that self becomes aware of what the changing body looks like. The body is the means by which a relationship is expressed, through speech, touch, look, expression, or gesture. Without the body relationships do not develop, evolve or mature in a genuine way. As the body undergoes physical changes the ability to maintain existing relationships becomes threatened.

Annie notes that her moods and ability to cope have changed.

I have noticed that I am getting a bit like that (laying the law down) – I am getting a bit naggy. Maybe it's one of the tablets? But I am misinterpreting things a wee bit. I have to remember which tablet I have had. I was just a bit uptight, like Nell had said the wrong thing. I apologised to her (A2 p18).

and later

. . . I just called her Mickey didn't I? See – I am going, I am backtracking now. Do you know what I mean? I seem to dream quite a lot, too. Little illusions and so on, dreaming odd things, coming into my mind (A2 p20).

Annie's body had developed secondary deposits of cancer in her brain; these resulted in swelling leading to confusion. A course of radiotherapy to the brain reduced some more major symptoms, but the confusion remained intermittently and unpredictably present. Annie was mostly aware when she confused names or used the wrong words but at other times insisted on a version of events which was at variance with other witnesses. A result of this was that all her accounts were treated as potentially incorrect by some of her caregivers. Both Annie and Nell observed this attitude but felt powerless to change it. Annie also noted a patronising attitude:

I can still sense it in the voice. They'll say (mimics a babyish voice) "how are you today, dear?". And I could imagine that happening to me when I was about eight months old. "Aren't you doing well!" To a child, instead of your own mind. They are saying you have no longer got the same brain you had before you had the brain cancer (A7 p21).

She describes some of the mix ups that occur.

I say things back to front. Have you noticed?

(You haven't said a single thing back to front this time.)

But I do, sometimes I'll say oh, this afternoon I think I'll go somewhere tomorrow. And I say the last word on every sentence kind of wrong. Almost as if the brain is slightly ahead. I say some stupid things. And I still call everybody a different name (A4 p 9).

Where there is a true acceptance of this state of affairs, and some practical solutions offered, the potential breakdown in relationships is avoided.

The best thing for me to do is to take my own tablets, Nell gets them for me, and I write it down. So I know I've had them. And as C (palliative care nurse) says, to get that suspicious thing out of your mind at the end of the week, you can count your whole bottle. And then you see, that makes you know that Nell has got nothing to do with your tablets, and it makes a fact of the matter that you know she is not doing what you thought she was doing. So, she said, that way it lets you both off the hook. Because it has happened before, and since, and it has worked out well (A4p 14).

Annie understands that she mixes things up, and also that she accused Nell unjustly of contributing to this, so she is aware that the relationship could be strained. She mentions her grumpiness, too, as further awareness of body changes which affect emotion and communication.

The body in its known physical parameters is accepted as satisfactory by the person using that body in established relationships. When the body changes, confidence in the continuance of relationships with a changed body may become the cause of concern. People have roles, such as spouse, grandparent, daughter, and these roles are normally established in embodied forms. As the body alters in appearance and function with illness the ability to maintain these roles is likely to be challenged.

The body is not just object for the person whose dwelling place it is, but also object for others. The person sees his body through the eyes of the other when the other communicates her visual perception and its significance through words or gestures. Ivan observes how people react to him.

Certain attitudes of people frightens me. I am gradually losing certain faculties. No sooner have I said that I have cancer, then a lot of people withdraw. They can't accept that just because you have got cancer, you don't stop being a full human in many other ways. It's not hard (for me) to accept (body) changes, but it's very hard to accept that other people cannot see it. They have such misgivings about it.

They are frightened. It is natural. Older animals are gradually forced out of the pack, and secluded in their dying, in their loneliness.

Especially in societies where the male leadership is predominant. . . this is what we must put up with.

(Are you feeling as though you are being pushed out of the mainstream of people's lives?)

Yes, definitely. Girl friends suddenly become miles distant. Your male compatriots suddenly lose their respect for you as a male – you are a has-been. No amount of sympathy can cover that. They start exerting dominance over you. Dictating certain changes. They have taken over your life for you. . . your decision is not relevant any more (D2 p15-16).

The feeling of being seen as no longer relevant in life is strong for Ivan, yet his family and caregivers believe decisions are collaboratively made. What he is seeing, accurately or not, is a subtle shift in his status as a whole and functioning participant in society. Other conversation and gestures strengthen the message so that he also feels he has lost his masculinity and is now a sexless body. Giddens (1991) claims that gender is a matter of learning and continuous work, rather than a simple extension of biologically given sexual difference. Giddens notes further that a “chronic monitoring” (p. 63) of body and bodily gestures is necessary to maintain sexual identity, and Ivan shows us that his monitoring of himself-as-male-through-the-eyes-of-others is essential for his male identity.

Jan, too, has concerns about her body as seen by others. She is concerned that her young grandchildren's memories of her would be pleasant.

What worries me is that I will be a burden. I don't want the kids to have a smelly Nana, you know. It is bad enough that their Nana is sick, but I don't want them to remember, and kids do remember, 'oh, Nana made awful smells' and I don't want them to think of that (F1 p3).

The person also has an idea of what the other may think, and may attribute perceptions and emotions to the other. Whether this is accurate or not does not matter, the person still has both the communicated perception of what he appears like and what it means to the observer, and the imagined perception and reaction.

These changes of physical, cognitive and relationship aspects of the body have in effect de-stabilised the familiar body boundaries. Firstly, and most importantly, the body has become unreliable. It is the only known means of continuing

existence in the world as experienced and suddenly it is not doing what it has always done. It has become 'other', alien, an object, unknown. There is a sense of betrayal at this body, with which the person has always existed in relative harmony, seemingly abandoning the joint project. Has the body become an agency on its own, and does the self now have to begin the process of separation? The body is increasingly under the control of outside agencies, knowing it better, controlling and directing it, and becoming increasingly unfamiliar. The body is in crisis.

Secondly, independent functioning in the world is threatened. The body must be attended to first, with urgent needs that interfere with established day-to-day routines. Chemotherapy breaks employment; tiredness prevents exercise; nausea makes meal preparation difficult. The power has shifted from the person to the body, and the person feels helpless in his own body. The fear of becoming a burden is a major concern for all participants.

Thirdly, the acceptability of the person's own body is shaken. Surgery, chemotherapy, radiotherapy, steroid therapy and the disease process cause small to major body changes, all of which require adjustment. Some of these challenges to familiar body boundaries may be readily met, other changes may be beyond the person's capacity for adjustment.

Coping with fate, crisis and an unreliable body in the midst of living

The diagnosis of a life-threatening illness produces a shock for the person and those around them. Losing trust in the once-reliable body adds further stress to the situation. The person has moved from a relatively predictable situation to one which is both un-nerving in its unpredictability and frightening in its predictable end. These are significant times for all involved, but intensely so for the key actor, the patient. How do people manage their lives in times of crisis? The final section of this chapter discusses the part that the self-narrative plays in the process of continually coming to terms with the day-to-day reality of being terminally ill. The discussion shows various types of narrative that are discernible in the participant accounts, and demonstrates how they work to help the individual make sense of his now-unstable environment and avoid the kind of chaos that would de-stabilise his whole situation.

The self-narrative

Death is not the only challenge of life, nor is it the only challenge facing those diagnosed with a terminal illness. With the always-present-but-kept-at-a-distance threat of death there are daily challenges that the individual must meet. Giddens suggests that self-identity at all times is related to the self narrative.

The existential question of self-identity is bound up with the fragile nature of the biography which the individual 'supplies' about herself. A person's identity is not to be found in behaviour, nor - important though this is - in the reactions of others, but in the capacity *to keep a particular narrative going*. (emphasis in original)

(Giddens, 1991, p. 54)

Varying narratives

Interviews with the participants in the study reveal a number of narratives which seem to serve differing purposes, and are constructed and maintained by many activities. Sometimes narratives are told in their entirety in one episode, other narratives emerge more gradually. For example, a health history narrative might be recounted quite efficiently, probably due to the practice the participant has in telling it to health professionals. On the other hand, the individual-within-a-family narrative tends to be commenced with an overview, and have details furnished as needed at a later stage. The excerpts below illustrate these and other styles and are followed by an exploration of the means of constructing, maintaining, editing and projecting personal narrative.

The term *narrative* in its broadest sense is an account of an event or events which has some significance in and of itself. The focus here is on personal narrative in which the significance and/or the purpose of the account is controlled by the narrator. Although narratives are often remembered in a linear or chronological form, they may not be told in this way, or understood so simply. Narratives run parallel to each other, overlap and contradict. Taken for granted in this study is that each account 'is' - that is, it does not need to correlate to externally understood events, nor to be congruent with other narratives.

Biographical narrative

The first two groups of narrative presented are the biographical accounts and the health history. Annie's biographical narrative illustrates the discontinuous character often present in these accounts.

I've known my friend for thirty years (A1 p1).

So, everybody's had to go, who I have loved you know, so I am not really scared about death (A1 p2).

I had to look after my mother because we were in Australia and it would have cost \$30,000. She had a pulmonary - emphysema, and the doctor told us to put her in a hospice (A1 p3).

I've had so much pain in my life (A1 p5).

I was in the bottom class all my life but my mind is as sound as a bell (A1 p11).

We went round the world together. We worked at the hospital, and a friend of ours, who lived with us, died. He was like a son to my mother (A2 p3).

My mother died in Queensland in 1979. That's when we came back. Nell's mother and father died more or less six months apart (A2 p6).

My mother never really grew up to be an elderly person, do you know what I mean? She was very happy-go-lucky, and she'd go off into the Irish jig. When I was a kid, because my Dad was in the War, she'd take me off bowling with her (A2 p12).

This account comes out sporadically, as Annie needs to illustrate a point, or explain something. It runs as a thread of biographical narrative throughout her conversations. The listener makes sense of it by grouping these similar items together, and arranging them in chronological order. Much biographical data is judged as peripheral to the recent narrative, and recounted as incidental material before and after the tape was turned on.

Health narrative

Much more ordered were accounts of health history, particularly the recent events. The following narrative illustrates a more complete account, as Abby tells of her growing awareness of being ill, and the diagnosis.

I went down to help my mother & father move into a nursing home. (...)I was just going flat tack, and sewing all these names on, so that was all right. But then on the Tuesday I went to bed and I could hear this – wheeze, but I didn't feel one bit ill. (...) the next minute a bed came up for mother (...) I had to carry on with this jolly noise. And then I had to come home and make clothes for myself and this noise and cough started. I went to my doctor and he said I had a virus.

So, I felt he should have sent me for an X-ray, but I am pleased he didn't because I wouldn't have gone over to spend time with my brother. Exhausted by the time I went over there. And trying to suppress this ghastly cough all the time. And I remember lying beside the pool one day thinking “my girl, you are not well.” So when I came home, a few days later, my friend came round (...) and said: “what on earth are you doing sitting there like that – you look absolutely terrible.” (...) so I made an appointment for that afternoon. The GP said: “I can't figure out what is wrong with you. We'll get your chest X-rayed this afternoon.” (...) he rang me about seven and said “you have a mystery chest infection” and he got me into the chest ward the next day.

So it was about three days later, I had a CT scan and sputum tests and they found out that I definitely had – cancer (B3 p8-9).

This narrative is more focused and is chronologically ordered. It is likely that it has been often rehearsed with family and friends as they inquire after her state of health. Abby is providing clues as she relates the story – being tired, the cough, the noise in the chest. There is drama as the general practitioner doesn't immediately pick the lung cancer, but suggests a virus. Why did he not get it right in the first instance? Abby does not blame him, but leaves an opportunity for the listener to do so. After her holiday Abby is still not well, but leaves it to her friend to take charge of getting her to the doctor. Has she begun to suspect something sinister at this stage? The doctor, she tells us, is perplexed. Is he really, or is he delaying? The immediate admission to the chest ward is an indication of urgency, and the listener suspects the doctor is aware of the seriousness of the situation. Abby allows him space not to be the conveyer of bad news.

What was her feeling about the urgency of her admission?

I was hoping it was TB, because I thought that would be easier to get rid of than anything else. I didn't actually think – my husband was

with me after the CT and he said: "we're going to get rid of this. It's going to be fine. You'll be home for Christmas, and everything will be terrific." And I was thinking: "how naïve. You're not in hospital for any old thing." (...) I thought it was something pretty major (B3 p9).

The narrative allows Abby to express the ambivalence she lived through at this time. She is both aware of the potential disaster lurking, and hopeful that it will not eventuate. She can portray herself as both stubbornly getting along with things (with her friend) and able to face grim possibilities (with her husband). At the same time she looks back and sees her anxiety and the support she received in the ward the night before the diagnosis was told to her.

The night before, the nurses made a great fuss of me. So I suppose - - yes, they certainly did. I often think of that night - they were absolutely wonderful (B3p9).

The shock of diagnosis is still with her as she recalls:

So, yes, a young doctor came down and had a talk with me. The chap that came along first said: "Mrs A you have cancer." Just like that. (...) the next morning this young house surgeon came along, and took my hands and said: "you have, you have cancer." And, ah, that was virtually it (B3 p9).

Listening to one's own narrative

This is the narrative 'supplied' by the individual to support self-identity. Recounting the events helps Abby to real-ise them. In telling the listener she also seems to be telling herself. The word 'cancer' is difficult to get out; she struggles with it, trying it with a small pause before, trying it quietly, trying it bluntly. She repeats it, and hears it, but it still doesn't fit well. She recognises that others are taking special care of her at this time, and this seems to confirm the cancer reality. Giddens (1991) notes that self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is "*the self as reflexively understood by the person in terms of her or his biography*" (p. 53). (emphasis in original).

The facts of Abby's biography have changed, and she is seeking to understand them. Firstly she is working on incorporating the information into her biography, and secondly she is seeking to understand what it will mean to her. Reflexive

understanding, as described by Giddens (1991) is an on-going process of understanding where the individual does not simply accept a single explanation, but actively integrates the meaning into his life and identity over a period of time. It is cumulative and open to revision. Continued work on personal narrative is seen in many accounts.

Narrative reflection

Ivan spent some time establishing his identity before he recounted his recent health history. He had considered this approach carefully and said that to understand his illness experience, it would first be necessary to understand him. In the text below he is reflecting on a story of his childhood where he and his brother had an adventure on an island in a river.

I call it the Robinson Crusoe syndrome. We were never born to be in such close proximity to each other. You lose your identity. And the little child knows that, right from the beginning. Apart from that, when you have to conduct your own life, without your parents being there – as I explained both my parents were kept very busy just surviving at the time. I suppose you get a bit disenchanted with society, and reading Robinson Crusoe encourages a rebellious, growing up child to establish his or her own domain. But then reality struck – the cold night, no mum, no dad, no bed and a younger brother who was crying – then suddenly it became a heavy and harsh responsibility.

He goes on to explain how this understanding persists through his life.

Suddenly you become very uncertain about your future plans, because they didn't work out the way it was written down in a book. And probably if I relate any of my other escapades in life, they are very much like that Robinson Crusoe attitude. Idealism, justice, freedom, spiritual, mental and physical freedom. The same sense of self respect and self achievement. (...) I felt the pressures of injustice and falsities and inhumanities. And then I somehow gathered the strength and the ability to be a Robinson Crusoe and find a Friday and followers. Then try to lead them to an enchanted island where everything is possible. Yet, inevitably, night descended with cruel reality, and there is no such thing as a deserted island, and no such thing as Robinson Crusoe. We are all slaves to society. Spitting against the wind.

Nevertheless, when the next occasion comes, I was again a Robinson Crusoe. I try to defy the odds. So I tackled a lot of tasks in my life, and in some of them I succeeded. I managed to attain a certain amount of

the freedom of a Robinson Crusoe. Probably you could say I lasted longer than the evening mist. I lasted maybe 'til midnight. And from somewhere the fog suddenly came up and I got lost again (D2 p1-2).

Ivan later reflected on how this particular aspect of his self-identity faces the current challenge.

I was pondering on that whole theory myself after you left. And I was examining myself and you know, here I am again, having to fight against the odds. And whether my attitude is changing because there is no more dreams left from Robinson Crusoe. Nobody ever wrote about what happens when Robinson Crusoe dies.

You know, before, one way or another, whether you succeeded in your adventure or you failed, you came out of it and you had another chance. Another chance. This time - this is it!

This closing off of options lead to behaviour which Ivan himself called vindictive, his children called stubborn, and the nurses called difficult. He explains how he understands it.

You could say that if you are being taken to court, you try to defend yourself, then you reach the end of the line, and they say, OK, you are condemned to death. If you can grab a gun you are inclined to go on the rampage and kill people. If you feel the sentence is unjust. And no normal logic or common sense can convince anybody who is dying under these circumstances that it is justified.

(You were condemned to death once before, weren't you?)

Yes, but it was different, because it was a condemnation of a human nature. There was a court of appeal. So where there was life, you appealed, and you fought, and you appealed. But in this court, it is the highest. I cannot appeal (D2 p3).

Ivan feels he has come suddenly to the edge of the grave, whereas he might have expected a slow living through to an old age. He is always aware of the closeness of death.

I know I am standing on the edge. You know, there is no two ways about it. I mightn't think of it every minute - I am still able to forget when there is a nice sunny day, and I feel a bit easier than yesterday. And I am still dreaming: "well, if I can improve a little bit more I will get back to work." Silly thoughts, but nevertheless the Robinson

Crusoe is quickly quietened down when the evening comes and you have a bad day (D2 p3).

Continuous monitoring of activities, Giddens (1991) says, is characteristic of human life. People can provide discursive interpretations about what they do. Ivan's narrative shows that he is able to do this. It seems important to him to show that his leadership and optimistic qualities are a strong thread throughout his life. Carrying them through to the present challenge he at first says he has run out of dreams, but later acknowledges that the dreams break through on good days. He is making sense of his life by telling and interpreting his story. He maintains his sense of self identity by showing that in some ways he remains who he has always been. Being able to sustain and continue a coherent narrative prevents the self identity from becoming shattered.

Modifying personal narrative

Part of sustaining a narrative may entail editing that narrative to fit in with later developments. For example treatment offered for cancer is understood to be a significant ordeal but those who had had treatment reported minimal discomfort. Annie said she was never nauseated; Abby said it was 'OK'; and Jan offered no details apart from the fact that she had had radiation treatment and did not want any more. Jan had kept a journal throughout her hospitalisation, and reading it six months later lead her to some interesting reflections.

I just wrote everything I felt. Every single thing. You know, I look back now, I didn't think I had gone through all those stages, the bargaining. I played the yes/no game a lot. I have written that, my yes/no. 'Am I going to live until July?' yes, no, yes, no. I have written that. I played a lot of the yes/no game. And bargaining, and then the grief, and then feeling sorry for yourself. You do go through the seven stages, you definitely do. Yet I thought I had accepted it quite well, yet I hadn't (F6 p3).

So, about the chemotherapy. I had four. I was supposed to have six. He was just saying the other day, when I went up to the clinic that the cancer I had, the tumour is a very aggressive one. But it actually responded to chemotherapy quite well. Often aggressive cancers do that. And I had only four. I wondered if he was thinking about giving me another two, but I don't want them. I don't think two would be too bad, because the first couple aren't too bad. It's when it starts building up.

You all sit there in lazy boy chairs, and you all sit there, and they just drip this stuff into you. and I was amazed. No one – everybody just sat there and took it.

I didn't seem to feel it much the first and second time, but after the third time it was – even just a couple of days after. And that's where the book was quite handy, because I looked back to see what days different things had happened and it was following along the same pattern all the time. The vomiting, the diarrhoea, the terrible sleepiness (F6 p4).

This doesn't quite fit with the picture she offered at the first interview.

The nurses in the surgical ward didn't know how to handle – they got upset, you know. They said: "how can you talk about it? How can you accept it? I really admire you." and things like that. It's just reality, isn't it?(F1 p3).

Jan portrays herself here as someone who is coping well with the dread cancer diagnosis and treatment. She is brave, inspirational and admired by professionals.

Berger (1997) claims that, in a context of literature, narratives can be categorised into such genres as heroic, romantic and so on. Literature narratives are complete, while those of living humans are on-going, and cannot be similarly cast into a mold. In therapy, a narrative type can be recognised and as such provide insights for the individual and the therapist (Monk, Winslade, Crocket & Epston, 1997; Sampson, 1989). When seen as pathographies²² (Sakalys, 2000) patient illness narratives provide a counter narrative to the dominant medical discourse.

Using such a framework Jan is presenting what may be seen as a 'coping' narrative which is incompatible with her journal's account of uncertainty and distress. As time has passed the previous experience has been modified in her memory as she works towards the style which she sees as best for coping in the emerging situation. Culbertson's writing on narrative and self-identity is a reminder of the normal nature of such editing.

²² Narratives focusing on illness.

. . . not everything is selected for retention in our memories. The structuring of a narrative requires recourse to a selective process in which we prune, from our experience, those events that do not fit with the dominant evolving stories that we and others have about ourselves.

(Culbertson, 2000, p. 60)

It is easy to imagine that a narrative focused on uncertainty and distress would not be helpful to Jan during the more stable period from which she was talking.

Conflicting narratives

During the passage towards death patient narratives involve stories of communication, treatment decisions, services offered or not offered, the prognosis, progress of the disease and other predictions. The potential for modification of material by both patient and family is high, given the significance of these items. When the general stress of the situation, and the side effects of cerebral damage from chemotherapy, are added to the everyday busy-ness and human failings of health professionals, it is surprising that more breakdown does not happen.

Jan's various understandings of the frailty of her leg bones illustrate some of the ways communication is kept flowing during times of potential misunderstanding. During the first interview she recounted that three months after the first surgery she suffered a pathological²³ fracture of her leg, and a tumour in her knee was discovered. In the second interview she said that the appearance of the tumour in her knee was significant in that it pointed to a poor prognosis. This was confirmed at the third interview:

Once they had found that tumour (in the knee) – I remember I cried and cried. I got it all out of my system. Well, you know. Because I thought: well, this is it. That is my life gone now. (...) and I will become more independent.

That's why I am getting told off now, because I try to do too much. But I try to explain to them, just let me do it, because soon I won't be able to do anything. So let me do it now. But they don't see it like that. They see me as taking too many risks.

²³ Where the primary cause of the break is the presence of disease in the bone.

(Perhaps they recall your frail bones?)

Yes, if I fracture anything, that is what they are scared of (F4 p1).

A little later Jan was admitted to the hospice for, among other things, 'a holiday for herself, from herself'. She expressed astonishment that she could fracture a leg bone if she walked, and said she should have been told about this. When reminded that she had previously talked about risks, she said that she knew her bones were frail, but didn't know they could break. She was able to re-edit to justify her position, but how do others cope with this? If she had broken a bone both nurses and kin would have felt responsible. Her kin, Lee, was aware of the frail bones.

The first thing that she found really hard was the loss of movement. And then they told her that she shouldn't be out of her wheel chair very often, walking round, because her bones are so frail. So even if she knocked herself, she could break something (F3 p4).

Some weeks later Lee had learned to worry less.

Last night she insisted on cooking dinner. Which is what I normally do. And she looked had it. She looked really tired, really weary, and she didn't sleep last night, either. And I knew she wasn't feeling up to it, so I came up and said: "do you want me to help you?" and she said: "no, no, I am fine." So I thought: rightio. Instead of bulldozing like I normally do, I let it go. So good.

(Well done!)

I was quite good, wasn't I? But you see, she gets up and walks around, and she is not supposed to.

(And that worries you?)

It does because the doctor doesn't want her up out of that chair. (...) even if she just staggers and knocks a hip, it could shatter, because it is that brittle. I have to let her do her own thing, because there will come a time when she can't do anything. (...) so I let her do what she wants to do now, I don't try to fuss over her too much (F7 p2).

The palliative care nurse confirmed that Jan had been warned about the risks of her frail bones. The nurse comments:

I used to arrive there and she would be making coffee and standing up in the kitchen, and both Lee and I would go: "you will break your leg!" and she'd go: "yeah, yeah." People will take the information when they are ready. They have got so much to deal with when they are dying. Though I don't really know why she might have accepted it now and not before (F9 p1).

Co-operative narratives

These narratives seem to show a high level of tolerance for multiple versions of events in the immediate family, though Lee had to be coached towards this attitude. As she was the chief caregiver she took her responsibilities seriously, and wanted to have things 'right'. This may account for her need for control clashing with Jan's need for control. That the nurse and other health professionals could also tolerate a variety of differing stories is interesting. There is always a risk that family and friends, taking the patient's account, will condemn the health service, yet the patient's narrative was allowed to stand as the central account in interactions with them.

Ivan's nurse explains how it was for her when he was having a hard time at home:

I wanted to get him into the hospice, and the hospice were quite happy to have him. He didn't want to go and I could see he didn't want to, and I wasn't going to push him. But I just alerted the other nurses. (...) I don't think we can - like, know what is best - we think! - for people. And you do feel frustrated, because we all knew that if he got in there he would be a lot more comfortable and cared for, and it is frustrating and distressing, particularly for a nurse who chooses to work in this area. You see somebody suffer, and they don't need to. So that was really difficult. While I saw it as our duty to tell him that the opportunity was there, I also see it as his right to choose, when he takes it. And I actually felt quite comfortable about that (D5 p3).

At the same time Ivan was blaming the system for everything that was going wrong, and it was clear to his caregivers that his physical situation would not improve without a short stay in the hospice. Yet this primary nurse and the others were prepared to continue accepting his complaints about the system they represented, allowing his version of events to stay unchallenged. In relation to another issue with Ivan, the nurse said that she could not afford to lose his trust

by over-riding his wishes, as later, when he had no independence, that trust would be all that was left.

It seems here as though the patient's ontological security is in part the business of all who care for him, and so important that in these cases at least, the caregivers are willing to tolerate quite a degree of reality shaping.

Developing fortitude

The diagnosis of cancer, especially when the outlook is very pessimistic, is an event that ruptures the lives of patients and kin. The enormity of this fateful moment is shown in their accounts and the various strategies they used to come to terms with it are part of maintaining their ontological security. Reflecting on body changes and what these meant for the participants illustrates both the progress of their cancers and their constant adjustment to these changes. The significance of body changes seems to be felt very much by the patients, but they work at resolving the difficulties produced. Overall, these people made sense of the dislocating situations and events by constantly working on a personal narrative that integrated them into coherent and acceptable accounts.

What was beginning to emerge was a sense of getting along with what life had presented to them - not in a sense of resignation, but in a sense of 'this is just how my life is now and I will live with it'. Different from raw courage it was a kind of fortitude or strength that could be seen.

The experiences and success in overcoming the challenges of the early days provided the participants with the knowledge and skills to continue their lives, confident they could face the constant challenges this would bring, while knowing that their future was toward death.

Chapter six – living in suspended time

Living with a terminal illness, toward death, is a passage in time and through time, yet time takes on a new quality of unreality. The period which follows the re-organisation of self necessitated by diagnosis is a time of paradoxes. While time seems to stand still there are occasions of momentous decision that are significant steps along the way toward death. Life has an outward normality that has an artificial, constructed and frail quality about it. Plans are made whose completion is in doubt. Hope is checked by realism, and stark realism tempered by hope.

This chapter examines the life changes of *suspended time*, following the re-establishment of self identity after diagnosis shock, though it is not time to begin to actually die. On the one hand life goes on in familiar patterns, yet there are adjustments to be made seemingly more related to the disease process than existential matters. Physical and emotional changes provide challenges, and relationships are reviewed. The experience of being suspended in time permeates these events and changes but underlying it all is the knowledge that time is not waiting. The chapter opens by examining the tribulations of the experience, the first and most important of these being having to use morphine. Other tribulations are summarised briefly. The middle section of the chapter focuses on the many adjustments that have to be negotiated in relationships with others. The final section is a discussion on the changing perception of time that is one of the key characteristics of this period. The complexity of all these adjustments is well illustrated by the patients' experiences with morphine.

An experience with morphine

Ivan, like the other participants, was reluctant to commence morphine, but his reflections on this tension are profound, and help throw light on the ambivalence of them all.

He does not wish to take morphine. His pain reminds him that he is in control and he is still alive. Morphine would be giving in – not just to

the idea of dying, but it would also be acknowledging the significance of the disease and his inability to be in charge (D1 p10, notes).

At this time Ivan had not commenced morphine, though he was experiencing pain. By the following visit he had commenced on MST²⁴ and he comments that it is now more difficult to remember the pain. He reflects on the significance of the pain.

I wasn't reluctant to live without the pain, I was reluctant to be without senses or feelings. So, it might be uncomfortable when a baby (in the womb) kicks, but you don't want to be without it, because then you wouldn't know whether the baby is alive or dead.

(I had the impression that the pain's meaning was more than physical to you.)

Sure. Especially for my family. I must be honest, I can't camouflage it, and make people believe that everything is hunky-dory. If I am not aware what is going on with me, I mislead myself and I mislead other people as well. It might sound a bit cruel to say, well, I want my family to know – that not everything is hunky-dory. And the only way I can tell them, is if I am aware of my own physical presence. Not when I am doped up to my eyebrow and I am seeing hallucinations.

It is an experience, on its own. Though I like drinking, I don't think I was drunk more than twice in my life. Ah, I like to keep control of my faculties. And, that's probably overcome my fear of pain, fear of death. Make no mistake, I might put up a brave face, but underneath I am just as scared as anybody else. Of the unknown. But I prefer to be aware of it, than to be ignorant of it (D2 p 12-13).

What seems to be important to Ivan here is his awareness of his own body. He wants to be alive to the physical deterioration so he is in touch with the progress of the disease and can communicate this to his children. Morphine will invade his body, preventing him from full sensory participation. It will also take over his moods and interfere with his control of his own self. The palliative care nurse confirms his reluctance to begin morphine.

When I first went to him, that very first time, he was actually charted, and meant to be having MST and elixir, but he wasn't taking it. Now I

²⁴ MST Continus is sustained release morphine in tablet form.

took out the hand out²⁵ and I talked to him a lot about it. And I talked to him about (how) you don't get addicted if you need it; and how he initially may have some side-effects, but they would adjust (. . .) But I am afraid, although I felt I had made contact with him, and we actually struck a good rapport, I lost the battle in that one. He was very clear that he did not want morphine.

When I actually looked at him at that stage, I am sure he was denying a lot of the symptoms, but he was actually functioning very well. I don't believe you can force people, and I just thought he would choose it when he wanted it.

So, my view was that, ideally, it would have been quite good if he had taken some, but it was his choice, and his feeling of control, and that was OK. You know it is really important for him to call the shots, and I really respect that (D3, p8).

Control

For this nurse the key issues are patient control and trust. While her distress at his pain is evident she allows that it is his pain and his assessment of the significance of it that matters. Does the family feel the pain management was handled well in these early days? Ivan's son had already recounted a little of the family history. He was asked if there were any similarities in his parents' illnesses.

In terms of similarities, no. The up and down, moods, and that sort of thing were sort of similar. The effects the drugs had on moods were similar. But, no, that is probably where the similarities ended. I guess the fact that both of them also didn't really want to give in to it, wanted to get things sorted out for themselves, didn't really want to just lie back and – let it happen(D8 p8).

(There was a stage when we were aware that he was having pain, and . . . pain was increasing and he was refusing to begin medication. Were you aware of that?)

From what we understood . . . he was scared because he had seen what happened to Mum. When she started taking morphine and things, and started to lose control of her thoughts. . . . And started the mood cycling and all the rest of it. I think he was quite scared. He didn't want to let that happen. He didn't want to become reliant on the heavier drugs.

²⁵ Pamphlet about taking morphine.

And he didn't want to lose control of what he was doing and thinking. That was the way I saw it. And yeah, he did hold out for quite some time. . . he had seen it before, and he didn't want to . . . he still had too much to do (D8 p8).

(Should he have been encouraged to start the morphine?)

You would never – he would never have done it! If he didn't want to do anything, he wouldn't do it. He would never – well it was very, very rare that anyone could actually tell him what to do. He was one of those people that always believed he knew best. Nobody would have ever been able to have told him to do something that he didn't want to do (D8 p8).

Ivan's son is aware of some of his fear and other issues, for example the bad experience with his mother's pain management and reaction to morphine, his need to be in control and the holding out while he had things to complete. But the time came when Ivan commenced morphine. What was this experience like for Ivan?

It has created certain differences. And it keeps changing. I don't feel that I have settled down with it yet. I am still experiencing new differences. They might be slight, but they are there. I am wheezing. I feel that morphine is drying the system. I have had no choice. I have had to do it. There was a level of discomfort which was overtaking (me) (D2 p15).

He is forced to adjust to taking the morphine by the amount of pain (discomfort) rising above the level at which he can cope. Coping means being able to function in the way he wishes to: for Ivan this means being able to get out in his car, and to manage the day-to-day issues of nutrition and hygiene. For another person, for example Florence, it means being able to think, sleep and communicate effectively.

Addiction

The morphine is not welcome in Ivan's body yet he knows he has to allow it in. This uneasy relationship is initially a little like a parasite, as it continues to have an individual nature, unlike other drugs. The addictive nature of morphine is alluded to by Ivan when he calls himself a 'druggie', but he does not dwell on this aspect. The explanations from the palliative care nurse would have informed

him that addiction is not an issue when narcotics are used for analgesia, so it is likely that he chooses not to discuss this aspect. However whether addiction is a personal issue for him or not, it is clear that the fact that the drug is an addictive substance alters its significance to him.

Ivan's relationship with morphine settles into a type of partnership where it allows him to continue to do the things he wishes to do, but he remains very cautious about increasing the dose, with the issue of control of his body being paramount. Perhaps he feels that the long-acting tablet, designed to last for 12 hours, means he is always 'drugged', or perhaps he wishes to keep a maintenance dose in his system and top up when needed. He is able to take morphine elixir²⁶ as needed, but this makes him feel a little nauseated and sleepy. When the hospice shows him that morphine can be inhaled with a nebulising dispenser he is pleased, as this keeps him more in control. It seems he is able to accept a particular level of morphine as necessary, even welcome, but beyond that, the issue of the drug as alien remains.

Florence, too, delayed beginning morphine.

Gradually the pain has increased, and I was just continuing on with the panadol, thinking that was sufficient. Perhaps the pain wasn't too bad. But last night – no, two nights ago – we had a really bad night, and the next night wasn't so good. So last night they gave me some morphine. (. . .) and I had the most wonderful sleep I have had for weeks and weeks. So I had been a bit foolish, really. I should have said something earlier (E6 p3).

(What were the things that were significant for you, that you thought, you didn't want to start it yet because . . .)

Because I might need more later. I think that would probably be the thing. You are never sure what the pain threshold is going to be. Today you think: well, that is a nasty pain, but how much worse? Dr (general practitioner) said: we will have to rely on you to say if the pain is, say from 1 to 10, so we can work out a scale. But I find that hard to do. Like yesterday, he said: what do you think it would be? And I said: oh, 4 or 5. And he said: oh!

But then – after having none! I realised that it was probably greater. (. . .) it could have been 6 or 7 (E6 p3).

²⁶ Short-acting liquid morphine.

(And the fact that the medicine was called 'morphine' . . . was that meaningful for you?)

Oh, yes, when he said (morphine) I said: oh, dear. But he explained that it is not so bad.

(What was in that 'oh, dear'?)

Oh, oh, what does this mean? How far along the track am I? I wonder how long I will have to be on it? (. . .) it is very, very significant, I would say, for a number of things (E6 p4).

The recurring issues for patients are pain and morphine. Both are alien and unwanted, yet despite resistance, they invade the body. Both threaten to subvert the individual's agency. There is fear about both – will the pain be more than they can tolerate? Will the pain be more than the morphine can deal with? Will the efficacy of the morphine decrease? The health professionals are reassuring, but it is not their pain, and they do not have to take the morphine.

Body awareness

The relationship between the self and body, routinely invisible, becomes sharply distinct at time of distress, disease or dysfunction, explain Hallam, Hockey and Howarth (1999). For the participants it seemed that the new awareness of the body was increased by pain, drawing unavoidable attention to itself by communicating these unpleasant sensations to the inner self. Agency was interrupted by pain, and neither the body nor the inner self could function normally. Paradoxically, the substance which could damp down the physical pain threatened the inner self again with potential effects such as hallucinations and mood swings.

Another writer (Charmaz, 1999) proposes that the body is contested territory in illness, and the important issue for autonomy of self is keeping control of the body. Further, she suggests that this is more important for men, citing a study showing men taking more knowing risks and engaging in death-defying actions. Their claim to autonomy as a moral right was over-ridingly important to them. The experience of Florence and Ivan illustrates how morphine contests autonomy in several ways: it is a public statement of the presence of pain and therefore disease progression; it is prescribed (ordered) by a third party; and as discussed below, it interferes with the person's will.

Using a dialectical approach, as suggested by Giddens (1991), it is possible to see that accepting the powerlessness of pain and agreeing to begin morphine is succeeded by the power of being free from pain. Giddens notes that it is easy to focus on loss and thus fail to see the gains in the changes of modern life. Both Ivan and Florence reluctantly begin morphine but retain the anxieties about any future increases in dosage. The loss/gain, powerlessness/power dichotomy is related to control and competence. Giddens (1991) reminds us that "Most importantly, routine control of the body is integral to the very nature of agency and of being accepted (trusted) by others as competent" (p. 57).

Competence

When competence breaks down ontological security is threatened. Competence, as Ivan and Florence show, is compromised by pain and threatened by morphine. Agency is diminished by extreme pain, by both the sensory experience and reduced mobility and ability to self care. The intellectual nature of agency is potentially undermined by morphine, and the autonomous self open to the take over of addiction. Against this threat to ontological security the health professionals offer information about pain and narcotics and the patient is able to assess the risks.

Risk management

Most risk in modern life is remote from the individual, that is, it has been distanced by increasing knowledge, by management of risk, and risk avoidance. Giddens (1991) argues that the preoccupation with risk in modern social life is to do with increasing control over it, which the individual has come to expect. Life expectancy has increased, morbidity and mortality have decreased and the environment is generally much safer. While the individual has less experience of things going wrong and therefore less practical knowledge to draw on, it also suggests that those offering information, the health professionals in this instance, will also have little first hand experience of life threatening events. If this is so, it could increase the gap between the apparently knowledgeable expert offering advice and the patient experiencing the fear of pain and disability. The more facts the expert has the more he or she is insulated from the minefield of fear and the more alone the patient feels.

Ivan's nurse knew she had communicated a good deal of information to him. However it was not until she allowed him space to do the work of risk assessment that he was able to make his own decision about what to do. She understood that his reluctance was about control, and at the same time was aware that taking morphine would not be as bad as he dreaded. She could not force him, partly because he would not be forced, and partly because she acknowledged his autonomy. She was also aware that in the future the trust between them would be important. But he was still reluctant. What is the issue here?

Social meaning

For health professionals morphine is a narcotic analgesic that is particularly useful in palliative care; for the public morphine is a class A drug of addiction; for the person diagnosed with a terminal illness morphine is a symbol of the approach of death. Yet his relationship with morphine changes gradually as he progresses through this time, moving from seeing it first as invader, then as parasite until finally he forms a kind of symbiotic relationship with it.

Morphine, as indicated above, has a social reputation as well as a medical and personal one. The public, and both patient and health professional are members of the public and therefore carry these views as part of their own set of understandings, sees morphine as dangerous, addictive, and belonging to the hidden areas of society. Therefore it is to be feared and avoided. Normally health professionals work past, or explode these concepts, but it may be better to work *with* them, acknowledging their existence and keeping in mind that a new set of information doesn't mean that the old is forgotten or ineffective.

The fact that morphine *is* physically addictive is important. The health professional explains that addiction occurs when morphine is given when there is no pain, no need for the drug. Pain, the patient is told, negates the morphine, as morphine negates the pain: there is a balance. However, as Ivan's conversation shows, this does not deal with the patient's hidden anxieties about dependence, and may indeed make it more difficult for him to express his concerns. Underlying the health professional's attitude is often the thought that it doesn't matter, anyway, because the patient will be taking morphine for the rest of his

life. The patient, if he perceives this, and he may well do so, may feel written off in some ways, as though *he* doesn't matter.

For the patient, addiction is an additional threat to autonomy. If a drug is addictive then it has a capacity to take over his will, or at least undermine it. Once it is commenced it will almost certainly continue. How much autonomy and agency will remain? How will it alter their person, their perceptions, the kin attitude towards them?

Personal meaning

Florence's conversation shows that beginning morphine has an irrevocable feel about it, that it really and truly signifies the fatal nature of the disease. It also indicates the commencement of the last phase or phases of living toward death. It is all very well for the nurse or doctor to say that patients sometimes come off morphine, or reduce the dose, but Florence and Ivan know that even if that happened, there would still be a return to it. There is a permanent feel to beginning morphine, a confirming of the diagnosis once again, and a further setting apart from 'others' who don't have cancer and are not terminally ill. It is another fateful moment, heavy in its consequence. Reluctance lies in the knowledge that it is another, irreversible step toward death.

Yet, like all fateful moments, however delayed, it comes, is faced and integrated, and life goes on. The paradox is that taking morphine, the extraordinary, becomes ordinary. The use of newer forms of morphine such as MST and Capanol²⁷ do not seem to cloak the morphine issue for the patient himself, though he may use it to hide this socially disreputable drug from his relatives and friends.

Other tribulations

Apart from this violent itching, which is really getting to me now – its all at the back side and the front of the stomach – and a bit of retching, which I expect I am going to get all the time now, I feel good. I didn't feel like exercising yesterday, and today I find I am a bit stiff (A7 p1).

I get that kind of pain every day when I wake up (A7 p2).

²⁷ More recent slow-release morphine capsules.

Even though I wobble when I am walking around sometimes, and sometimes I feel as though I am going to retch, I don't get my headaches (A7 p8).

I get very niggly at times. I can get very, very quick tempered (A7 p24).

The uncertainty of Annie's appetite is a challenge for both her and Nell, as Nell explains:

Sometimes Annie will say: I want this. So I get up and get the food. She looks at it and she can't eat it. Or she'll have just a little bit, and that's it (A7 p36).

Sequestration of experience

During the middle time of living toward death - having coped with diagnosis and living in a kind of stability - the patient experiences an increasing number of symptoms which provide a challenge for him. In a way these experiences *discomfort* the patient. The archaic meaning of com-fort was *to provide strength*, and coping with nausea, anorexia, pain, insomnia and fatigue results in a loss of strength. Often physically demanding, these symptoms also require persistence and stoicism to overcome. Having to accept a less than optimum state of well-being proves difficult for some individuals and families. Modern society portrays the ideal life as free from disease, crime, madness and death in a way Giddens (1991) terms "*the sequestration of experience*" (p. 149). Society is able to shut these issues away from everyday life, and further, promotes a healthy happiness attained through the individual's own effort. For the patient, not only does the disease challenge the protective cocoon, but the symptoms persistently break through, reminding him that all continues to be not well. The person not only fails to fit his own and society's ideal, which he has a moral duty to work towards, but also has the indignity of an invasion of unpleasant experiences.

Suffering

These tribulations cause *suffering*. While suffering means to experience or undergo, it is the sense of enduring an unpleasant experience that is most relevant in illness. It encompasses but transcends physical sensations, including a complex of bodily ailments with social, mental and spiritual distress. Often beyond the reach of medication to alleviate, suffering can greatly exercise both patient and caregivers. The pre-modern theological stance of seeking meaning in

suffering, re-interpreted in the late 20th century as a claim that suffering is good for you, does not seem useful or even morally justifiable. However recent studies and reflections are re-evaluating the position on suffering and meaning. In the main the participants in this study cope, endure, hope and accept their suffering, and they do it over and over again. Adaptation to suffering is a common response to suffering (Pollock & Sands, 1997) and through this process, personal meaning may emerge. They note:

The process of adaptation and the subsequent meaning or value found in suffering enabled some individuals to grow and benefit from their experience. Although subjects expressed a great deal of suffering in accepting and living with their illness, those who found meaning in their experience were not in a state of anguish or distress.

(Pollock & Sands, 1997, p. 177)

Suffering also allows the individual to self-portray in modes that invoke helpful responses from others. Perhaps it is the patient's bravery and stoicism that encourages the kin to continue caring so selflessly. Charmaz (1999) notes that heroic status often follows facing illness and death earlier than one's peers. She also notes that prolonged suffering wears out the compassion of work colleagues. In her study, and that of Pollock and Sands (1997), the conditions the subjects endured were chronic, whereas the participants in this study and their kin knew that there was a time limit on their lives and therefore on their suffering, so the issue of compassion-fatigue may have been altered.

Both these studies address the difficult question of the purpose of suffering. If suffering can have a beneficial outcome can it be inherently good? If it is inherently good, then do sufferers and health personnel allow it to happen or discount the pain of it in describing it as transformative. If suffering can be beneficial, is it Divinely intended? If it is God's intention, what kind of God is that? If it is not Divinely intended, then why does suffering exist at all?

Engagement with the question and place of suffering, and with the experience of suffering is a complex and personal struggle, and if meaning is to be found it will be the outcome of that work. Julia Keegan, who died aged 26 in 1997, reveals the complexity of her suffering in the address she wrote for her own funeral:

I must share with you how lucky I feel to have had the privilege to live the life I have, and the chance to learn and see life through the light that a terminal illness brings. Think not for one moment that I have wanted any of this, and I wish with all my heart that nobody should have to go through this trial in life - ever. This ghastly disease, cancer, as with any other terminal illness is evil and cruel. The treatments available presently are far from foolproof. Quite the opposite. But through the dirty waters of this life-destroying illness I found a beauty, a level of being that I had never imagined possible.

(Cardy, 1997, p. 2)

The personal aspect of suffering produces anguish for kin, who would wish to carry a burden for the patient, but cannot do so. To support another in his suffering can lead to the pain of helplessness for kin, from which they are only released when they accept that they cannot remove the burden from him.

Personal agency

The values of personal agency, autonomy and responsibility are powerful and appear as constitutive elements in such abstract systems²⁸ as the legal system, health and government (Giddens, 1991). In the past the value of personal agency was not present in these systems, as their focus was more on the common good, to which the individual would subjugate his personal wishes. Though today post-structuralists argue the self to be frail and fragmented, Giddens (1991), claims that such fragmentation, where it exists, does not necessarily undermine the concept of self-direction, but makes it more brittle. Accepting autonomy as a social ideal adds a moral imperative to it, which is felt by the patient who attempts to make himself better. More, the key participants in this study show that personal responsibility for health and well-being is a heavy responsibility. Efforts to manage symptoms and get on with life, and put on a good face for the world are evident in the accounts.

In terms of his personal narrative the participant experiences the accumulation of symptoms as a constant and unwelcome reminder of his mortality. He tries to continue to fit within the self he has built for himself. He does not allow the disease to become the defining fact of his life, thus continuing a partial

²⁸ Symbolic tokens and expert systems taken generically (Giddens, 1991).

sequestration of this experience. However, as will be shown below, he continually re-constructs his self-hood to incorporate that which could not be denied.

Each challenge faced and surmounted provides another building block for the state of *readiness for change*, a key issue of chapter seven. The tribulations of this time also contribute to a reviewing of relationships.

Reviewing relationships

The patient meets new challenges by seeking information and developing relationships with experts. He needs to rely on kin in new ways and there is a re-negotiation of existing relationships. With mortality closer, issues of culture, tradition, and family moved into the foreground. Finally, for some, the contemplation of the unknown appeared to be happening.

Relationships with experts

The patient has learned to communicate with many experts by the time he reaches this relatively stable phase, but a sense of autonomy may emerge when he does not accept the roles expected of him. For example, Abby does not like the attitude of the well-meaning Cancer Society visitor.

Listen, but there are people who come into my home – that I have had problems with, who have gone out, and I haven't known why they came. Oh, I know why they came! But the real meaning of their visit, and what good it is for me. Because after all I am the one with – cancer, I'm the one with the problem. And not just another patient for them to visit. (. . .) the district nurse has been just fabulous, but I have found this with the hospice nurse, whom I won't have back, and just recently with the Cancer Society nurse. (. . .) I was a bit taken aback (B1 p3).

This increasing clarity about their own needs and the asserting of autonomy with experts is shown to some degree in all the patient narratives.

Experts represent systems in which we have developed trust, and patients had more difficulty with the abstract system of medical science than they had with the specific individuals with whom they came in contact. Giddens (1991) describes abstract systems as systems of knowledge which permeate society and which perform useful functions for us. We trust them to be there and to do for us

the specific functions inherent in their structure. For example the national and world-wide money systems underpin national and personal economies. Individuals trust abstract systems to a greater or lesser degree, depending on personal knowledge and the complexity of the expert system. Giddens (1991) explains that “the wholesale penetration of abstract systems into daily life creates risks which the individual is not well placed to confront” (p. 136).

As medical science has become more complex, has successfully treated much disease and has pushed back the borders of death, people have accumulated a lifetime of experience of cure or alleviation of all ills. While intellectually they may know this is not a fail-safe system, the reality that their current condition is ultimately untreatable is unpleasant. Ivan, for example, feels abandoned by the health professions.

I don't know what is going to happen. I might have a long time to go, I might have a short time to go. One thing is sure, I feel terribly let down by the system and I include everybody in that now. From the first day they assured not only me, but also my family, that though they cannot save my life they will provide pain-free, quality life. I am not a person who runs away from problems, and I accept a certain amount of discomfort in my condition, but I wouldn't call it quality of life when a morning toilet takes 24 hours to recover from. Agony and agony. Why cannot the system be better organised (D6 p3).

It seems to me that the medical profession cannot admit their limitations. They say: sorry, we can't help you any more. But they don't go a step further and call in more expert advice, and if doesn't work, another. It doesn't happen (D6 p9).

This system is failing Ivan, he doesn't have personal expertise to help judge which expert to trust; there are too many, and too much advice, and he's too distressed with the symptoms to regain control. His trust in the system is lost, but he still needs it to survive. The possibility of disaster is seen by the nurse caring for Ivan as she offers advice on managing his diet, medications and bowels - advice he did not completely accept. She chose not to over-ride his autonomy, indeed, his son suggests she could not do so. Eventually the system redeemed itself in Ivan's eyes and he re-established a functional relationship.

This was helped by his triumph over the system's inadequacies. To remain independent Ivan needed a portable 12volt nebuliser²⁹ to administer morphine via the inhaled route. He worked past the 'they don't exist/they're not available/they're too expensive/you're not eligible' blocks with ingenuity and persistence eventually arranging for the machine to be delivered to him. Retrieving his agency and regaining control re-established his self-identity and gave him back his place 'in' the world.

Relationships with kin

Relationships with kin undergo continuous revision as independence decreases. The patients had to learn how to receive help from their family, and this was often not easy. Jan's story, outlined in chapter 5, shows an ambivalence about being helped. Partly to do with control, this issue also seems to impinge on the area of inadequacy. Giddens (1991) differentiates between shame and guilt, noting that shame should be understood in relation to the integrity of the self, while guilt derives from feelings of wrongdoing.

It depends, he says, on feelings of personal inadequacy and this fits in well with both Annie and Florence's not wanting to be a burden. If a burden is seen as someone having to do for one what one would normally do for oneself then it is clearly more of a lack than a transgression. Self-identity loses part of its coherence and social acceptability when one cannot self-care. Realising that the kin will have to make good this loss in order for the patient to maintain self-identity returns us to the paradox of loss and gain. To move from the powerlessness of this situation the patient takes back her agency and uses it to permit or allow the kin to do for her. Florence and her daughter are both aware of the burden issue though they don't discuss it in depth. Florence wonders:

. . . I wasn't going to get stronger. My energy was going to be more depleted. And that concerns you. you think: well, I wonder how long Pip can manage it, if it is going to be harder. It is a bit hard to accept, though, that you will just get weaker (E6 p5).

And Pip comments:

Quite early this morning I was helping her and she said to me: "am I a trouble to you? Am I causing you trouble?" And I said: "no,

²⁹ A machine that converted liquid medication to an ultra-fine, inhalable spray.

sweetheart, no." we had just come back from the toilet or whatever it was we had done. And I said: "I don't mind at all. It's all right." And I went to give her a hug, and she went: "oh, Pip, don't." as though she didn't want me to say it's all right, as though she wanted me to stop saying what she thought I was going to say (E7 p4).

However Florence clearly appreciates Pip's care:

And you know that some days I seem to have to struggle harder. Like to sit up on my own, and that sort of thing. Some days I just can't get up. And then Pip is always there, of course. I haven't got a big problem (E6 p6).

Direct communication is not needed to move particular items of caring from Florence's agency to Pip's. Pip notes that caring remains bi-directional as she comments that Florence continues to care for her in being easy to care for, grateful but not effusive, and always appreciative.

These issues of allowing the self to be cared for by others, and the place of shame in the equation are issues which would be suitable for further study. Shame, burden and dignity seem to be linked, as dignity seems to be related to not being shamed. Retaining dignity to the end is a common wish of dying people, (Hudson & Richmond, 1994) and expressed by those in this study. Particularly where women are concerned, being cared for personally, and handing over other caring duties can be problematic. Jan's story illustrates some of these challenges, and chapter 7 will explore them further with the area of *handing over*.

The threat of mortality shatters notions of autonomy and causes a revision of relationships with others, according to Crowell (1997). As the individual cannot survive alone, the other becomes vital to his existence. The other feels the call of the one in need, and a relationship is created which goes beyond the normal. This view is supported by the main caregivers and the participants in this study, as they experienced a new closeness. It also invokes a re-examination of Ivan's account of his friends treating him as less than fully human. Was his anxiety related to a search for someone who could confirm his existence through a mutually caring relationship?

Relationships with family, culture and past and future

As people began their own progress toward death they frequently reflected on their family history, particularly how those known to them have lived and died. Except for Abby, all had some experience of close kin death. This reflection seemed to serve two purposes. Firstly, it provided some knowledge of the process of dying, death and how the dead continue in the lives of the living. Secondly, it allowed the person to re-connect with those who were dead, to bring them close. In many cultures the closer the individual is to death, the more likely he is to feel close to his dead ancestors, and even in some cases to see them. Samoan people recognise that death is only hours away when departed maternal relatives make their presence known to the dying person, and sometimes to others as well.³⁰

The influence of ancestors is a question raised by Hallam, Hockey and Howarth (1999) as they note it falls outside of the dominant belief systems of society today. At worst it is seen as pathological, or superstitious, or, slightly more positively, as a quaint cultural belief. The authors note an increasing exploration of these areas, and provide their own research and interpretation into a field of growing interest.

Yet the experience of those in this study shows that not only do the recently departed family come closer in memory and discussion, but also it is common to review family history. It seems that the purpose of this is partly to answer the question of historically placed identity, but also it seems to provide a sense of continuity beyond death. This is similar to the life-review process:

In general, the life-review process connects one's own life with the future as one tells one's story to younger generations; at the same time, links with past generations are renewed as one remembers what one's parents, grandparents, and even great-grandparents did and thought. One's relationship to humanity, to nature, to the whole of life also becomes a topic for reflection.

(Berger, 1988, p. 570)

It seems that connecting with family offered some stability in the inherently destabilising process of dying. People knew where they fit with their present

³⁰ Oral tradition of both nurses and Pacifika peoples.

families and seemed to need to uncover the same clear links with their departed family. Abby alone, had no adequate memories or oral history. Her elderly parents were both alive and seemed too remote to provide this link. It seemed her location was with the living, and she could not ensure a personal continuity by projecting forward in the company of her ancestors. She did, however, work at maintaining her own future link with the family after her death, in the allocation of personal items and advice.

For the other patients there was a sense of gathering up the past behind them, both their own and their family history, and of drawing up this past with a continuous thread so it was close to them. This closeness allows them to be part of the departed group when the time is right. Being able to tentatively place themselves among the ancestors also facilitates the creation of links from living family to their future, departed self. A sense of the self enduring through and beyond physical death seemed to be emerging.

Relationships with the unknown

Contemplation of the unknown does not appear to be the major concern that is imagined by those outside of the living toward death experience. It is common for the helping professions to be taught that terminal illness and approaching death can be a time of spiritual crisis. Concepts such as existential angst or crisis are perceived to be relevant as people prepare for death. These issues do not appear critical for the patients in this study, nor for their kin. While it is possible that this particular group are different, the question must also be asked whether helping professionals project their own personal concerns onto people in their dying. It may also be that anxieties about dying itself shut out issues of after death; it may be that as in other life crises, once the course has begun the end is 'there', already in some ways defined, and concerns seem somewhat irrelevant.

So the majority of the participants in this study appeared to have either resolved these crises or were resolving them day by day. Florence and Annie were confident of a form of heavenly life; Jan's faith provided what she needed. Abby did not say whether she had considered the issue though it seemed likely that she had not been able to do so. Ivan, having been close to death through his own and his wife's experiences, had reflected deeply, and offered the following poem for inclusion in this work.

INVITATION TO THE LAST WALTZ

We are old acquaintances, you and I,
We have danced many times to life's airs:
You daring and bold, I always eluding,
As constant your chase, and futile my race.

No promissory notes, no bargains struck,
Half measures are not for my pal:
Yet peace at the last could be mine
If I yield to your dark, cold embrace.

O, oft have I cheated you, kept you at bay,
As I lived for those whom I've loved:
But jealous you snatched them ever away,
Your greed without passion or pity.

The need for my loving is done,
Those who care for me are few;
I stand in the ballroom alone
Life's melody shocking and shrill.

The rhythm of dance arouses me still,
But no partner to sweep into step,
None to adore, be adored,
And wasted the strength of my arms.

And now I see you return,
Our dance is beginning again.
Your kiss I'll no longer evade
Nor its promise of balm for my pain.

So, my old adversary, into my arms,
Without orchestra, quartet or band,
Whistle the tune, give me your hand,
And waltz me through shadows to peace.

Ivan reflects on the unknown, death, and acknowledges a lifetime's acquaintance with death. Interestingly, he can write the whole poem without naming death, which seems to emphasise the metaphor of a dance. He appears to

take comfort from this familiarity, and knows that this time he will yield without protest, indeed with grace. Whether other participants have considered the issues in the same detail is not clear, but there is no overt evidence of unresolved issues.

The potential for mis-communication with visitors coming with their own understandings of the 'shoulds' of the course towards death is illustrated by Abby's response to the hospice and Cancer Society visitors. The theological model of preparing to meet God and the semi-psychiatric model of Kübler-Ross (1969) influences helpers into thinking there is a 'way' to die, and tasks to achieve. While the models are often helpful they are not the only or even necessary approaches, and their use can prevent good communication and discovering what the patient actually needs.

Bridging time and space

These relationships with experts, kin, the self and the nature of the person's situated culture can also be understood in terms of how they influence management of the future. Here, future encompasses a time in which the person's existence endures in some way or form.

The work of sustaining and editing a personal narrative would be pointless if people did not have a sense of future, both personal and group. Maintaining a credible identity for the on-going present is described above and those actions contribute to the identity of the future as well. In order to prepare the self for the future, the individual must have a concept of what that future will be like, and how he will be in that time to come. As a society and as individuals, Giddens (1991) argues, we control time in a process he terms "colonisation of the future" (p. 114). This process, he argues, allows us to formulate and action life plans which are the design aspect of the trajectory of self.

A future which is available for colonisation, a key factor of High Modernity, is a relatively new phenomenon. Life plans of the past depended more on tradition and culture; those of today are based on risk management and trend projection. Identification of the future 'terrains' allows colonisation to occur. Once the terrain is mapped out (theoretically) incursions can be made, future actions determined and today's precursors taken (Giddens, 1991, p. 111). He notes further:

Individuals seek to colonise the future for themselves as an intrinsic part of their life-planning. As in the case of collective futures, the degree to which the future realm can be successfully invaded is partial, and subject to the vagaries of risk assessment.

(Giddens, 1991, p. 125)

For the patient in the study his future has become suddenly much more bounded by the predicted end of life. Now 'seeable', that is closer than foreseeable, he wants more information so he can plan for tomorrow and act accordingly today. The information he seeks is partly risk management, and partly forecasting from previous knowledge. He asks for life expectancy information and is given as much truth as his doctors are able to provide. As yet there is no way of accurately fixing a date of death, and of course this degree of prediction would have changed everything that lay between diagnosis and demise. The openness of the final date keeps hope alive, allowing for options and choice, and most importantly, keeps some control in his hands. To increase control the management of risk is significant. Information about symptoms, what to expect next, and how to cope reduces the unknown factors. For families, too, prediction provides reassurance and a feeling of trust. Ivan's son, though angry at a general practitioner who was slow to investigate Ivan's symptoms, acknowledges that the hospital consultant was accurate:

They sort of ran me through it in a little more depth as to what to expect. It was interesting. One thing the doctor said was (that) he will be fine on his own, right up to a couple of days before the end. And then he will come into hospital and that will be it. And I thought: no! it doesn't work like that. But in actual fact, you know, and the doctor said it will be a couple of months (from diagnosis to death) and they were pretty on to it (D8 p2).

Giddens (1991) does not discuss the issue of cultural difference in the concept of colonisation of the future. In the matter of life-threatening illness some cultures, particularly where little influenced by Western medicine and values, do not share a negative prognosis with the patient. A study undertaken by English hospice nurses working in Russia (Becker, 1999) shows that using this concealing attitude as a protective cocoon risks the patient facing death alone and lonely.

Colonising the future as well as providing a measure of control over what is to come, also potentially affects the future. Simply, those who calculate and believe in a specific future, take actions which contribute to that future. If they see themselves as being alive for some future they eat well and try to keep physically active. Theoretically there is also the chance of changing the projected future by engaging in activities which prolong life. Participants were aware of stories of others who had achieved remission of disease through self-chosen treatments, but all appeared to accept that they were beyond this possibility.

Living in suspended time

Alteration in the pace, quality and direction of time is present for participants and kin. Time proceeds in its usual way and it also goes on differently. A sense of waiting is common. Annie reflects on the passage of time and the pace of her life:

To me, its just that I know it is terminal, and when I think the right time is to go, and you've got pain and all that, I hope that I go. But right now I would say that I had three quarters of a life. Do you know what I mean? One quarter has gone, that you can't just go chasing off wherever you want to go – that kind of life is gone. (. . .) so maybe we are on to the middle part (A4 p17).

Nell doesn't quite accept it; she says: "when the time comes, if it comes." I have to keep saying to her – "it is going to come." She thinks maybe a miracle will happen, or that it will come out all right. But you see this is what they call the in-between time, when it is good to think about your life, and to do exactly what you want with your life, while you can do it. Because if you don't take this time to do it now, and you keep saying: oh, I'll leave it until tomorrow, it wouldn't get done (A4 p18).

Waiting

Annie describes what the waiting time is like:

You're looking through a – sort of frosted window. I should be able to look that far, but I don't. My eyes start to flicker over. So it's like being able to see in a row, like that (straight ahead) but not around you. So you feel a bit listless.

(when you talk about it being like that – I have an impression you don't just mean physically, I have an impression that your life is misty?)

Yeah, yeah, that's exactly correct! That's how I feel, that the life on this side now, and the life on that side, if I really wanted to see it, that I'd have to turn around to see it (A2 p19).

Some weeks later, waiting persists:

I was sitting here, and I was looking at the garden and all the flowers. And I kept thinking to myself: they're growing so lovely. All these flowers, and the trees and the things growing so beautiful, each day I can see them, they've grown a bit better, because we've given them some food. And yet I am sitting here, doing the same old thing. I don't know if I want to keep doing this all the time – just sitting here, even though the flowers are beautiful (A7 p2).

And I think to myself, well, if am going to go, I am quite happy to go. I'll miss Nell, but then, if I've gone, I've gone. And if you really believe things are what they're supposed to be, when you leave earth you go somewhere else. So you haven't got a memory of earth. Your soul's gone out of your body, and that's it. I keep thinking to myself: how long is it that you've got to see the same pattern, before you can go to where you're actually going (A7 p3).

I feel as if someone said to me: do you want to go into hospital right now? I'd say: no, there's nothing to go for (A7 p23).

Annie's final reflection on this stage is again metaphorical:

I think it makes you feel, when you are sitting down with cancer, you feel all tired. As if you have been running a long, long way. You know, if I were me, I should be sitting up straight, but instead I am just slouched, and it is just comfortable. You know what I mean, just being slouched. And really, you should sit up straight (A7 p38).

Time as a phenomenon

Heidegger (1962) points out that to focus on time renders it more precious. He also notes (section 81) that the individual has a need to match his time with that of the 'others'. Time, he says, is experienced as a sequences of ever-flowing 'nows' giving it a continuity, thus becoming infinite. This view compares with the Aristotelian view of time as the present, the place of change between earlier and later. Matching time to 'others' and acknowledging its infinity imbues it with characteristics of shared-with-the-world, reliability and consistency. The terminal diagnosis immediately moves time from being a shared-with-the-world-time to

time-as-experienced-primarily-personally. Such experience is not entirely new, as it will have part of the individual's history in events such as absence of loved ones. However during such absences the individual experiences both shared-with-the-world time and personal time, and, importantly, knows there is a future when the heaviness of time experienced as primarily personal will lighten. The knowledge of impending death, though, changes this, as time has moved from open-ended to finite. Thus the events of this period are highly significant. They are all of the person's life, all that they have left, everything.

Time's influence on other phenomena

The importance of time to and in a phenomenon is emphasised also by Lingus (1998) who says that an apprehension of the quality of time is essential for a full comprehension of a phenomenon. He suggests that misleading appearances are as empirical as an actual appearance, as they influence perception, colour interpretation and remain in the individual's experience. Time, he says, can present itself in different ways, and all need to be considered. The participants in this study who experience personal time as elapsing at a different rate from their kin, yet acknowledge that days are the same as they had ever been, confirm this. Suspension of time is both a retreat for the participants, and the reality for them. Lingus also identifies that knowledge of impending death – actual, not merely prospective – alters the perception of time:

In the measure that one knows one is dying, one knows that the power to take hold of things, to advance in the world are being taken from one. In the end one can do nothing. One can effect no action, one cannot advance into a future made of promises and chances and possibilities. One can do nothing but wait. Wait for death itself to come. One is in suspense, held in life, held in the present, without being able to continue to another present, another possibility. One waits, as in Edgar Allen Poe's "The Pit and the Pendulum", as death in the blade of the pendulum imperceptibly descends. This is not the Heideggerian anxiety, which resolutely of its own forces confronts death and hurls oneself into the abyss. It is the anxiety of having fallen out of the advance of the world, the time of history, in to a time that is dead but not extinguished, a time that endures, a time in which one goes on without going anywhere.

(Lingus, 1998, p. 61)

This description of altered perception of time affirms the suspension experienced by the participants, almost a capture by time, where they cannot step out of the enchantment. To look toward a different future is seen as a kind of betrayal of this present haven. It may help to understand why some do not engage with the existential, make preparations or arrangements, and see no need to hand over any responsibilities. The urgency that characterises early times of diagnosis and treatment, and later times of drawing closer to death is generally absent during this suspended time, and patient narratives appear relatively free of anxiety related to the imminence of death. Kin and health care team members may be disconcerted by this apparent freedom from anxiety about the future, particularly if they believe the patient should be progressing toward death.

Time as self-interpreted

Yet, at the same time, life goes on in the old way, flowers grow and bloom, trees spring into leaf. Beside this, the patient's life seems stalled. Intellectually aware that this is all the time they have, they are lacking energy to 'do something' with the precious time. Their focus moves from doing to reflecting, from action to planning, from achievement to relationships.

Giddens (1991) notes that an aspect of self actualisation is the skill of creating time which is personal, that is, personally significant, and not controlled by measured time. According to Peck (1997) acceptance of one's death is the apex of self actualisation, and recognised by a glowing serenity. Annie's experience shows that for her it is not so straightforward. Her explanations illustrate neatly Giddens comment that: "self-identity is such continuity (in time and space) as interpreted reflexively by the agent" (p. 53).

Another concept of time is the theological *chronos* and *kairos* (Kittel & Friedrich, 1985). Chronos is time which is measured precisely and consistently, and usually refers to elapsed time, the passage of time. Kairos is God's time, event time, time which is personal and significant. Both times are present together, and rather than viewing the experiences as dichotomous, it seems helpful to view them as parallel events of either chronos or kairos. The discussion below provides a number of instances to illustrate the continuous dialogue of chronos and kairos in patients' lives.

In chronos, time goes on as it always has, at the same rate and with the same reliability. In kairos the falsity of this 'normality' is recognised, giving a feeling of unreality contrasting oddly with the comfort of the chronos. The patient lives day to day, doing the same sorts of things in the same sorts of routines, yet experiencing a staged quality about this, as he knows that behind the curtains of this lived drama is the real, underlying and inevitable process of the disease. Time passes, but death remains in the wings. Phrases like 'feeling a fraud' and 'still waiting' express the contrast between the passage of time but feeling it halted.

In chronos time is measured in hours and days, consistent and familiar, but the patient's time is time left, kairos time, and measured as proportions of that. It is measured in what can be achieved in time left. The patient often asks what time he has left when diagnosed with a life-threatening illness, and are answered in chronos. It may be better to answer in kairos terms as well as chronos. In chronos time is infinite and in kairos it is finite. In chronos it is managed and in kairos it is savoured, suffered, traversed, endured, enjoyed, lived. Chronos and kairos are parallel, not alternatives. The patient experiences them both, though sometimes one more than the other. While all people experience chronos and kairos, for the terminally ill patients the recognition of finitude makes their relationship with time entirely different.

Time as multi-layered

One mode of understanding and being in time seems insufficient for the participant, as he makes forays into the past and the future, establishing a personal continuity. He sees himself as existing in past, present and future, understanding that this will be in many different ways. His experience of present time often differs from others around him, as it elapses at a faster, or slower pace, or even appears suspended. Dislocation with common time has the potential to produce a sense of alienation from others, and can lead to a focus on different goals. His existence continues, he is living, but paradoxically *living toward death*, while others live with multiple possibilities.

Conclusion

The 'in-between time' as Annie calls it is a time of much adjustment. Beginning morphine stamps the patient as 'terminally ill' in their own eyes; there are

physical and emotional adjustments to be made related to the disease process. Narrative work relates to exploring relationships with themselves, kin, society and the unknown. Yet permeating all this is the ever-present knowledge that this hiatus will not last.

Chapter seven – handing over

Living toward death continues, marked by a realisation, sometimes gradual and sometimes sudden, that suspended time is over. Recognition of the change may lead to a review of moral and existential questions, incorporating on-going reflections. Relationships with others increase in importance during the process of *handing over*, which is a significant activity of this period. Work on self-identity includes projecting forward and coping with ambiguity, as maintaining an acceptable self-narrative continues.

Chapter seven recounts and discusses firstly how the movement from suspended time is experienced by the participants. The middle section of the chapter presents the theme of handing over in some detail, showing that parts of these actions can be seen at many times between diagnosis and death, but are more pronounced at this time. Finally the paradoxes of dependence/independence, living/dying and hope/realism are discussed in relation to the participants' experience and explicated using Giddens (1991) dilemmas of the self.

Awareness of the end of suspended time

The feeling of time standing still recedes abruptly or gradually for the patients and necessitates a shift in focus. There is a sense of leaving the path of 'living to death' and stepping on the parallel path 'dying to death'. Suspended time, that seemed as if it could go on indefinitely, is clearly over.

"The end has come suddenly," said a friend (personal notes). It was nearly two years since diagnosis, 18 months since she had learned that her condition was not amenable to treatment and almost a year since a previous life-threatening episode – yet it was still sudden. The suddenness was felt by all those sharing the course with her, as the finite-but-indefinite became definably finite.

Annie reflects on her progress:

I am more at peace now, than when I saw you the other day. We have done a bit more, and more days have gone on, and more of our things have settled. We have worked things out, and we are good, now, Nell, aren't we? In other words, I am not just waiting for it to come. It's going to happen – it will happen. I am not going to bed thinking: oh, I might not even wake up tomorrow morning. I am just going to bed, watching TV and going to sleep. And that's it (A7 p35).

It seems a slow realisation for Annie as her world shrinks in. She feels less like going out, is interested in little outside herself and Nell, and has even lost her appetite. Abby also notes that she is further along the progress to death:

I do find that people are very keen on saying: well, it doesn't have to be (fatal) and so on. And that kind of gets to me in a way. It really gets in your way, because I am trying to cope with it as realistically as possible, and then you have someone saying it doesn't have to be like that. I have two friends who are now becoming more real. But I was speaking to M the other day, and she said something. And I had to say to her: "I am a very sick girl!" (B3 p4).

Abby seems to realise that the time for dreaming of cure is past, and she won't enter into those conversations with her friends any more. As time went on she withdrew from those friends who persisted in the belief that if you have the 'right' attitude you will get better.

Florence observes physical deterioration:

I have been a bit up and down. I had felt quite sure that I was going to make a little bit of progress. Then I realised that I didn't think that was going to be the case (E6 p1).

(What other things have been helpful in moving you to this stage?)

Well, just the acceptance that I wasn't going to get stronger. That my energy was going to get more depleted (E6 p5).

Florence puts aside the hope that she will improve, and with it comes the knowledge that she is getting weaker. Yet she can still put the significance of this depletion aside, as her daughter recounts:

The other day she (Florence) was saying: "I am feeling so frail, and I don't know why I am not feeling any better. I think it is the morphine."

She hasn't got any pain, and she thinks if you haven't got pain you must be all right. So I said to her: "dear, you know that the morphine stops the pain hurting you, but you are still very sick. Everything is still going wrong inside you. You are still really sick, but you can't tell that you are."

And she stared at me for a few moments. And she said: "everyone is saying that I am really on to it, and I am. So it's really dumb if I didn't realise that, isn't it?"

I think that she is realising that she is quite sick. That she is – quite – far – on (E7p3-4).

Florence's intentions in a statement like this cannot be known but the ambiguities of the situation are apparent – she is free of pain, so feels 'better', yet recognises she is weaker. She explores the situation with her daughter who clarifies it gently and honestly.

For Ivan, too, the end came suddenly, yet at the same time there was a sense of readiness. At the last interview he said that he had shared all the information and stories of his life that he wished to, but that he did not want to lose altogether the human contact that had built up. He would keep in touch if there were new insights he felt the study would benefit from. However, he went into hospital two days after this interview and died less than a week later. The feeling of having completed the reflection on his life that the interview process provided may have assisted him to recognise his life's closure.

Rather than a new fateful moment, it seems that this is a re-visiting of the existential questions that first arise during the time of diagnosis. The existential questions of time, space, continuity and identity, (Giddens, 1991) thrown out of their taken-for-granted status by diagnosis, appear to have taken a back seat during the period of *living in suspended time*.

The issue of denial

When people seem reluctant to discuss existential issues in relation to their own impending death the question arises: are they in denial? Morse (2000a) reminds us that the judgement of 'being in denial' is made by another and thus contains an element of the order being imposed from the outside of the person's experience. Nevertheless, the issue is frequently considered by caregivers when

they evaluate a patient's mental state. If they are not expressing emotions about the possibility of death, could they be in denial. While this is possible, it is a question that needs careful consideration to avoid the closure and potential labeling of the 'in denial' judgement.

There may be many reasons for the apparent lack of discussion about possible death. The person may choose not to open this conversation with those who invite it. He may be reflecting on his own, doing his own reading and find this entirely satisfactory. He may ask isolated questions of various people, and put the fragments together himself. He may have short discussions with others which seem to these others as unfinished, but to him are part of an evolving understanding. These last choices, taking place over extended periods of time, may not be apparent to family or caregivers, who may then wonder how the person is facing his coming death.

Giddens' (1991) categories of duration and extension,³¹ argued as sources of potential anxiety and managed by living life 'as if' they were not areas of chaos, are given limits with the diagnosis of a terminal illness. Now that they have boundaries, have they moved from disorganisation to a structure? Can the dying person see a pattern in their finiteness not perceptible to those contemplating a more ephemeral finitude? Certainly the people in this study do not evince the 'dread' that some of their helpers expect. It is possible that they are too tired to do this kind of thinking, or maybe they see it as pointless now death is coming anyway. It may also be that they are happy with the amount and depth of work that they have done in relation to seeking meaning in their impending death, and see no need to re-evaluate their understandings. One person said: "*I've done all that (meaning of life/death) stuff. I don't need to do it again*" (personal notes).

So how is this issue different for participants at this stage from how it is at the time of diagnosis? It seems that there is more comfort, more acceptance, and perhaps a kind of submission to the fate aspect, to the inevitability. One thing that seems to help the patient reach this state is the work of *handing over* himself as he begins to take leave of his life.

³¹ Duration and extension relate to the individual's existence as being somewhat reliable in the present, and possessing a future dimension (Giddens, 1991).

Handing over

Participants hand over much during their living toward death, including tangible items of varying significance and abstract items such as duties and responsibilities. At times handing over is deliberate and planned, and at other times it is less consciously organised. While some duties are willingly handed over others may be held quite firmly. Lee discusses Jan's continuing contribution to the household:

She feels like she is still contributing to the household. She does the ironing. That's one job she loves to do. I mean, I hate ironing, but she loves doing it. And I only used to iron (the men's) shirts for work, and that would be about it. But she irons everything. The kids' clothes. If you leave anything lying around, she sticks it in the ironing pile. And if there's not enough clothes in there, she gets the kids to go upstairs and take stuff out of their drawers and bring it down. And she said to me: "when I die, you make sure you keep doing all this ironing." (and I say) "yes, yes." But, no, I am not going to iron that or that. Every time I iron I will be thinking of her (F3 p5).

Lee allows Jan to be responsible for this household task. Much of it is unnecessary on the surface but it contains symbolism of contribution, an 'extra' that busy households normally can't do, and a link to old-fashioned values. While Lee would prefer Jan to rest she recognises the importance for her of feeling useful. The two women use the situation to confirm that Jan will continue to be remembered in the future.

Sometimes an apparently simple exchange contained much significance for the people. The following small conversation between a wife who knew she was dying and her husband was reassuring to both:

You do know how to make a white sauce, don't you?

Yes.

Good. (personal notes)

The question asks more than whether the husband can undertake a culinary skill. It says: "you won't let standards slip when I've gone, will you? You will look after yourself, won't you? You'll remember what is important? You will be able to get along without me?" The response says: "I know white sauce is important, and I know how to

find out how to make it. I'll make sauce and look after myself as you've shown me. I'll be OK." He knows he doesn't have to demonstrate that he can make a white sauce just now, that the question is deeper, asking for reassurance. He will be able to take care of himself. This is a task his wife can relinquish safely to him.

The final *Handing over* which is death is always theoretically possible, and it seems that it may be somewhat continuously present as the following excerpt, where Jan lives a vicarious experience of death, shows.

When someone dies, they just disappear. One patient collapsed and she was just taken out. There was no comment from the nurses. It was as though she didn't exist. One of the patients saw the death notice in the paper. It wouldn't have hurt them to talk about it.

(Did any of you ask after the collapsed patient?)

Yes, I did. They told me. They should allow for death to be more part of the unit's reality.

(why do you suppose they don't do this?)

I suppose it is trauma. It reminds you of your own mortality. Another patient spoke of watching me during the times I was so sick. She said she had felt really sorry for me, especially when they came to take me away to treatment.

(How would it be if you really knew how sick people were?)

It would remind you that you could be next. There were a couple of times during that year I would gladly have died (F2 p2).

The interplay between knowing and not-knowing seemed to allow the patients to control the amount of information that confronts them. While Jan knew what had probably happened to the collapsed patient she chose to both conceal and admit the knowledge. The significance of a fellow patient dying was recognised by the nurses as they chose not to make an announcement but neither to hide the truth from enquiries. Jan really understood the meaning of it – if she dies, I could, too. She used the situation to imagine herself in the same crisis, recognising that that not only had she come close to death on a couple of occasions, but also that she was so sick she would have welcomed death. Another episode brings the possibility of personal death close again.

There was a friend of mine who had another friend, R, who had been dying of cancer for about two years. She had it in the liver. And I was always asking: how is R? She was getting worse. Then (friend) rang to say that R had died. I really took it quite badly. I wrote (in the journal):

(Friend) rang to say R has died. I am next. Can't stop crying. Very frightened. Felt so bad last night just went to bed and cried. Couldn't stop. R dying just showed me it's going to happen.' (F6 p2).

Jan was a similar age and life stage to R, and was acquainted with her, so it feels much closer and more real than the collapsed patient. She is watching these scenes, learning from them, and wondering when the role will be hers.

For Florence the knowledge that she will have to take leave of her house is a cause of anxiety.

I had quite a lot of restless nights because of trying to sort out so many things. You are wondering about your house and wondering about your family and you are wondering about yourself and going through it. A few quite bad days.

(What were some of the things you thought about during that time?)

How do you go about deciding whether you sell the house or whether you let it drift. It is so hard to make decisions like that. Especially when you don't know whether you should do it, or whether you should just leave it to your family and they can get on and do it. I have come to a decision that I will sell the house.

(It's quite a significant thing, isn't it?)

Well, you know, 33 years in a house. All its memories. (. . .) I said to the grandchildren: "whatever anyone has given us for presents, if you want them, you have them" (E6 p1).

Florence's daughter Pip recognises that it is important to visit the old home.

She was keen to go back home to pick up some papers. We thought we could pop in there and get them but it seemed very important for her to go. (. . .) I was surprised how calm she was – I thought she would be more upset. (. . .) I said to her: "why don't you sit here, and I'll bring you the drawer, and you can go through it here." And we pulled the blind up, because there is a beautiful view, and she said: "perhaps we should take a picture of the house while the bougainvillea is out – it would be a good selling point." Of course, she had never said anything

about selling the house before. She sort of laughed as though it was a joke.(. . .) We hadn't discussed the house, because we thought it would be a really hard thing for her (E2 p6-7).

When Pip and Florence discussed the visit later, Pip told Florence that she thought her mother might have found it harder. Florence replied that it was hard, and that she was wondering if she would ever come back to live in the house. They both note that the visit seems to have settled the restless, anxious nights. Nothing formal is said, but both know Florence will not return home, and that she is happy for her children to make the decisions about property.

Abby, too, thinks about personal property.

I also want to sort out (some things). I know my husband will possibly keep a certain amount of roses and so on, but not as many as I have got. I want to plan – friends and sisters and so on – who can have certain roses. (. . .) I want to work out who to have certain pieces of jewellery. It is very difficult. I have only one daughter, but beautiful little grand-daughters. So what I (will) do is leave something to my son who hasn't any children as yet, and that way he can do what he thinks fair. (. . .) But I certainly don't want people taking everything out of the house (B3 p7).

The last comments shows that she recognises that what is personal is also meaningful to her husband, so she moves from the notion of handing over property to handing over the responsibility to make these decisions, saying:

I have heard of husbands who have been broken-hearted because things have been taken out of the house. So I'd actually like to have the adult members of the family here and just have a chat to them about that sort of thing (B3 p7).

It seems that there are a number of distinctive issues present here – an enabling environment that could be called *allowing*; encouraging actions collected together under *coaching*; and some actual or vicarious experience termed *rehearsing*. Together these build the process of *Handing Over*.

Allowing

More than an action, *allowing* is an attitude. It seems to include such stances and understandings as tolerance; an ability to judge what is essential and what is non-essential; an ability to let be; an ability to let what will happen, happen; a

willingness to let things go wrong a bit, or even a lot. Underlying it all seems to be a valuing of self-determination based on the idea that the person himself is the best judge of what is beneficial to him. The New Zealand Nurses' Organisation's Code of Ethics confirms this as a prime value of autonomy:

Autonomy is the right of individuals to self determination which encompasses an assumption that the individual/group/client/agent of the person has the wisdom to make the best choice for that person.

(NZNO, 1995)

Allowing provides an environment for people to change, or to experiment with different ways of doing things. It goes beyond known situations, as the boundaries of what is acceptable are increased. Behaviours, statements and understandings that might normally be amended or challenged may be permitted or tolerated. Sometimes this may be because it is realised they don't actually matter, sometimes it may be because people accept that they are part of a larger picture.

Annie and Nell's satisfaction that Annie's cancer is 'ordinary cancer' and not 'carcinoma cancer' (personal notes) illustrates both of these possibilities. The nurse *allows* the situation to continue, judging that the misunderstanding is not important enough to correct, and expressing the possibility that seeing her disease process as less horrifying is helpful to Annie. This stance permits autonomy to continue. Lee provides an environment in which Jan can do as much self-care and family chores as possible. Although she discourages Jan's walking, and is anxious about it, she does not try to prevent it in any stronger way. Ivan's care team *allows* him the freedom of choice over his laxatives, though they know the outcome may be problematic. Rather than an attitude of 'letting him reap the consequence', the nurse is motivated by wishing Ivan to continue to trust that his self-determination was paramount. She reasons that if he trusts the team and system, he will be able to allow himself to be cared for at a later stage.

It seems that the attitude of respect for the individual in allowing self-determination to continue, even if risky for the person's safety, maintains their personal power, and in effect, empowers them in a dis-empowering situation.

Within the *allowing* environment is the issue of providing special privileges for those who are dying *because* they are dying. Examples are in the expenditure of resources, and also in allowing the dying person to speak their mind. Nurses related situations they had experienced where the dying person seemed to control kin by expecting a continuous indulgence. However they admitted that such an attitude had seldom been resented by the kin. With the people in this study special privileges were uncommonly sought, lovingly provided, and mutually enjoyed. Allowing in this interpretation can also be linked to the moral claim made by living an heroic narrative, as discussed in chapter five.

Coaching

A stance of encouragement can be observed in all parties as they seek to facilitate the process of handing over. It is a type of coaching.

The patient does it in terms of preparing the kin for the time when he is gone. There is a handing on of familial knowledge and traditions; there is an establishing of confidence that the kin will be able to get along without the patient. It involves creating a picture of the kin coping without the patient.

I was going to be cremated, but now I am not. My mother said that after my father died, if she hadn't had a grave to visit, she'd have gone mad. I have written out all my instructions, so they will know what to do. I don't know what to do about the death certificate when you die at home – I'll talk to the doctor about that today.

(What is the effect of all this planning?)

I am not worrying about dying. I am not worrying about anything. There are lots of friends who will help (F2 p3).

The kin coaches the patient to hand over care of himself; encourages the patient as he begins to hand over, and takes instructions about how and what to do with an accepting attitude. The kin learns to do the handed over duty, allowing the patient to critique and correct. Other actions are in encouraging and coaching the patient to tolerate treatment and palliation. Also important is coaching in the dying process and the living through process assisting integration of new knowing into the continuously evolving selfhood. Pip's conversation (see p. 161) as she gently brings Florence back to the underlying disease progression

encourages Florence to avoid the deception of the analgesia and illustrates coaching.

The nurse has a key coaching role, as might be expected. She is more familiar with the trajectory than the patient and kin, and has expert knowledge which will help their performance. As one who is not a key player, she has the ability to stand back and critique, and does not have to 'take the field for the final test'. This metaphor is useful, as it reminds her that she has a supporting role and the important work is being done by the central players. She is thus able to acknowledge their expertise and recognise needs for new skills or information. She can sketch out probable scenarios and equip them with the means to meet them. Her knowledge of the up and down nature of the journey, expressed in phrases like 'good day: bad day', help kin and patient keep optimistic through difficult times.

Jan's nurse exemplifies this in her comments to Lee, anxious about Jan's walking: "let it go, let it go"; and to Jan, irritated by Lee's protection: "she wants to save your energy".

It is not a one-way transaction, though. The nurse allows herself to be coached by the patient and kin, as they let her in to their family, and share their ways of doing things. Jan's nurse outlines the approach she uses:

She needs someone who will let her have control. And we will. It's their home, their territory, and they dictate to us. And fair enough (F5 p2).

Jan just feels that she needs to keep some things to herself. That's how Jan works. She is private, unless she wants to tell you (F5 p9).

What seems to be important here is a real desire to see things done well, a willingness to share expertise and a willingness to listen to advice. It includes encouragement and affirmation, and leads to new abilities and self-confidence.

Rehearsing

The last discernible aspect of *Handing Over* is that of *rehearsing*. Both *allowing* and *coaching* are precursors for rehearsing. Rehearsing has an actual and a symbolic part to it. Practising all the components which are to be *handed over* becomes a rehearsal for the final *Handing Over*, that of life itself. While all of life's losses are

in their own way a rehearsal for death, the losses, both involuntary and voluntary, of the last stage of living towards death loom more significant for the patient. Previous losses and rehearsals may be recalled and reviewed so that the patient builds up a working experience of coping with loss. Ivan's reflection on his political sentencing to death is one illustration of this. His poem illustrates much vicarious experience and acknowledges that his future relationship with death will be personal.

Some losses belong to the current time such as Florence's leaving of her house. This leaving is in a sense a leaving of her previous life, both possessions, the history attached to these, and to the self-determination of decision making about such things. There is a feeling of freedom gained from the handing over of these responsibilities, but also a sense of rehearsal for the next handing over.

Jan admitted that it was easier to allow people to do ordinary things, like meal preparation, than to allow them to do intimate tasks. She retained control of her medications and managed her symptoms and activities. When all this proved too much for her, she agreed to be admitted to the hospice for what her husband described as 'sorting out'. Notes taken after visiting her there show that she recognised the rehearsing nature of the admission.

We talked about her being cared for, and she said she was just letting them (the nurses) do everything, even making decisions about what to do. I put it to her that she was testing them to see if they could care for her as she would wish. She agreed that she was, and on further questioning, said they were doing a good job. I asked if she had handed over herself to them, and she said she had. She also said she would take it back (her self determination) when she went home.

She noted that she really did already know that they could take care of her well, but that was a long time ago, and now she knew it again, she would be more relaxed about coming in to the hospice in the future.

She acknowledges that this is a kind of practice run for the next admission, a kind of rehearsal (F10 p1).

This handing over is both rehearsal and handing over.

Exploring handing over

Handing over can be seen throughout life, for example when parents devolve self-responsibility to their children, so what makes it different at this stage? It is both *what* is handed over and the cumulative significance of the actions that makes a difference. Where the self is seen as created through an individually maintained personal narrative (Giddens, 1991) biographical continuity is central. Biographical elements of personal significance, such as contributing to the lives of those close by and influencing the path of one's own life, are normally sustained or reshaped as life unfolds. For the terminally ill person each handing over leaves a potential gap, and a loss of personhood.

The duties and responsibilities that are handed over are those things that help make a person what they are. Often these actions contain an issue of power-as-control, both in controlling resources and others' behaviour, but also in self determination or agency. Who we are is established in part in the *in-between* of relationships with others, and where there are fewer and fewer transactions with others, then the sense of self becomes diminished. As more and more duties and responsibilities are handed over, the relationship with the outside lessens and this involuntary withdrawal may cause anxiety. Reluctance to hand over may be related to this reduction in the sense of self which threatens.

Paradoxically handing over also allows space for other activities, and this may be a comfort. Kin may wish to reduce burden on the patient, and encourage handing over for this reason. Handing over is a further means of colonising the future, as it gives the patient the opportunity to shape the way those to whom he has handed his duty or responsibility will perform it.

The probable permanence of each handing over adds to its significance. Certainly agency may be regained, but it is likely to be temporary, and people are aware of this. A duty that is handed over for example 'while I'm away' is of a different magnitude from a duty that is relinquished, totally given over, given into the personal self of another. It will move from being part of the giver's construction of self to being an element of another's. Viewing it as a constitutive characteristic rather than a duty or responsibility helps show the very personal nature of these items and allows us to recognise the potential for diminishment of self and the inner struggle which are often present at these times. It also demonstrates that

for the patient, to retain agency by actively handing over, rather than being taken over from, maintains some sense of control over events and thus self identity.

Regimes and Roles

Regimes and Roles provide some insight into the activities of *Handing Over*. Giddens (1991) suggests that regimes are socially and culturally organised modes of providing for organic needs, including such areas as food, dress and sexual behaviour. Modified by the individual, these modes build into habits, fitting into social and cultural conventions, and are centrally important to self identity. Their importance lies in their ability to *express* the individual as he wishes. Interference with these regimes blocks the individual's performance by which he both knows himself and makes himself known to others. An individual's performance, according to Goffman (1959) must reach standards of aptness, fitness, propriety and decorum, and these must be congruent with social and cultural regimes. When such standards and compliance seem no longer possible for an individual, then the way change is managed becomes important to all involved. If change is respectfully negotiated, with an environment of acceptance, encouragement and rehearsal, as shown in the accounts above, a good outcome is possible. If there is taking over rather than handing over, or if a regime vanishes without discussion, as Ivan experienced (see p. 118) with the loss of his gender-identity, the process is likely to be painful for the individual.

Sets of behaviours are also understood as *roles*. Roles may be seen as closely related to status, or as more fluid and relationship dependent (Friedman, 1981). The importance of role is emphasised by Culbertson (2000): "adopting a role teaches us a certain way of being in the world. . . . In the end, we don't *have* a role; we *become* a role" (p. 17).

Separation of role and status appears problematic where there is a high level of cultural, social and historical closeness between the two. For example mother/nurturer; father/income provider are both closely linked, more strongly than daughter-in-law/caregiver. While Jan kept her status of mother, her role as nurturer was challenged by her inability to take responsibility for the associated tasks. This in turn undermined her status as mother, risking that her only status would be 'terminally ill person'. Where the individual can hand over a role, or elements of the role, he can maintain a legitimate interest in it, guiding, coaching,

approving and affirming others. To hand over allows that the new agent is a proper extension of the old.

Narrative work to cope with the paradoxes of dying

With the realisation that the suspension of time had come to an end there was a greater emphasis in personal narrative work on projecting forward. At the same time the sharpness of the dichotomies of dependence/independence, living/dying, and hope/realism increased, introducing a poignancy shared by kin. Continued experience with coping helped the patients increase their confidence that they could face future challenges.

Dependence/independence

The dependence/independence issue remained a challenge for patients and families even to the end of their lives. It was an early concern for Jan.

The hardest thing I have had to deal with is the loss of independence. To me, that would be the number one thing.

From being totally independent and working, and just doing everything, then having (the operation) and everything falling apart. Right from the first I lost my independence, and was dependent on my husband for transferring, for getting up and going to the toilet at night time. (. . .) that is the hardest of all. (F4 p1).

(If there was one thing you could pass on to someone in a similar situation, what would it be?)

Not to dwell too much on the dependency thing, I think. I think that is sort of morally – that sort of worries me the most. I think if you can get over that feeling and realise that people want to help you. Possibly this is their only way of helping you.

(How do you do that?)

I don't know! By accepting the fact that you can't do it. (. . .) it worries me a little if we go out, and he has got to lift that chair in and out. So I try to limit, if we go anywhere, to the one lift. (. . .) the other day as he pushed me over to the bank, and it was a long way, I said: "I hate this!"

And he said: "well, would you push me?" And I said: "yes, of course I would." You know, so you have to accept it (F4 p5).

Where the patient has greater physical independence and can be left alone, issues of support shift from practical to moral. Annie reflects on her ability to cope and on Nell's help.

At this stage I can cope. Nell is going back to work next week, and I know very well I can cope. I can get my own meal, I can get Nell a meal. In fact, I'll probably cope a bit more, because sometimes you like to be petted. It is awful to say this, but you like to be a bit petted (A7 p23).

A little later in the same session Nell observes the effects of company on Annie's well-being.

You know something? While we are talking, I notice (something). This morning, since you have been here, and since Annie has been talking to you, to me she feels, she looks as though she feels good, and great, and she gets no pain. Right?

And it is because she is talking. In essence, Annie likes to be talking, to explain to people how she feels – she comes out on top (A7 p27).

These observations of Nell's seem to show an awareness that independence may include isolation and a diminishing of Annie's well-being, and this contributes to Nell's ambivalence about returning to work. They are moral issues – should Annie do for herself? Should Nell go back to work? Should Annie be alone (lonely)? Annie, however, had Nell's future independence in mind as she encouraged her to find employment.

Living/dying

Ivan expresses his living-and-dying:

I would be lying if I said that I didn't know I was dying. But there could be two or three days when I don't even think about it. I don't feel 100% and I come against restrictions all along, but I am not thinking in terms of 'I am dying'. I am thinking in terms of 'I am handicapped'. I am thinking in terms of overcoming handicaps and not in preparing myself for death or for overcoming death (D6 p4).

Annie, too, reflects on her situation:

You do feel a bit of a fraud, because you've told people you are terminal, and yet you are still here (A7 p21).

Nell's response to Annie's health is also ambivalent. Annie tells her:

That's the only thing you haven't accepted. Deep, deep down, Nell, you must accept that sooner or later, I –

Nell breaks in:

Yeah – I know. I know what you are saying. I know – but you have to see my point as well. I've accepted it, too, you know, but then again I haven't, if you know. (A7 p24).

A little later Annie reflects further:

I couldn't say I was enjoying it. If I was somewhere else, I would be somewhere else. But it would be just getting to that somewhere else, if you know what I mean? Just popping into a car or having to walk or go somewhere doesn't interest me. So I am just kind of sitting here at the moment, not really thinking about it (A7 p36).

Annie's nurse notes that she is describing herself differently as she approaches death:

One of the most significant things that she said to me the other day was that she said she had been talking to Nell and she said – she was referring back to the medications (misunderstandings) and she was saying to Nell: "don't – there's no point in trying to knock me off, Nell, because I am going to die anyway. So you might as well just let it happen when it happens." And that was quite a significant comment I thought (A5 p3).

(She tells me that she sees herself looking forward to the next six months)

Has she got six months in mind? Like, if she can see herself in six months time – she – it is unlikely. She won't be here in six months (A5 p4).

Keeping the challenge of living/ dying appropriately balanced for each person in each situation was in turn influenced by the dichotomy of hope/realism.

Hope/realism

A further constant dance is seen between maintaining hope and being realistic. Often both are present almost simultaneously, sometimes it seems apologetically.

The focus of the emotion or attitude shifts during the course to death and they seem to converge. Annie's nurse expresses concern about the balance of hope and realism and ponders her best response:

I've talked about how it was ages ago with them. I think the time is going to be near where I am perhaps going to bring up with them about plans. Because if you said she's thinking about six months –

(That's today)

Yes, today, maybe. But the future is in her mind, so she'll know. I have this strong belief that people who have a terminal illness actually know – and they will talk about the future, because where there's life there's hope. You are always going to have that little bit of hope, aren't you? and you can't take that away from people, but . . . (A5 p6).

The same day Annie discussed her visit to the clinic:

I had a blood test and an X-ray, and I don't know whether he did or not, but I got the impression that he didn't have the light on, and the X-ray! I mean, I could be wrong of course, but the X-ray had gone so dull and grey. That's how the lungs have gone, of course (A4p1).

Her medications were adjusted at the visit, and she was told she was much the same as at the last visit. She is pleased:

Since my tablets have altered I feel a hundred percent better. It's almost as if I have doubled my life (A4p1).

Later she reflected on an impression she had gained that her clinic doctor was unrealistic:

Dr X is entirely different. When he talks to me, he talks as if I am going to be here next year. And I say to myself: oh, I wouldn't say that, because I know that I am not going to be here next year (A7p21).

Annie's future and what it will bring continued to be of importance to her and she describes an encounter with a clairvoyant which happened about 8 weeks previously:

She was outside a coffee bar, and I said "hello" and she said "would you like a reading for only \$10.00?" And I thought – I had been at the doctors, and I knew I had cancer – I'd just see what she said without letting anything go.

So she told me about Nell, which was good. I said: "what about me," and she said: "oh, you're in the best of health." She said "you have got a bit of blood pressure, but otherwise, no. And you are going to meet a lovely man, and he is going to be quite rich." And I thought: \$10.00 for this! But I didn't mind giving the money, I just wanted to see what she would say (A7 p28).

Annie was hoping for hope, but when she is given this unrealistic hope in such abundance she finds she cannot accept it; it contrasts too greatly with reality. However she chooses not to disillusion the clairvoyant, and in making this choice does not entirely destroy this impossible but tempting forecast.

It is clear that work on the self narrative continues as the patients recount events, reflect on them and interpret the meaning of them. Understandings are incorporated into the self and influence how future events are further interpreted.

Giddens (1991) describes how individuals cope with the complexity of modern life by describing four dilemmas that have to be resolved in order to preserve a coherent narrative of self identity. He explains:

'Living in the world', where the world is that of late modernity, involves various distinctive tensions and difficulties on the level of the self. We can analyse these most easily by understanding them as dilemmas which, on one level or another, have to be resolved in order to preserve a coherent narrative of self-identity.

(Giddens, 1991, p. 188)

Three of Giddens' dilemmas of modern life are used below to explore further the participants' challenges of dependence/independence, living/dying and hope/realism. Those used are fragmentation versus unification, powerlessness versus appropriation and authority versus uncertainty. Giddens' fourth dilemma, personalised versus commodified experience, did not seem of use for the experience of these participants, as overall, their living toward death did not seem enormously influenced by overt commodification.

Dependence/independence and fragmentation versus unification

The balance between dependence and independence that the participants struggled with may be seen as a struggle in changing roles. Role changes were

likely to be permanent and successful integration of change would contribute to a coherent sense of self. Giddens' modern dilemma of fragmentation versus unification offers an explanation of how role challenges may be managed. Giddens (1991) notes that modern society requires many roles and relationships of an individual, and that such diversity has a tendency to fragment the self. On the other hand the individual learns to present different selves as required, and as these are parts of the whole, this process can also be unifying. Presentation of the self was earlier developed by Goffman (1959) who notes that the factors of status, position and social place form a pattern, which the individual realises through action - in other words, plays himself into being. The individual knows that this performance must reach tacitly agreed standards of aptness, fitness, propriety and decorum, and the fear he will misrepresent himself through a poor performance causes concern when a situation is new or altered from the known.

Successfully presenting oneself to the world guards against fragmentation, building a unification which in turn engenders confidence. During the internal dependence/independence debates experienced by these participants questions around how to present satisfactorily are shown. Jan struggles to accept her dependence and acknowledges it as 'the hardest thing'. Her husband's re-framing it as potentially reciprocal if their situations had been reversed enables her to swap positions momentarily, and it becomes unifying. Jan's reflection that allowing people to help her is beneficial suggests that Giddens' (1991) concept of unification may work in relationships as well as intra-personally.

Annie appears to have resolved this dilemma, and this may be related to the fact that her relationship with Nell was exclusive and mutual, where Jan had cared for three generations and was almost always the primary caregiver. In Annie noting that she likes to be 'petted' she also expresses the ambivalence of this stance. (*I can cope, I'll probably cope a bit more*). In allowing Nell to care for her she seems to recognise that their relationship depends on the actions that move between them, from one to another. This is unifying, cementing, holding the relationship together. Independence would isolate them one from the other.

Living/dying and powerlessness versus appropriation

Giddens' (1991) second dilemma of modernity, powerlessness versus appropriation, is helpful in appreciating the dichotomy of living/dying

experienced by the people in this study. Giddens takes issue with the common theme in modern sociological writings that the self is powerless and alienated in a high modernity dominated by machines and markets. These writers, he claims, contrast ceding of control to the supposed individual agency assumed of pre-modern society. Giddens argues that the traditional communities offered the individual less power than he has today, and, while he agrees that modern society does expropriate a good deal, there are many ways in which these same processes facilitate mastery over life circumstances in a new way. For example while the abstract systems of international monetary control move rates and markets way beyond the individual's influence, access to those same systems via electronic media allows the individual to manage his own resources in a way previously not possible. Giddens suggests therefore that using a dialectical process allows a more complex picture to emerge.

The dialectical process applied to the dilemma of living/dying where agency is sometimes with the patient, and sometimes apparently beyond his power, seems to allow the fluidity of the experience to be seen anew. The movement between being a person-who-is-dying and a person-who-is-living forms a dance. At first the individual spends little time in the dying role, as it is strange and unfamiliar, retreating to the known role of living. However the living dimension has changed by the presence of the dying dimension and each is constantly visited to check its boundaries. Exploration of boundaries produces tension which in turn affects what is in the middle. Hallam, Hockey and Howarth, (1999) note that dichotomous thinking opens up the possibility of a more active engagement with the middle ground.

Because living and dying represent polar opposites both patient and kin may be uncomfortable with a reality which encompasses both. However the conversations recorded with Ivan, and with Annie and Nell (see pp181/182) show a continuous dance with the two dimensions. Rochefoucauld (1613-1680) observed that "Neither the sun nor death can be looked at steadily", and this seems to still be true. Ivan's conversation illustrates looking at death, then looking away. His comments let us know that he is aware that death is always present, for him to look at any time. He knows that is different for others who have not entered his world, and is clear that it is an absolutely singular experience. It is his death, his vision, his interpretation.

Nell knows that Annie's death will be a death for her, too, and she struggles to understand its proximity. She asks Annie to 'see' her point as well, a point of ambiguity, where both the possibility of Annie dying and the possibility of Annie living exist. Annie is impatient with this, as she has been moving between the two dichotomous points for longer, and her journeys between have woven them closer together.

Hope/realism and authority versus uncertainty

The third dichotomy outlined for these patients, that of hope/realism, may be explored using Giddens' authority versus uncertainty as a base. Giddens (1991) suggests that authority is more diffuse in high modernity than in pre-modern cultures. Though there are more claims to authority these sources compete more, and are less reliable. In normal life doubt is put aside as the individual creates routines which produce a certain reliability and predictability to life. Doubt also serves to allow the claims of authority to be assessed, and in this way becomes a modifying factor. A dichotomous relationship permits exploration of each position, and a strengthening of the safe situation for the individual.

For the patients in this study the diagnosis and prognosis may be seen as authority, as they are based on a recognised and accepted scientific discipline. The facts are as they are, and represent reality. Doubting this reality is expressed in hope - hope that the facts will be otherwise, hope that a successful treatment will be found, hope that the prognosis will be lengthened.

In the early times of diagnosis it is common for patient and kin to express their doubt in disbelief (*they've made a mistake; it can't be true; my family don't have cancer*) and the hope underlying these doubts is apparent. The movements between looking at the facts and away from them provide a continuous check between hope and realism, and the patient can add in the environmental facts of history, symptoms and experience to verify either position. Exploring the edges allows the centre to become known. Knowing hope permits realism to be explored, as the patient is aware that there is a safe retreat from the dangers of a too-brutal reality; realism counter-balances the possibility of hope creating an unreal world.

If either hope or realism is ignored then an imbalance will result. In the account below Abby's general practitioner's locum decides that Abby was not facing 'reality' squarely enough.

I went to my doctor's locum on Friday. She went ahead without listening to me, really. She told me all about what was going to happen to me in the next few days or weeks. It was the most traumatic experience. I would never expect a cat to go through what I went through. She virtually told me that I wasn't going to last (B5 p1).

She kept going on how (X) at the hospital had said I was in a really bad state, and that I was getting worse and worse. And she just kept going on about it. How much worse I was getting (B5 p1).

For the first time I realised I had cancer. I think I have been pretty good over this. It was a terrible thing to happen to anyone. Really wicked (B5 p2).

Of course, I realise I am not going to last for too terribly long (B5 p4).

I am an absolute mess since this happened. She was just terrible. We (have) still kept our roles, as (husband) going to work, and me at home. (husband) was rather frightened by this (B5 p6).

I said to her: " this is my life, my cancer and my death!" (B5 p8).

Although the interview was 10 days since this event the shock is still apparent. Abby had made the appointment as she was aware she was not as well as she had been, and wanted some clarity about time frames. While previous conversations indicate a fairly good understanding of her diagnosis and prognosis the uncompromising frankness of the approach of the locum made it all feel new. "For the first time I realised I had cancer." Her journeying between hope and reality has been gradually bringing them closer, as is shown by such comments above as "I am trying to cope with it as realistically as possible".

The actions of the locum, evidently encouraged by the concerns of someone at the hospital, stop this to-and-fro action that has been providing a balance for Abby, allowing her to retain a kind of equilibrium. Now she has no place of retreat and her repetitive comments indicate a sense of being trapped in an unwelcome reality. The anxieties of the locum and hospital staff are real for them, but seem to stem from an inadequate understanding of the place of hope in terminal illness.

As time went on, patients hoped for different things. Florence had hoped that she would get better, then that she might feel stronger, and towards the end her hopes changed:

(What kind of things are you hoping for now?)

Well, that I'll still keep charge of my mind, you know. And that I will still be able to get to the toilet(E6 p5).

The hope of retaining some self determination and dignity has been identified as common and this is reflected above, and in both Jan and Annie's wishes not to become a burden. It seems as though hope provides a relief from the awfulness of reality; that its presence allows reality to be contemplated. Without hope Abby was forced to 'look at death steadily', and trapped with no retreat she could not reflect on her coming death or discuss it with her family.

This compromised position was not experienced by the other patients and kin, who kept the dichotomous exploration alive, weaving strands between the opposing poles until they formed a bridge between the two positions. This allowed them to tolerate the seeming ambiguities and live with the paradoxes in growing understanding.

Integration of experience

The cumulative effect of reflecting on experience and building it into the project of the self was that the patient became receptive to change. He learned that some days were good, and some bad and that he was able to cope with both. He survived some severe tribulations and acquired useful experiences in doing so. Gradually he grew in confidence that he could face further changes. A sense of enduring and durability became clear as each day and week was completed.

The trust that built up between nurse and patient and kin contributed to this confidence. Jan explains how this developed for her:

They (nurses) seem to have all the answers. If you have a problem you can ask them and they will always seem to know the right answer. If they don't, they will go away and find out for you.

She has been very good with Lee, too. They walk out together and I see them 'chit, chit, chit'. (laughs)

Which is good, because she has kept Lee up to exactly what stage I am at and what to expect. The swelling of the feet. And the swelling of the feet is happening quite badly now. Lee is expecting that, so she knows what to do (F4 p2).

Because those around her are ready for change by knowing what to expect and what to do, Jan develops trust in the process, accepting that if they can manage the symptoms, she will be able to cope with what comes.

An open attitude to whatever will come is shown by Florence, her daughter Pip, and their nurse. Florence comments:

I feel that really that's the best way to take each day as it comes, and not thinking, will it be like this or will it be like that. I don't think it will do much good thinking like that. I just decide to take each day as it comes, and each one to the full (E3 p8).

She doesn't hide from the difficulties, saying:

I find it frustrating. Some days I seem to be able to do it, and other days I struggle harder (E6 p6).

Pip acknowledges that some of this is just the way Florence has always been:

I think it is more her nature. She is always cheerful, happy and positive about things and focusing on the things that have gone well for the last day. The doctor is very good at helping her (cope with the day to day pains and so on) without it seeming like she is moaning (E2 p9).

Pip also coaches her mother when she becomes concerned about the future, reviewing all they have done so far, and discussing possibilities for the future. Their nurse likes to pace her explanations to the family's needs:

I just really like to go with the flow on a day by day basis.

(Why do you choose to do things that way?)

Because I think you get in to all sorts of trouble when you do the other. Especially for them. You can worry them with unnecessary things that may not happen.

(So in what ways do you think it appropriate to prepare them?)

I think really just general support, and answer each problem as it arises. It did happen with Florence the other day. She was suddenly starting to feel drowsy, and that is often a sign that the disease is progressing. So then I would say: "well, it could be your disease, and this is what you need to feel about it, or check with your doctor"(E5 p5).

Preparing for a change which has previously been experienced is very different from preparing for something new. There are parallels with a first birthing experience, but the new parents will be able to talk to those who have been through this life change and learn from their interpretations of events. Midwives, too, have personal and professional experience to draw on. In the transition *out* of life, no one is able to say what it will be like. The patient is coached by those who have no first-hand experience or vicarious accounts of the transition. The nurses' experience is limited to accompanying a person to the edge of life and stops there. Giddens claims that:

Death tends to be the more completely hidden away of the two, perhaps because it is the more dangerous in terms of the return of the external criteria. For childbirth is a process of entry into life and can be technically managed as such. The process of dying, on the other hand, cannot be seen as anything other than the incipient loss of control: death is unintelligible exactly because it is the point zero at which control lapses.

(Giddens, 1991, p. 203)

Conclusion

The patients' work has been undertaken with this threat of the lapse of control always present. As they have traversed the new ground of a life-threatening illness they have become competent at facing disaster and coping with challenges. They have learned and practised new skills and accumulated much useful experience. They know they are approaching 'point zero' and they are making the preparations that they believe will be what they need.

They are ready.

Interlude

Leaving the participants

The participants are 'ready' for what will happen next, having spent their time acquiring experience and confidence. They do not know exactly how and when death will arrive, but they believe it will, and though some anxieties persist about details, they are ready and able to face it.

The text leaves them at this point, in moving to a more theoretical discussion, based on what they have taught us. As real people, Abby, Florence, Ivan, Jan and Annie have died, but their narratives do not stop. They continue as part of the narratives of their kin, and they endure as lively and real narratives in this text. Their practical courage permeates their conversations, providing both hope and role models for their kin and for us.

Chapter eight – enduring work

The patient's course has taken him from the fateful moment of diagnosis to the edge of death. He has met many challenges with a variety of responses, each time meeting the threat and integrating it into himself, so that he continually rebuilds both how he sees himself, and who he is. The purpose of this chapter is to summarise the discussions of the previous three chapters in order to move them from the experience of the five participants to a kind of 'everypatient' experience. Lifting the experience out of the personal allows for a more objective scrutiny, and a debate that is not linked to particular instances. In this way we are able to discern the essential elements more clearly. The second part of the chapter lifts the summary to a more abstract level, proposing some themes by which the now-generic experiences may find recognition in the life experiences of people outside of this study.

First challenges

While the whole human experience of being terminally ill is characterised by fateful moments, the first – the crisis of diagnosis – is the most remembered and highly significant. What are the responses to the first challenge that facilitated survival through it?

Coping with mortality

The threat to ontological security is absolute, with the abrupt alteration of what had been an open future moving to a calculable life-span. Mortality, with its double meaning of 'being mortal and alive' and 'being mortal therefore having a limit on life' takes on a personal and therefore sharply true meaning. The philosophical work of others appears hollow and inapposite for the patient when he becomes aware that dying can only ever be a personal experience. As Giddens (1991) notes subjective death is something of which the living can have no intrinsic understanding.

Yet there is no time for reflection for most. The responses shown are those of practical engagements with treatment or preparations. After the shock, the patient meets the challenge by seeking to control. Where the information seems to be a particularly immediate threat, efforts are made to limit the enormity of the news. For example, patient and kin might delay full comprehension of the significance by focusing on another action. While these distracting actions could be related to diagnosis or disease, they are a means of putting aside thoughts of death. A flurry of activity is sometimes seen, in order to control all the aspects that could be controlled or organised, leaving as a smaller and more manageable part the less controllable portions. Annie's focus on organising her funeral illustrates a need to grasp and manage the more controllable aspects of a potentially chaotic experience. Sometimes the amount of information taken in at a time is controlled by the patient, by such means as seeking peripheral information. At other times very specific information is sought about the disease, causes, treatment and support groups, and this serves to delay considering a bad prognosis.

The processes the patient engages with – persistence and surviving, acquired by experience – serve him well. Having survived the first awful 24 hours as the numbing effect of the news fades, he realises that he has continued to live, and many things have not changed at all. Hope does not take long to emerge and buoys him up quickly. The threat to ontological security, first seen as immediate, retreats somewhat, allowing space to manoeuvre. In Giddens' (1991) terms, chaos has threatened the patient's ontological security, and he has begun to recognise and manage the new risks in order to maintain his protective cocoon.

Coping with a different body

The experience of his body being in crisis has a number of different but related effects on the patient. Recognition of the embodied nature of his being is forced by the threat of disembodiment that death would bring. The disease makes him aware of his taken-for-granted body, as he consider how and who he is in the physicality of human form. His only known existence is within this form, yet he can no longer trust it to house him, or to be 'for him'. It seems, in fact, to be working against him. Such destabilisation is recognised by Hallam, Hockey and Howarth (1999) as being one of the challenges of relationships during ageing or severe illness.

The body is the means of being in relationships with others, as discussed in chapter 5, and all these relationships are rapidly altering as a result of the body's new unreliability. In turn, the changed relationships alters the patient's perception of his body. What actions does the patient take to cope with this 'new' body? Undertaking whatever medical treatment is available is one way of coping, and this is based on a life-time's experience of treatments effectively restoring the body to its previous state. When there are no formal and potentially effective treatments available, and often even when there are, the patient seeks to maximise the body's health himself. Sometimes he might consider using folk, herbal or alternative treatments, at other times he would eat as well as he could, or rest, pray or do whatever seemed to him to be an *active* response to the situation. It seems that he needs to self-direct some activity in order to assert control over his wayward body.

Over time, he discusses the physical changes, reasoning them through, and seeking reassurance from medical staff that he is going along 'normally' and from family that he is still physically acceptable. He re-builds his self concept to include the changes that occurred, providing a personally acceptable narrative (Giddens, 1991).

It would be incorrect to say that he learns to accept his changed body. It is more an 'OK'-ness that the body is as it is, a sort of tolerance for the meantime. If his appearance or body's functioning improves he is pleased, and he becomes disappointed all over again if things deteriorate.

Narrative as a means of coping

The work to integrate the threats to his well-being and maintain a reasonable relationship with the changing body is achieved via personal narrative. Being able to provide a personally acceptable account of events and his place in them allows the patient to externalise, examine and edit such stories. Every narrative constructed by the patient includes specific details to convey particular messages to the listener and to the patient himself.

Sometimes the narrative is a communication to others of what has happened; sometimes explanation about why things happen the way they do, is included. At other times the patient listens to his own narrative, sometimes to real-ise the diagnosis or its details, sometimes to confirm his own role. Editing and alteration

of details provides an opportunity for the patient to keep some control of a situation that often seemed more in the control of others than himself. It also allows a particular role to prevail as necessary. Sometimes the person needs to see himself, or to convey himself as 'patient sufferer'; and at other times it may be the role of 'heroic survivor' that is most useful. The role type chosen facilitates responses from the kin, and to a lesser extent, the caregivers, and also confirms for the patient his deservingness for the care required.

Narratives provided for experts are usually dictated by the particular style of questions from the professional, but the patient also uses these health and illness progression narratives to convey details to kin that he does not want to offer in his own voice. In addition, he is able to contrast the expert narrative with his own reflections, self-knowledge and opinion in order to demonstrate that the experts do not know the patient as well as they might think. This asserting of independent voice is not often a strong one - though it can be persistent - but it is important for the patient as a counter narrative (Sakalys, 2000) to the medical account.

Narrative work goes on all the time, as it needs to, because of continuous challenges to the person and on-going changes in his physical, social, mental and emotional state. It is aided by the frequent need to give accounts of progress or current status to health professionals, kin and visitors.

Differing accounts are provided quite deliberately at times. For example, a casual inquirer might be told that the patient is 'quite well' and that 'results looked good'. Kin are sometimes surprised to be told how well their sick patient is doing, when their daily experience seems very different. While these accounts are understandable if the patient does not want the particular inquirer's sympathy, the kin can be left wondering if outsiders think the situation is better than it is in fact. In this way narratives are significant in helping the patient cope with events, as he uses them to make sense of information, to integrate events into his personal life story, and to communicate to himself and others.

Agency and time

The disease process itself interrupts the patient's agency. While agency includes facets of autonomy and self-direction it also conveys a more active meaning,

suggesting that beyond the 'rights' aspect of autonomy, agency is to do with the 'power' to act for oneself. For the terminally ill patient all aspects of his independence are important and agency is affected in many ways.

Firstly, the actual diagnosis removes the control of the patient's future from himself to 'this disease, cancer'. Plans for the future, even for such trivial items as going to work tomorrow, are suddenly altered. The patient feels at the mercy of the disease, the necessary treatment and the effects it will have on him.

Secondly, this movement includes a submission to expert direction, as the person sees himself as no longer competent to manage his own health, and therefore cannot make the best choices for his own survival. While he participates in decision making, he is aware that the choices are difficult and that he does not have the knowledge to make them on his own.

Thirdly, symptoms such as physical weakness mean that the patient needs help to take basic care of himself. Sometimes physical symptoms include cerebral interference, leading to confusion, hallucinations or misperceptions. These affect the reliability the patient places on his own assessment of reality, and the way others interact with him.

Fourthly, the use of morphine affects agency on personal, perceptual, social and existential levels. When the patient agrees to commence morphine there is a feeling of personal agency being subverted by this powerful drug. With the body dulled, the person feels he will no longer know his body, or be able to assess its state. There is also often, but not always, a blunting of interactions with the outer physical world, and sometimes the presence of mood-swings, which are unpredictable, producing a sense of alienation for the person and kin. The social meaning of taking morphine, with its addictive nature and the negative public perception of it is also an ever-present factor. Finally, the significance of commencing morphine, and then of each increase in dose diminishes the person's agency further, as he recognises death advancing to meet him with each alteration.

Keeping agency in the face of its removal

In modern society, maintaining personal competence is very important. It is a personal goal and an expectation of society. Giddens (1991) explains that to

become a competent agent the individual must “exert a continuous, and successful, monitoring of face and body” (p. 56). To lose competence risks losing one’s respect and place as a functioning and adequate member of the community. Therefore the patient seeks to keep agency in some way. It is a struggle, beset with continuous assaults.

Three useful responses are noted. Sometimes the patient fights stubbornly on, giving ground only under duress, at the last possible moment. Another patient may submit early to what he believes he cannot usefully resist, keeping energy for the areas where he can more easily, or more importantly to him, keep his autonomy. A further response is to give away agency, thus paradoxically retaining it. Whatever response is used, and sometimes all are, there is almost always a struggle, as the person comes to terms with the reduction in agency, the movement from the previous state of self-determination to the new state of a lessening of personal autonomy.

Personal suffering

The disease produces many unpleasant experiences, mostly physical, but these often have effects on the social aspects as well. The limitations of pain, disability, nausea, loss of energy and general malaise³² are cumulatively debilitating. Though efforts are made to reduce these symptoms with medication, diet, folk remedies and pacing of activities³³ the patient still suffers with them. Normally society expects the effects of illness to be hidden away – in Giddens’ (1991) terms ‘the sequestration of experience’ – so the patient is both living an unpleasant life, and living a life which is outside of the accepted norm.

Suffering itself could potentially be enough to dominate a person’s life, but it does not. The patient works hard at coping with these symptoms, and Annie’s descriptions in Chapter 6 (p. 140-141) show her recognising and putting aside each item. Kin’s recognition of the severity of the tribulations aids the patient in surmounting them, contributing as the recognition does to the heroic narrative.

To some extent or another, the patient is able to transcend his suffering, to get beyond it in some way. This is not to suggest that a sublime meaning necessarily

³² An overall feeling of being unwell.

³³ This refers both to the timing of activities to the most appropriate time of the patient’s day, and also to grouping activities to conserve energy.

emerges for him, but he does struggle, and he does get past the suffering, and he does see that it does not consume him. The struggle is not, however, a once only event, making transcending in a way a continuing event. The admiration of his kin for his survival through his suffering is essential for the transcending.

In order to arrive there,
To arrive where you are, to get from where you are not,
You must go by a way wherein there is no ecstasy.
In order to arrive at what you do not know
You must go by a way which is the way of ignorance.
In order to possess what you do not possess
You must go by the way of dispossession.

(Eliot, 1944 p. 17)

Eliot's notion of dispossession preceding a gain exemplifies what happens through personal suffering - there has to be a submission to the suffering experience in order to go beyond it. Submission in this view is more accepting suffering as a fact of life that cannot be readily altered, rather than seeing it as acceptable in itself.

Changing relationships

Relationships change immediately in terms of power, authority, agency, duty, responsibility and commitment. Changes are in the strength, direction, future and recognition of the interactions and their meaning.

Part of the change in relationships with experts has been summarised above, and in addition there is a change in trust with the experts and the systems they represent. The patient is faced with the dilemma of the expert betraying trust by pronouncing a fatal disease and terminal diagnosis, but remaining the person on whom the patient will rely for treatment and care. The sense of loss of trust is masked by the continuing relationship, but a bitterness often remains, and is increased if there is any experience of a failure in the system. Sometimes it is the kin who experience and express bitterness at an unreliable health system and it is possible that they are speaking for the patient here, as he may not wish to risk his necessary relationship with the expert. The patient may feel abandoned by the expert systems, and remain somewhat suspicious in on-going relationships.

Relationships with kin change immediately, as the patient requires support and the kin begins the long mission of providing it. To accept assistance from others, even if family, undermines the competence expected in our society. For women this is doubly hard. Financial dependence is another change, but does not appear to be highly problematic, possibly related to the number of other issues to be dealt with.

The continuity of relationships with kin into the future is addressed by many activities. Giddens' (1991, p. 242) term 'colonising the future' is helpful here, as the patient actually envisages a future time, and considers his part in it, though he knows he will be physically absent. He knows that the quality of the relationships of the present will carry forward, and he works to keep these as good as he can. Some instruction is given, usually in relation to the patient himself, though sometimes hopes for children and grandchildren were expressed. He may, for instance, say how he wishes things to be done in a future from which he will be absent.

It is not uncommon for the patient to review family history to a greater or lesser extent, almost as if he is placing himself among these forebears.

We die with the dying:
See, they depart, and we go with them.
We are born with the dead:
See, they return, and bring us with them.

(Eliot, 1944 p. 42)

Another review is of his own life, evaluating the worth of his personal life in his own terms. When this is undertaken in conversations with kin, it both contributes to and forms part of the immediate picture painted following death, usually in the initial bereavement period. The process of working towards an enduring relationship becomes shared when this happens, and the patient is able to mold and influence the lasting image.

Relationships with the 'unknown' - that is, what was to come after physical death - is not a major concern for the patient in this study. Experience in the field of palliative care nursing shows that it is rare for people to be enormously worried by these issues, and this is supported by literature, and discussion with

other practitioners. Anxieties and queries that dying people do have seem to be fairly readily answered for most people, but those who approach death with terror seem to have captured the popular mind and professional concerns. In literature, for example, dramatic interpretations contribute to a communal fear of death. In *Dr Faustus*, for example, death is portrayed as terrifying. Faustus sees that mortal limitation is worse than ending, it is a no-end (Neill, 1997). In contrast, a recent study on the dying experience for those in terminal illness situations in England (Exley, 1999) noted that few respondents spoke explicitly about their faith in an afterlife.

The day-to-day business of managing changing relationships is achieved via continuously negotiated interactions. Previous patterns are both widened and narrowed, and roles, as discussed below, shift. Trust with experts is slowly regained in most cases, though it remains somewhat tenuous. The ability to review the self as continuing in some form after death, whether it is in the memories of kin, or as a spiritual being, seems to bring confidence to the patient. He works with this knowledge, building a bridge from the present into the future, thus making dimensions of time and space increasingly less relevant for himself.

Living within altered time

The perception of the passage of time alters for the patient, no longer moving at the same rate, or with a predictable consistency. He becomes aware that his time is different from others, though they are existing in the same world, bounded by the same sunrises and sunsets. Past and present and future seem to move about:

Time present and time past
Are both perhaps present in time future,
And time future contained in time past.

(Eliot, 1944 p. 3)

Time becomes multi-layered and personal, and influences the perception of other events. The feeling of living in suspended time, often recognised by the patient, communicates itself to the kin. The kin also feel the suspension of time, but if the patient remains apparently unconcerned by the passage of time for 'too long' the kin become anxious. The potential for dislocation between patient and kin

increases when the kin become aware that time is running out, but the patient knows that he has 'all his time' left. The patient transcends problems of time, but the kin remains bound by a different kind of time.

Handing over

Suspended time does not last for ever, and the patient recognises that waiting is over. Describing suspended time as denial can and does happen, but generally without a strong moral imperative to change the patient's perceived state. Usually it is felt that the attitude the patient chose to take is his business, and though kin might wish it was otherwise they do not try to shift the view. The exception, shown in chapter 7, where Abby's doctor believed she had a duty to challenge Abby's understandings, shows the risks of attempting to impose a personal opinion on another person.

Another concern of kin is often the handing over of duties and responsibilities. Kin want to lighten the patient's load, and the patient does not want to lose the things that are important to him, the things that give him authority and standing in the family group. The process by which a balance between reducing work and maintaining authority is achieved is through the actions of allowing, coaching, rehearsing and handing over. All parties are involved in the process, including nurses. Handing over works best when achieved in a relaxed fashion, without pressure or hurrying. It is also important that any handing over is actively done by the patient, and that the item or duty is not 'taken over' by well-meaning kin. The patient thus keeps the control of the duty or responsibility, and an on-going interest in seeing it is done to his satisfaction. In addition, the patient can theoretically take back what he has given away, and this leaves power with him.

Reluctance, or even a refusal to hand over or relinquish responsibilities or duties is generally accepted by kin in a quite pragmatic fashion. Even where things can be problematic, such as in the paying of bills, kin seem relaxed, appearing to believe that they would sort things out in due course.

Roles and regimes are some of the means by which people are constituted as individuals in their world, and the diminishment of these aspects of self have the potential to diminish the person. The patient has a need to maintain a self-concept that is more than 'terminally ill person'. While kin understand this

intellectually, the motivation of taking the load from the patient to conserve his energy sometimes gets in the way of facilitating role maintenance.

Ambiguities

There are several ambiguities which run throughout the patient's living toward death, where he struggles with three seemingly incompatible extremes.

The first described, dependence/independence, is present in many of the issues outlined above. It is one of the first personal issues to be challenged, and, aware that dependence will only increase throughout the course of the disease, the patient is keen to keep as much as possible. For example, the patient has previously been in control of his own financial issues - independent. When he loses earning capacity, he still tries to keep some financial and other resources management. Then when he can no longer do this, he wishes to make the decisions about the actions. When he cannot decide, he wishes to be consulted, or informed about these issues.

Kin are generally active in keeping decision making and choices with the patient, but understandably, do not fully comprehend the loss for the patient.

The second paradox offered is that of the living/dying situation in which he has found himself since diagnosis. The Chorus in *Murder in the Cathedral* repeats throughout the play:

Yet we have gone on living,
Living and partly living.

(Eliot, 1938 p. 10)

While the concern of the chorus is more related to living and merely existing, or living and not-really-living, the paradox remains. The patient is living toward death. All experience, media and philosophy tell him that all humankind, all living things, live toward death, but now it is real. Yet, day to day, he lives; dying recedes. Life and death are both present, both dwell within him. Over time the two become less distinct, co-existing in a more habitual manner, until the day, perhaps, when both are equally real.

Hope and realism is a third ambiguity that the patient experiences. Hope is one of the main means by which future is constructed. If we see hope as simply 'better than now' we can see that this involves two concepts, that of time to come and the placement in that time not being worse than today. The patient without hope becomes trapped in the present because he is unable to project himself toward a 'better than now'. Without a notion of continued existence despair can break in. Despair also threatens via the facts of the disease and its prognosis – the 'realism' provided by reason and experts. Both are present for the patients, the influence of each keeping the patient from straying too far in one direction. Kin and professionals also have ideas about the appropriate place for the patient between hope and realism, sometimes letting things be, though this could engender its own anxiety, and at other times moving the patient back to a more median position. If the patient, or the kin, or friends have a very different stance from others, it can cause dislocation, and there may be a need to respond if the situation becomes dysfunctional. Abby's friends, who retained the hope that she would recover, eventually became cumbersome to her own progress, and she had to move away from them.

Managing dichotomies

The key issue in independence is maintaining a sense of the whole self, which dependence threatens to break up. The patient manages this dilemma effectively when he actively controls the movement from independence to dependence. Sometimes he is able to perceive that actively accepting dependence strengthens an existing relationship, particularly when he does not fret against the loss of independence, and allows new dimensions to develop in his relationships. Such graciousness unifies rather than fragments relationships.

Living/dying is probably the most extreme of the dichotomies, and with the most threat of chaos. While the patient cannot dwell in the dying-person state for prolonged periods at first, the possibility has to be contemplated. By a process of looking at and looking away, engaging and disengaging, the patient gradually encompasses his eventual death into his construct of himself. By this action of taking – appropriation in Giddens' (1991) terms – he avoids the potential powerlessness which regarding death as the single focus of his life would bring.

The situation of hope/realism is understood using the construct of authority versus uncertainty. Realism signifies that the bald facts of diagnosis and prognosis come from the expert position, and have the power of science and professional voice. Hope is the brave thought that doubts the evidence.

Hope thus provides a counter to realism, preventing it from taking over. It also asks that realism be checked out, questioning its authority, and undermining its power. Realism counters by allowing the evidence that supports its claims to emerge, so that hope does not blanket reality. Such a relationship is healthy, allowing the patient and kin to negotiate the middle ground and continuously balance their position.

Growing in confidence

With the passage of time, of good days and bad days, the patient works on, integrating events into his self construct. He realises that he has acquired the ability to meet challenges and overcome them and that he has the skills and knowledge to meet what lies ahead.

Identifying an over-arching meaning from the living toward death narrative

The participants in this study have shared the details of their living toward death: these have been recounted and the work of philosophers, notably Giddens, used to assist the process of making meaning clearer. The various constructs that have been used shed light on this human travail, allowing others to engage with the experience. The next challenge is to bring the disparate elements together in a way which will communicate the whole more clearly and permit the greater understanding that leads to better practice, better living and better dying.

The following text proposes a structure that seeks to show the whole. It is a tentative outline that emerges from the summary above, where its justification lies. It does not claim to represent all dying experience, but suggests that some elements of its structure may be found in any dying experience. Its openness allows a variety of living to death to be seen within it, but not be constrained by it. The structure may provide some insights for patient, kin and practitioner.

Enduring Work

Living toward death can be described as *Enduring Work*. The key features of Enduring Work are: threats to ontological security; the constant reconstruction of selfhood; negotiating support; handing over; transcending; readiness for change; and an enduring ontology.

Enduring work

The word 'enduring' seems to capture the key elements of the work the patient undertook in his living toward death. The elements of the word 'endure' include firstly *to undergo (hardship, strain etc.) without yielding; bear* and secondly *to permit or tolerate* and thirdly *to last or continue to exist* (Hanks, 1990).

The patient has to work hard at coping with the suffering, tribulations, challenges and experiences of living with cancer. Such work is an active stance, where what he does makes a difference to the experience. It is often not easy and takes much courage and fortitude. It is certainly undergoing hardship. The patient also has to permit and tolerate the variety of indignities and adversities that cannot be modified by his actions. While such tolerating is a more passive stance than the work of actively enduring the situation, there is sometimes a determination about tolerating that has a very focused nature.

The part of enduring that is to do with continuance permeates undergoing and tolerating. Continuance is the immediate and long term goal, and gradually it becomes the extended goal, as the patient develops a concept of endurance *through* death. The issue of endurance as assisted by the comforting patterns of nursing work is presented by Morse & Proctor (1998) but in their study instance is time or event limited rather than the extended and extending goal shown by terminally ill patients. At the same time, the notion of enduring *through* is helpful, as each episode of successful enduring through contributes to a pattern of enduring.

Threats to ontological security

Threats to continued existence are the most severe threat to ontological security, as they shake not only the present and the future, but also the past existence of the person. The present becomes uncertain, unreliable, and a place where past

experience does not count. This shakes the past; at the same time the value and purpose of the past is thrown into question. If existence could be as fragile as it has become, then was the past a fool's paradise? If one's personhood is so easily dismissed through this capricious disease, then was it ever worth anything? Future is now bounded by the disease and its ramifications and all other futures, possible until a metaphorical yesterday, have now evaporated.

Understanding of death anxiety has been traditionally more bounded by the researchers' feelings and experience than that of the dying person (Neimeyer & Brunt, 1995), and does not answer the questions troublesome to the patient. These studies also show that prior experience with death does not necessarily aid or hinder personal experience. Reflections on life and death by a Dutch physician working in a nursing home (Keizer, 1996) show the variety and unpredictability of people's responses to their dying. That there is little pattern to guide the patient does not stop him from seeking one, nor his kin from wanting some predictability.

The various threats to the patient and his responses have been discussed in the data chapters, aided by insights from Giddens (1991) and others. What needs to be added is the notion of persistence, and the development of a wish to endure. These notions do not always exist, with persistence depending very much on custom, personal beliefs and age. While persistence seems to gradually diminish as death becomes closer, the wish to endure continues and may become stronger. Not all terminally ill people wish to ensure their continued presence by such means as on-going memories, and not all believe they will have some continued existence after death. However, for those who do work at either of these tasks, a recognition, exploration and description of these concepts may be useful.

It might be argued that the wish to endure is an instinctive response to threat, and it is probable that this guided the patients in the early stages. However, soon it became conscious and deliberate, often producing a determination that would be challenged by the unfolding disease processes. Persistence continues to underpin the patient's activities and contributes to the enduring that develops.

As the patient grapples with the issues of autonomy, agency and control, the idea of an enduring self takes stronger form. Such development is also a part of a continuous spiral of threat, recognition, response and integration.

The constant reconstruction of selfhood

The process of reconstruction is achieved through maintaining an active personal narrative. The narrative allows the patient to review himself and his past as he provides personal history to strangers many times in the early days of illness. As he does so, he is responding to recognised or unrecognised questions about how and why this disease has arrived. He is able to shape the narrative he provides for the professionals so that he will be deserving of treatment. This justification is both personal and public; and especially necessary to establish if treatment outcomes are uncertain, when the narrative confirms his deservingness for care.

The narrative provided for family allows the patient to present himself as a person with a life-threatening illness, and in doing so, he both communicates with his kin and himself. He listens to his story to real-ise his situation, internally re-shaping himself from his previous healthy form. Narrative allows continuous monitoring of the situation, as reports are given and interpreted. Narrative also allows the patient to present a more favourable picture than reality warrants, so he can reconstruct a selfhood that remains acceptable to him. The fact that the narrative is continuous, and many layered, also allows the patient to edit and modify redundant narratives, and to try out variations on both himself and kin as listeners and assessors.

Over time the narrative allows the patient to see himself as one with a definable past and an on-going, evolving present, thus building a picture of himself as enduring through the past and dwelling in the present. The narrative accumulates accounts of surviving tribulations and challenges, and a concept of an enduring self emerges. The attempt to maintain normal social interactions as long as possible - to endure - is noted by others (Exley, 1999).

Negotiating support

In order to endure, the patient must negotiate support and this is done both consciously and unconsciously. The narratives used by the patient provoke particular responses in kin and friends, and in professional helpers. As discussed above, the heroic narrative (dying before one's due time) signals his deservingness to others. Part of this is the aspect of enduring tribulations in a patient and courageous way, as this allows the kin to recognise and reward the good behaviour.

The patient also learns to ask directly for help, or to signal needs in other ways. He must overcome any reluctance to be helped, and carefully balance the kin and professional wish to help and potential for them to tire of helping. The ability to endure difficulties assists this by affirming his willingness to do what he can, and only ask when really needed. Whether this latter stance is really necessary does not seem to be the point; what matters, it seems, is establishing deservingness. Killilea (1988) suggests that there are social connections and mutual benefits in supporting one another in terminal illness. He notes that it is in this caring duty that each party discovers his real identity, thereby making death bearable and valuable. The key purpose of negotiating help is so that the patient can endure both the adversities of his situation, and endure forward.

Handing over

From diagnosis the patient is faced with having to leave aside his anticipated future, and at the same time he is giving up his immediate plans. Initially, when there is nothing to replace this future and present, the gap is unsettling. Gradually his narrative work helps him develop a sense of enduring self, and the relinquished future is replaced with a different one. In old age Jung considered his life's work and experience, recognising that what was sure had become unsure, but that in spite of all the uncertainties he felt a solidity underlying all existence and a continuity in being (Jung, 1961).

There is a considerable giving up of autonomy when self direction and agency are undermined by a lack of expertise, by disease processes, and by treatments and medications. Independence is also a focus of re-evaluation, and at least a part of it will be relinquished, with the always-there prospect of this dependence increasing. As described in chapter 6, roles are handed over, and there is a degree of shift in physical, temporal, and social issues. The patient seems to be deciding what will endure with him through his living toward death, and also what will be needed for his continued endurance in a future without his presence. Such handing over has an active element, moving it from a loss to a gift. Yet the patient does not want to give everything away, particularly when it is something that is constitutive of his person. When what is given moves from personal to common, or is handed over in a kind of trust, loss is diminished. What is important is the action of handing over. The patient must hand over in order to keep; he must give away so that he can endure.

Transcending

The accumulation of experience is integrated into the patient's selfhood by his continuous narrative, and he makes what sense he can of it in this process. As he endures the tribulations of being terminally ill he comes to recognise that they are not all there is to his life. After experiencing more endurance and more tribulations he realises that he is actually able to move the suffering away from the central focus, and go beyond this experience. Some have described the process of working past suffering as finding meaning (Pollock & Sands, 1997), redemptive (Peck, 1997), going beyond, transformation (Bondi, 1999; Charmaz, 1999) transcendence (Williams, 1995) and finding grace (Tillich, 1952; Van Tholen, 1999). It does not imply that suffering is good, or necessary, but identifies that for some people the suffering can move away from being the focus of the patient's existence and become a kind of lens through which that existence is seen anew.

The living, embodied passage toward disembodiment is also in a sense transcending. The focus on the body as the centre of self identity begins to shift with the unreliability of the body, and as it grows increasingly weaker. Exley (1999) notes a move away from physical issues to the spirit as more important than the body. It seems the patient, having identified that the physical body will not endure, learns to put his work into his spiritual being. He has recognised that this aspect of self is unaffected by mortal frailty or bodily disease or decay and seems to develop a tentative or firm faith in its continuity.

The vexed question of separation of mind-body is addressed by many writers for example Campbell (1984) and Heidegger (1962). However Broom (1997) points out such examinations begin by accepting the constructs of mind-body separation. He proposes a more integrated view of human, that would include all known ways of being in the world. However, for these patients, the body-spirit issues are in fact thrown into immediate prominence, as it is the body that has changed, and the spirit that is increasingly seen as enduring.

There is also a transcending of time, as it is measured in new ways for the patient, and sometimes for the kin as well. Where time limited and shaped the patient's being in the world in the past, through enduring the experiences of the disease, time went beyond the patient's previous understanding and became

subordinate to experience. Paradoxically, it was the recognition of finitude that permitted time to be ignored.

The patient endured through suffering, and endured through the limitations of *chronos*, to transcendence, which would eventually allow him to endure beyond physical death.

Readiness for change

The work of enduring, lived over and over again, with increasing personal wisdom, keeps the patient in the on-going present, always becoming. Each challenge is succeeded by another, tribulations, old and new, present continually. The patient recognises and responds, persisting and enduring, building up increasing confidence in himself.

He is not prepared to stop this process, or to see a closure as particularly imminent. While he recognises the end as definite, it is also 'not yet' - while it is not there, he does not need to engage fully with it. He does not see the need to expect death every tomorrow, but he is increasingly ready for it. The ability to encompass life and death together is recognised by palliative care nurses (Sherson, 1998) noting that we should acknowledge and affirm the pull of life, where it exists even in the face of death.

He is, it seems, ready for whatever the day will bring; ready for any change, as he has become expert in coping with change. He is hopeful that any such change would contain positive aspects, but knows that he can endure if it does not. In an overview of the literature on hope it is claimed that hope is central to the existence of an individual (MacLeod & Carter, 1999).

Readiness for change is not overtly recognised by kin, who are more socialised by many professionals and other helpers to expect a kind of readiness for death. Some kin and caregivers become somewhat uncomfortable, particularly if they hold views that the patient should be 'preparing for death'. When death is closer some kin find talk of 'when I feel a bit better' quite discomfiting and are not able to reconcile that the patient could recognise the imminence of death at the same time as being prepared for another, nameless, possibility.

It seems that the state of readiness for change is highly functional for the patient, and with cancer becoming more of a chronic illness, the concept of readiness for change will be more useful as an on-going description than acceptance of death.

An enduring ontology

During living from diagnosis towards death, the patient gradually builds up for himself an enduring ontology. Surviving repeated threats to his ontological security brings him the knowledge that he could endure through them. Transcending the tribulations of the illness creates a self image of a person who is able to persistently endure hardships. The business of handing over, and that of constant reconstruction of selfhood via narrative provide a link to a future, a link that he can control and shape. In this way he is able to see that he will endure beyond the present incarnation (bodily form) and endure in a way that will keep him among his kin. Being able to shape how this future 'self' would be, means that it is his own enduring, not one created by others.

It is possible that becoming aware of enduring beyond death in this particular form provides comfort and confidence for the patient that he will endure or continue in some personal way beyond death. Even talking about 'not knowing what will happen after I have died' shows that they encompassed an 'I' and a 'happening', which indicate continuance. Recognition of some continuance beyond death is recorded as far back as 60,000 years ago as ancient peoples in the now Iraq buried their dead with preparation for afterlife, indicating that this belief is long-held and tenacious. Modern skepticism and science may suddenly seem over-certain in the face of the uncertainty with accompanies diagnosis, and the patient may prefer to live with less certainty and more hope about his continued existence.

A concept of future in which people have a part is confirmed by the following:

. . . respondents did look forward and think about the future beyond their deaths. Although the dying are not able totally to control and order the events which may occur after their deaths, they can attempt to influence the living after they are gone and negotiate roles for themselves in their survivors' lives.

(Exley, 1999, p. 245)

However, when endurance beyond death, for example as going to heaven, is seen as the only way to find meaning in death, Killilea (1988), argues that our views of death will be limited. Such stances fail to allow the interconnected nature of death to emerge, and stand in the way of people finding their own meanings. When the patient reflects on his forebears and instructs his descendants he is ensuring a form of endurance. Even the person who has no interest in his ancestry and commands his kin to 'forget me when I am gone' is building the picture by which he wishes to be remembered.

The notion of enduring ontology is not a staged understanding, where the person moves through phases toward a recognised point. Certainly there is a beginning point, but from there any process can only be described as cumulative. Progress is of uncertain pace, and some areas may be traversed many times. The end point shifts in time and space, and when it is reached it is not there any more, and is no longer the goal. Its overall purpose seems to be the creation of a sense of self that is beyond physical and temporal being that will allow death not to be the end.

Conclusion

Viewing living toward death as Enduring Work recognises the complexity and openness of the experience for the patient, and that his understanding develops through the tribulations, challenges and the sense he makes of it all. It is a suggested lens, that some may find helpful, but does not seek to explain all things for all people, indeed allows that any such attempt would be contradictory. In the end it is the patient's experience that stands out, yet it would not be as it is without the relationships of kin and nurse, and others more peripheral. The paradox of the lonely travail, accompanied by kin and stranger, makes sense when the departed patient's existence in the temporal world endures through the continued lives of these others.

The final step in the research process is to establish the usefulness of the findings by placing them within the contemporary context of literature and practice, and the discussing the limitations of study. The final chapter addresses these issues.

Chapter nine – discussion

Evaluating the usefulness of the ideas developed from the examination of the lived experience of terminal illness from the view of the patient, kin and nurse is an important final step of the study. This chapter shows that viewing living toward death as 'enduring work' fits within contemporary developments in the field of caring for dying people. The findings show the limitations of older models and demonstrate that practitioners need to continue developing skills of understanding the patient's story and its meaning. Although the chapter opens with a discussion on the limitations of the study, this is brief, as most have been identified earlier, and more are self evident. Questions that arose during the research process were noted earlier, though a short discussion here expands the issues. Possible research questions from the findings of the study are limited to the major issues, as these provide a kind of umbrella under which related smaller-scale questions can be placed.

The structure of the chapter follows the chronology of the study: firstly the limitations are reviewed, then the questions arising during the study. Possible research questions from the findings, and from the themes identified follow. These link to examining the findings within current theories, contemporary literature and present practice. The chapter closes with a discussion on the implications arising from the study.

Limitations

The study was designed to be limited in number of participants and the scope of exploration. These limitations permit the depth and richness of data that has eventuated, but naturally do not provide the verification that comes from using large numbers of subjects and a narrow field of data. In order to manage the amount of data that would accumulate from the sets of participants, each set had to be restricted to three people. This meant that some potentially relevant views would not be expressed. In this study limiting the kin to one person does not appear to have been significant, in that in each case the patient identified the kin

as 'the person most closely going through this experience with you', and the interviews and observations confirmed this position. However, the views and experiences of other family members could also be enriching, and their absence is noted.

Similarly the nurse, when the patient is cared for in his own home, is the most significant person, but in some cases there were several nurses involved, and their views, and those of the medical practitioners and others are absent in this study.

A further area where the design of the study produces its own boundaries is the selection of participants. As the intention was to begin interviewing when the patient had made the transition to realising they would not get better, and had begun a dying process, the people approached would all have made a good deal of progress in understanding and accepting their fate. In addition, nurses, who made the first approach, were likely to select people who would respond positively, a further indication of coping with the situation. Finally, the people who might agree to participate could have personal needs which they believed being in the study could resolve. To what degree these are significant limitations is not presently clear. Certainly it is useful to study 'ordinary' people living toward death, as much of the patient voice to date is from those who are especially articulate (French, 1998; Warburg, 1988; Schwartz, 1996). How average the experience of the participants in this study is may only be known when other similar studies are done.

Small scale qualitative studies do not seek representative samples, working on convenience groups, so the relative homogeneity of the study group, in terms of age, culture, life experience, faith and education is not a concern in this project. Even a very similar group of people could relate quite different narratives if this study were replicated, but it would be interesting to note if the central themes were similar.

All of the patients in the group had relatively 'hidden' cancers, that did not intrude constantly on their lives. When cancers are highly odorous, visually intrusive, or where treatment has changed the body function markedly, as with people who use artificial voice boxes following laryngectomy, living toward death becomes much more complex. Avoiding patients with obvious disease

processes was deliberate, as it was recognised that it would probably complicate the experience and subsequently the findings. However, it must be noted as an issue that has been circumvented.

The study was limited in its findings by the time constraints of doctoral study, by the size of the group, and by the limitations produced by the participants' illnesses and amount of researcher time available for data collection. These are natural limitations of a kind within which any study must work. Without such constraints study would be open, and unshaped – an end may not be recognised. Patient, kin, nurse and researcher seemed to be continuously aware of the feeling of pressure imposed by being terminally ill, even when in 'suspended time'. These limitations, rather than being negative, seemed to focus the experience and the interviews. The content of interviews with the patient and kin, as described in chapter 4, seemed to become repetitive in three or four sessions, indicating a type of saturation and suggesting that any feeling of time pressure related to terminal illness was not problematic.

The context of health care in any country has a fluidity about it, especially where funding affects services very directly. Even within the few years of data collection, the provision of palliative and terminal care in the city changed several times, and at the time of writing is changing yet again. Increasing hospice provision in the community is the trend, reflected in the life experience of those in the study. Any study must be seen as a snapshot or slice in the context of the day, and when that context changes, the implications of the study need to be placed within the developing new context.

There were many other probable influences on the participants in the study, and the context, which would be impossible to measure, but could have had their own effects. During these years the debate on alternative treatments for cancer was almost always in the news, with patients and families sometimes eschewing mainstream treatment and opting for alternatives ranging from semi-respectable treatments to way-out, even charlatan type cures (Hosking, 2000). At the same time the numbers of medical practitioners who were in court for failing to provide appropriate care seemed to increase (Johnston, 2000a; NZPA, 2000). The effect of these influences was not investigated; while it did not appear significant, it must simply be noted.

The study does not, of course, seek to uncover all truth about living toward death, but claims to reveal a part of a truth – that of these people, in this time, in this city. The characteristics of the study design, outlined above, limit the findings and their application beyond what is appropriate for qualitative research. Yet these same attributes are what provide the richness and lead to new understandings. Recognising and exploring the limitations allows the reader to use the findings appropriately in future situations.

Questions arising during the research process

Ivan's experience of feeling let down by medical science brings up the issue of the expectation that life will continue to extreme old age because of ever-improved medical interventions. As Callahan (1993) reminds us the technological imperative of "if we have the technology we *ought* to use it" is translated for the patient to "if the technology exists, I have a *right* to it". This adds to the expectations that life will be long and healthy, and that medical science will ensure it is so. The strength of such expectations and how they influence participation in treatment, particularly when treatment has little or no prospect of cure may be worth exploring. Ivan's narrative also brings up the question of general practitioners whose apparent delay in diagnosis costs patient and family precious time together. Investigating the extent and characteristics of such situations has the potential outcome of managing questions of good practice professionally rather than through litigation. Lee's interest in alternative treatments for Jan indicates another area where research could guide kin, participants and practitioners so that the most effective care is balanced with autonomy and the maintenance of hope.

Abby's experience in learning her diagnosis shows just how difficult this information can be to take in, as she works over the information again and again. Most of the participants reported shock and pain on hearing the news, and this was repeated when cancer recurred or when a turn for the worse was identified and conveyed. These experiences suggest that the issue is appropriate for careful exploration, via qualitative research, to develop more effective communication. A recent study in Northern Ireland (Dunniece & Slevin, 2000) contributes to such exploration by investigating nurses' experiences of being with patients receiving a cancer diagnosis.

Florence's transfer from acute curative care to palliative care seemed to progress smoothly, whereas Jan's was more problematic, as she needed acute care at times to achieve palliation. The transfer of the patient's care from acute to palliative care warrants investigation. Nurses note that some medical practitioners appear reluctant to begin the transfer, leaving little time for adjustment for patient and kin (Panek-Hudson, 1998). Some issues for exploration in this area include who benefits from transfer; who decides, and how; are all patients and kin the same in this situation; is it more difficult to transfer patients from some services; and what is the effect on patient and kin when transfer is suggested.

Ivan's perplexity about who was 'in charge' of his care is a reminder that what is well planned and co-ordinated care from the professional point of view can be confusing for the patient. In addition, Ivan's comment shows that the notion of a team approach can leave the patient with a sense of disorganisation. Observation showed that where there was one close kin involved in the patient care to interpret and manage the various services, confusion was minimised. The experiences of Florence and Jan affirm that the work of Pip and Lee buffered difficulties and negotiated problems. However, when the patient was effectively on his own, co-ordination could easily become confusing. Ivan's experience - and his independent nature - shows up the gaps that can appear without the presence of a day-to-day kin. Health professionals assessment of the interrelationships did not always match the patient and kin experience. Study could uncover and explore all each separate experience and establish how congruent each party's understandings of the integration of services was with each other.

The increasing chronicity of cancer introduces several issues suitable for further study. Annie lived for almost two years beyond initial expectations, as treatment was fortunately more effective than is common. However she did not return to work, and was a semi-invalid. Jan's response to steroids prolonged her life by many months, though she too, needed a high level of care. This seems at variance with publicly held negative perceptions of cancer (Hosking, 2000) in that cancer was not an immediate 'death sentence'. The issue to investigate here is how the patient adjusts his personal narrative of being 'heroic' and deserving of special care, to living with a chronic illness. While for Annie and Jan the period of

chronicity was relatively short, for others it can be years, and include a return to work while still coping with the tribulations of cancer.

When cancer is chronic some people do not return to their previous employment, and many require continued support from kin. Research into the effect on kin is needed, in terms of social, psychological, spiritual and economic stress. Moral obligation, imposed by family, society and the state could be explored, and cultural and gender influence would also be useful to explore in this area.

When patients are treated with steroids to prolong life there is frequently a subtle or overt personality change that may disrupt or force change in existing relationships. The questions here are moral, and we see a hint of them in Jan's introduction (see p. 92) as she tells us how well she feels, acknowledges it is the drugs, then thinks she may be getting better while recognising that she is not. There are moral issues in beginning and continuing such treatment; in the patient giving 'informed consent' when he cannot know how he will change, and will not recognise these personality changes when they happen. There are moral issues for the kin in this arguably artificial extension of life; in the cost to the state in prolonging life in this way; and in not prolonging life. These are difficult questions, and should be investigated before the use of steroids becomes the norm by de facto process.

Potential research question arising from the study findings

By the end of the study a number of areas for further study had been identified that were in some ways outside of the articulated findings. These were: the use of language, the use of narrative, the effect of initial and developing expectations and viewing the illness experience through the eyes of a secondary participant as the primary narrator but including the patient narrative as well. These issues go beyond the terminal illness experience, and could be studied in any practice arena.

Research into language as indicators of the patient's current situation could be carried out. For example, speaking of *the* body or *my* body could provide an indication for caregivers of the level of engagement the patient was experiencing with his body at a particular time, and guide them to respond appropriately. Jan's talk of *my femur* and *the knee* (p. 112-113) shows some probable

objectification of her body, but the reasons underlying the language - if any - are not clear.

Further work related to narratives and responses would also be useful for practitioners and kin. When a patient offers a number of accounts of one issue that are all subtly or clearly different, such as Jan's narrative about the frailty and potential for fracture of her long bones, there is a high potential for miscommunication. Explorative research could address such concerns as the response triggered by each version; the cognisance of kin and others of the existence of several versions of the story; whether the kin seek to rationalise the accounts; and the way the versions assist the patient to maintain an acceptable view of himself. There is no doubt that patients and kin make some sense of what is happening to them, and the study shows that narrative is important in interpreting events. Examination of each episode of narrative using such means as content analysis, genre, metaphor, tense, person, tone, audience and relationship with previous narratives could throw light on how this process of constant reconstruction is developed. It might be possible to understand to what extent such narrative construction is conscious, and how it may be affected by other, concurrent and historical narratives.

Annie's first expectation that terminally ill meant 'immediately terminally ill', and her responses to manage what she believed would be her imminent demise, show the strong influence of patient assumptions over medical information. Identifying the beginning expectations of the patient, kin, nurse and others would be a fruitful area for research, and could include how expectations are modified over time, and what effects this has, especially on caregivers.

Although this study set out to explore the lived experience of the three central parties in living with a terminal illness, the eventual focus was much more on the patient, with the kin and nurse as supporting persons. It would be useful to undertake further study with the kin as central character, examining the roles of patient and nurse on the kin experience, as they related to her. Similarly, it would be interesting to focus on the nurse's experience with the patient and kin as peripheral to her work.

Specific issues

The more specific issues for research arising from the findings are those of fateful moments; negotiating support; handing over, readiness for change and enduring work. Possible explorations are outlined below.

The concept of fateful moments, offered by Giddens (1991), has helped understanding of the events of diagnosis. Further work specifically designed to encompass the detail of his construct could assist increased knowledge of this event, and could also provide challenge and enrichment for the original concept. A focus on this period of the experience could also include knowledge from the work of other theorists and researchers, such as thanatologists, sociologists, theologians and nurses (Howarth & Jupp, 1996; Wass & Neimeyer, 1995; Aranda, 1998; Hallam, Hockey & Howarth, 1999; Van Tholen, 1999).

The idea that the patient actively negotiates support and care for himself may be somewhat challenging for many in the palliative care field. Investigation into the place of narrative, as outlined above, could identify various conversational cues that elicit caring responses. However, the patient also has to openly adjust to changing independence and learn to accept assistance. The need for help will normally only grow during terminal illness, and balancing the maintenance of independence with the need for increasing assistance is a challenge for patient, kin and health providers. Research into how support is invoked, negotiated and provided has the potential to benefit all parties. Such a study would need a multi-faceted approach, examining the actions of patient, kin and caregivers by observation, reporting and reflection. Most difficult to examine would be situations of reluctance to provide care, particularly on the part of the kin, as the moral imperative to support the patient who is dying is very strong. Nevertheless, it would be important, as the expectation that they are willing to provide care that is placed on the kin will continue to grow as health care devolves to family. Such research could address issues of how easy is it for kin to say that they can no longer care; what the effect of such an admission is on the people involved; and how the health team encourage kin to provide support. Research into negotiating help, particularly into the moral aspects, would also benefit caregivers in situations where patients have chronic illness, including mental illness, and Alzheimer's disease and related disorders.

The idea of handing over as part of constant reconstruction of selfhood and as preparation for death would also be interesting to examine more closely. Giving up, in part or whole, autonomy, independence, roles and eventually life may have recognisable aspects to it that would assist caregivers to support the process. Attitudes, culture, age, gender and faith could all have a part to play in handing over. Also important would be establishing the precise factors that make relinquishment at the end of life different from the mere passing over of duties and responsibilities that occur regularly throughout life. Related to this concept is the situation where the patient relinquishes his hold on life as a result of kin actions, perhaps related to closure, that seem premature in relation to the patient's physical status. Although kin actions that pressure a patient toward closure are recognisable when overt, the more subtle actions are less easy to identify and there are complex moral issues in exploration of them.

Readiness for change is a key finding of this study that extends existing theory, and challenges present understandings. The character of readiness for change is that the patient, having learned through his illness experience, the skills of meeting and surmounting threats to his well-being, has developed a sense of enduring. Hope is a part of this attitude so that the patient is ready for whatever tomorrow will bring, confident that he can meet it. While readiness for change appears to fit, and is confirmed by kin and practitioners as fitting better than other models, it does need expansion and testing. 'Readiness to die', as proposed by Copp (1998), is described as a state where the patient is ready in both body and person for death. Research could show how the two ideas of readiness for change and readiness to die fit together; where they overlap; and if there is movement between them.

The various aspects of enduring work proposed in this study - enduring as suffering, enduring as stoicism and enduring forward through death - could be explored through both literature and experience. The notions proposed need to be more fully expressed as propositions and tested, though this may need to follow further qualitative exploration.

The context of the literature and contemporary society

As the present study was being written up, and the findings identified and debated, the question of a title for the work arose. The theme of living toward

death had emerged throughout the data chapters and gradually claimed its place as a key element of the study. Chapters 7 and 8, the final data chapters, bring out, from an early notion of fortitude in chapter 5 and a sense of continuity in chapter 6, the presence of an enduring self. Chapter 8, titled *Enduring work*, identifies the elements of this enduring, claiming its centrality for the study. Following much discussion the title *Living toward death: the enduring work of terminally ill people* was created.

Enduring work gives voice to the patient's story, showing how he maintains a sense of selfhood by creating a competent personal narrative through a series of fateful moments. Identifiable elements within enduring work are negotiating support, handing over, transcendence, and readiness for change. The whole culminates in a sense of enduring ontology as the patient recognises that he will endure through death in some form. The next section of this chapter examines how enduring work fits with related literature and contemporary society, and begins with a comparison with the commonly used theories of dying.

The five-stage model of Kübler-Ross is arguably the best-known and most influential of death and dying theories. Beginning with denial, stemming from diagnosis shock and moving toward acceptance, the model is largely progressive and unidirectional. Enduring work suggests a cumulative spiraling of the patient work which may move in more directions than closure. Kübler-Ross' theory describes the patient activity as emotional and cognitive, and therefore mostly internally focused. Compared with enduring work, which acknowledges that the patient work is primarily interpersonal, and includes physical, social and spiritual work, Kübler-Ross' work seems more passive. While she was clear that the stages were not prescriptive, the model has developed a normative feel, where the patient's place in the stages is diagnosed by the health professional. Enduring work is more descriptive and develops from the patient's own interpretation. Acceptance in Kübler-Ross' model is interpreted as 'a womb-like state' (Seale, 1998) and as such it appears to be a closed state. Transcending, as proposed in enduring work, is very much more a continuous becoming, a kind of continuing to make sense of the ever-present suffering. Rather than 'transcendence', it is expressed as *transcending* deliberately, to underline its on-goingness.

Enduring work relates a little better to Buckman's (1993) model which argues that patients have individual responses, related to their previous history and character. Buckman's focus remains on the psychological, and although a chronic stage is identified, movement toward closure is the direction of development. Enduring work is more active than Buckman's model appears, and is more holistic. In addition the presumed direction of enduring work is open, allowing for improvement, stability or closure.

Glaser & Strauss' (1965) descriptions of the dying passage are based on the patient's awareness of dying and are somewhat dated in that it is now common for the patient to be constantly made aware of his prognosis. However, as Copp (1998) points out, the studies do show up the uncertainties of situations where the expectations of patients and staff differ. Enduring work is clear about the always-possible disjunction between patient, kin and health professional expectations, and asks to what extent they need to be congruent. Glaser & Strauss' second study (1968) developed the concept of dying trajectories, upon which further studies have been based. Dying trajectories have a closed feel about them that enduring work challenges, arguing that the patient does not necessarily express the imminence of closure. Enduring work suggests that the patient prefers to remain open to possibility. Glaser & Strauss' models continue the implicit attitude that the health professional judges the patient's state, as do other models.

Pattison's model (1977), using stage and trajectory concepts, continues the assumption that the health professional facilitates the patient's progress through his dying trajectory to his death. However he acknowledges a crisis period, an interim he calls chronic living-dying, and a terminal phase. Enduring work fits well with this more open model, except that the downward and progressive direction still permeates Pattison's model, and enduring work demonstrates a more open attitude. Pattison's model is more holistic and individual than prior models, though there is still a heavy focus on the psychological.

Work that examines particular aspects of death and dying, or debates identified attitudes, also provides comparison for enduring work. Copp's 'readiness to die' (Copp, 1998) is developed from a study with people close to death, and therefore has a closed focus in contrast to enduring work's open focus of readiness for change. Nevertheless, the notions of being open to what is coming, of being

prepared in some ways, and accepting of what will come are similar. Copp's work conveys the impression that it is the patient who demonstrates readiness - rather than the observer judging that the patient is ready - so that even when close to death the patient may remain active in choice and direction. Acknowledgment of the individual's personal control is also described in enduring work.

Enduring work does not claim on the evidence of the study that there is existence beyond physical death, but there is an emerging sense that the patients were building a sense of some personal form of an enduring self that was helpful to them. Support for this more open stance is found in the work of three British scholars. Hallam, Hockey and Howarth's (1999) explorations of the relationships between body and spirit at, around and after death challenge the implicit message in the major models above that death is an end to existence.

In enduring work the patient colonises the future and instructs his kin to create an enduring self. In this way he has control over the character of his future self, contributes to it, and ensures some continuity with his kin. A similar theme is seen in Exley's (1999) study in the construction of post-death identity. Both Exley's study and enduring work note no evidence of spiritual angst in the people who were creating an enduring self or constructing a post-death identity. Whether there is a relationship between a functional construction of post-death identity and spiritual ease during dying is not claimed by either study.

Transcending beyond the immediate tribulations to a space of calm is seen in enduring work, as the patient recognises the increasing presence of his spiritual self. This process moves the patient beyond immediate suffering, and may transform suffering into a kind of lens through which life is re-evaluated. Actively promoting this process is a physician working in a Dublin hospice. Kearney (1996), looking at the experience of suffering where it is so intense that it is beyond pharmaceutical intervention, introduces a term 'soul pain'. He describes a way of facilitating transcendence to move the patient from the suffering by means of creative visualisation. By this process the person mentally constructs a personal passage from the problematic present to an alternative and better place. His process, an obvious metaphor for death, enables his patients to see themselves enduring through dying, and envisage a kind of continued existence beyond physical death. Enduring work suggests that it is possible for

people to gradually develop the sense of enduring self through living toward death.

Enduring work and contemporary health literature

Enduring work emerges from the contemporary context of literature, health provision and social experience, so it is not surprising to find many of its elements present in current literature. Beginning with threats to ontological security and working through to enduring ontology, the following section provides some of the literature that supports the direction of the findings of this study.

Diagnosis of a terminal illness threatens ontological security, bringing up questions of what it means to be human, as are addressed in existential thinking, psychology, theology, biology and other disciplines. Giddens (1991) discusses popular writings on self fulfillment in his sociological philosophy, acknowledging ordinary human experience and aspirations. Such actions that bridge literature which is more accessible to the average reader have the potential to benefit both the person-in-the-street and the academic. It is hoped that the elements of enduring work, such as *living in suspended time* and *living toward death* will speak clearly to patients, kin and professionals, as well as having credibility with researchers and academics.

The constant reconstruction of self

The place of narrative in understanding human life is of current interest in several disciplines, including nursing (Harden, 2000). The issues that are of importance to researchers in these disciplines are: who decides where meaning lies, what are the influences on personal narratives and how should they be interpreted (Carson & Mitchell, 1998; Gubrium & Holstein, 1998; Moules & Streitberger, 1997). Harden (2000) argues that meaning should not be evaluated from a single perspective or discipline, which affirms the approach taken in the present study. The fluidity of patient experience and its constant shaping by personal narrative is confirmed in therapeutic approaches (Monk, Winslade, Crocket & Epston, 1997), and the shaping of future identity is opened up in sociology and death studies (Bradbury, 1999; Exley, 1999; Hallam, Hockey & Howarth, 1999; Howarth & Jupp, 1996). The development, application and multi-

disciplinary interest of narrative as a research method supports its use in the present study.

Negotiating support

The notion that the patient who is faced with a life-threatening illness has to work at gaining the care needed may seem somewhat surprising to practitioners and kin, particularly when these caregivers often work very hard at providing patient-centred care. However the present study shows that there are more aspects to be explored in the area of the patient as recipient of care, or manager of his own carer. A Canadian study (Bottorff et al., 1998) showed that patients make conscious decisions about which choices they have the energy to cope with. A more recent study (Reynolds, Scott, & Austin, 2000) indicated that despite improvements in educational preparation, nurses are still not adequately recognising these moral aspects to the helping relationship. Questioning of assumptions about practice and knowledge is also evident in the increasing number of qualitative studies, examining what *is*, rather than taking what is for granted and researching the *how* of what has been assumed (Smythe, 1998; Spence, 1999).

Handing over

In the cancer experience giving up is often seen as defeat, giving *in*, and patients are encouraged to fight, and not give up (hope of cure). Such language demands a thorough exploration of its meaning and influence on living toward death. Enduring work indicates that the more negative aspects may belong to a passive giving up, and that an active giving up may be functional and useful. The language of relinquishment has always been present in death, seen as early as the death of Jesus where John records “Then he bowed his head and *gave up his spirit*” (John 19:30 NRSV) or “It is finished: and he bowed his head, and *gave up the ghost*” (John 19:30 King James) and in a more modern voice “Bowing his head, he *offered up his spirit*” (John 19:30 The Message). The developing change in the words used suggests that the translators wish to keep the voluntary nature, or the active aspect of handing over present as part of the death experience. This is important for individuals in faith communities where Jesus’ death is seen as a model, and where his death signifies the transcending of death. Included in the idea of handing over is a concept of relationship, and a recent study explores

such connectedness. Secomb (1999) argues that existing and prevalent understanding of death is based on a concept of *individual*, where the feminine relation to death includes a more connected way of being in the world. She says:

. . . in addition to this atomistic mode of being-towards-death there is also a certain 'feminine' relation to death which arises in being-with the dying other and grieving for those who have died. This experience suggests that our death is approached in the context of the death of others and is immanent within life: this death is inter-relational and intrinsic rather than isolated and futural and impending.

(Secomb, 1999, p. 111)

Accepting the losses of disease and dying with grace is challenged by McHugh (1999) as he compares the death of Morrie Schwartz with one of Kevorkian's victims, Thomas Youk. McHugh finds Morrie's advice which includes maxims such as "learn to forgive yourself and others", and "accept what you are able to do and what you are not able to do", superficial and insufficient to reflect the mystery of death. McHugh would like more respect for the mystery of death, including exploration of whether is there anything beyond ourselves that can judge us. Such a viewpoint is likely to find handing over, particularly in death, inadequate. This debate illustrates once again the individual nature of finding meaning in death, as Morrie's meaning would not do for McHugh, yet has found resonance with the many terminally ill people and kin who buy books such as *Tuesdays with Morrie* (Albom, 1997).

Transcending

Transcending suffering is a difficult concept to engage, as people argue the theological implications and moral dimensions of positive meaning being derived from negative experience. Nevertheless, the topic is being explored on its edges (Joachim & Acorn, 2000) in the experiences of having or not having visible signs of a chronic illness; particular aspects of suffering (Charmaz, 1999); the body in illness (Van Manen, 1998) and spiritual meaning (Thomas & Retsas, 1999). The concerns of time as an aspect of qualitative research is discussed in a recent article (Sandelowski, 1999) and this is important in transcending. How patients adapt to suffering in chronic illness (Pollock & Sands, 1997) has led to some understanding of the meaning of this suffering for them, and has implications for all areas of nursing. These authors note that the challenge for

nurses is to create and maintain an atmosphere where clients realize that finding meaning in their suffering is a possibility and through finding meaning, they may be able to better cope with their current situation. This seems a challenge, but it is worth reiterating that it is the *client* who finds meaning, that meaning is not imposed or described by an outsider.

Enduring ontology

Building an ontology that endures beyond death is linked to the constant reconstruction of self, yet contains a future that is different from presently recognisable futures. Work related to meaning in chronic illness contributes to this knowledge (Temmink, Francke, Hutten, Zee, & Abu-Saad, 2000; Thorne, 1999; Wellard, 1998) showing that the patient, constructing a view of the self as enduring presently, having endured the past and able to endure forward, makes inroads into the unknown - in Giddens' terms 'colonising the future'. Negotiating after-death identities (Exley, 1999) also bridges the present to the future, with a sense of the road spanning the abyss of death. Traditions surrounding death are not as lost in modern society as popularly believed (Bradbury, 1999) showing, that for many people, some sense of enduring beyond death is persistent. However studies on the impact of death *imagined* by adults (Widera-Wysoczanska, 1999) confirm that to imagine dying is not the same as being actually engaged in the business of living toward death. Literary, theological and philosophical discussions on the individual's beyond-death existence (Schmidt, 1997) often focus on generalities, myth, and imagination, but still provide theoretical possibilities for the individual to engage with. All of these types of studies and philosophical explorations have the potential to develop enduring work by challenge, confirmation and negation.

Implications of enduring work for patients, kin and professional

What enduring work could mean for all those who are part of an individual's living toward death falls into three somewhat general groups - issues already quite well known to practitioners, issues that are presently experiencing change, and issues that are exposed in a new way through the study.

Implications for accepted knowledge

The philosophy of patient centred-care is not new, yet remains a challenge for health professionals who wish to promote patient independence and decision making at a time when patients need increasing support. Complex decisions are required, time is constrained and stress becomes high. How moral is it to require the patient to make significant decisions 'autonomously'? Yet to not do so has moral implications. The dilemma is felt by both parties. Enduring work, in the accounts of Ivan and Jan, shows that the health professional confidence in their practice may not always be confirmed by patient perception. The tension between the patient knowing himself best and the health professional having more experience in living toward death is difficult to manage. Enduring work indicates that the situation may be best worked with by continuously seeking resolution and accepting that the goal may have to be the least bad or the slightly better outcome. Ivan's nurse, in not attempting to force her advice on him, was aware that it could have a bad outcome - and it did - but her clarity that he "*called the shots*" (D3 p8) meant that the trust between them was maintained. Practitioners accept the idea of patient centred care; enduring work confirms its importance and reminds practitioners that it is not easily achieved.

The limitations of Kübler-Ross' model are accepted in the field of death and dying, yet there is a strong influence remaining, particularly evident in voluntary groups and kin. Kübler-Ross' model may also be used by professionals who do not normally care for patients with a life-threatening illness. Abby's experience suggests a Cancer Society volunteer who expected her to fit within the classic stages. Her later distress seemed to be initiated by a locum general practitioner who attempted to impose her own judgement of where Abby 'ought' to be psychologically to match the assessed physical state. When used as a template beneath which the patient experience is expected to fit, Kübler-Ross's theory limits possibilities and confines the patient's life to another's interpretation. Enduring work confirms practitioners' knowledge that the use of this, or indeed any model, masks, or at times, denies the patient reality.

Implications for currently challenged knowledge

Listening to the patient's voice is an established and growing part of death and dying work and encompasses both patient centred care and the acceptance of

the patient experience as unique. Such studies as those by Sakalys (2000), examining the political role of illness narrative in restoring the patient voice; and Sitzia and Wood (1998), whose evaluation focused on patient centred experience, confirm the importance of the patient view point. Research into the nurse experience of working with death and dying (Jones, 1998, 1999) acknowledges both the strain of the patient and kin lives at this time, and the value of narrative in expressing experience. Enduring work confirms the importance of a focus on experience and the continuing attempts of health practitioners to hear and include the voice. The study does not overtly show that the caregiver role is stressful but it is clear that kin put enormous effort into doing it well.

More recent study and debate on suffering and its meaning, handing over personal roles and creating post-death identities, reflects the shift from a dominance of the view of death as immoral, hidden or a primarily physical event that should be medically managed. Enduring work affirms the pattern of a shift from attempts to control or hide death towards a wider and less clear appreciation of death. What this suggests for practitioners is that patients may find their own meaning in the mystery of suffering, and that this experience may be beyond both description and the understanding of outsiders. Accustomed to a practice domain that is measurable, definable and describable, such mystery may be uncomfortable. The handing over of personal roles and regimes is an area of interest in the death and dying field, that has not yet gained much momentum in the health and illness sector. Concerns relating to the language used, such as *giving up*, with its connotations of *giving in* influence attitudes, with the moral imperative to *fight cancer*. Enduring work affirms that handing over is an issue of enormous pragmatic concern to patients and kin.

Enduring work makes clear that the increasing chronicity of cancer will ensure that questions of suffering, handing over, and the well-being of caregivers during terminal illness will remain as significant issues. Some of these areas have been avoided in the past, but the moral imperative of the new burden placed by longer survival times for cancer patients demands that further attention is paid to them. Studies such as those of Ellingson and Fuller (1998) arguing that both caregivers and patients have legitimate needs, and of Brown and Stetz (1999) examining the labor of caregiving, confirm the importance of the moral and practical issues of kin caring. The implications for practitioners are that they

must be alert to this concern, open to change and keep up to date with both research and social policy which directly affects kin caregiving.

Research involving vulnerable participants such as patients with life-threatening illness is always morally and practically challenging, but is more and more open to discussion and to being carried out. Increasing openness to debate the concerns is shown in Spiers (2000) study which looks at risk and experience in relation to such studies, arguing that the individual research participant may not define himself as vulnerable in the same way as approving bodies. Enduring work confirms patient willingness to contribute to wider understanding by offering their experience, and encourages approving bodies to support such studies. Similarly Morse (2000b) argues that ethical concerns in researching vulnerable persons can and should be worked through so that useful research can be carried out. The implications are that research should be well planned and safely done, and that it is worthy of support. The present study received support at all stages, notwithstanding early anxiety from the university's Human Ethics Committee.

New challenges from enduring work

Outcomes from enduring work that contain revitalised ideas are those of negotiating for support and readiness for change. Negotiating for support is suggested as part of the purpose of patient narratives, and, as discussed above, is an area for research. However, the notion that the patient has a need, expresses it clearly and assistance is provided, or that the health professional knows what the patient and kin will need and fills the need, must be re-examined. Implications for practice are many, and include first that existing assumptions are put aside. The question of deservingness, not merely a moral question, but one on which the patient bases his right to invite, request or demand support, needs both recognition and research. The practitioner also needs to recognise that the kin may not always provide the support that the patient needs and that the practitioner believes is being provided.

The notion of readiness for change as an open attitude of the patient, in contrast to the traditional view of working toward closure, seems to be a fresh way of understanding living to death. Presenting this idea as interim research findings during the interpretation phase of the study elicited a positive response from

practitioners, who confirmed that such a positive position was a better reflection of their patients' reality. It is likely that the longer chronic period of the cancer experience has contributed to such an outlook on the part of the patients. However, Ivan's time from diagnosis to death was short, and he was always ready for change. It is possible that what is real for the patients is that their lives are both shortened - and therefore more precious - and the same length as they always were - all the time left. What this means for practitioners, particularly volunteers, and for kin is profound. It suggests that if caregivers are working toward closure and the patient is working toward possibilities, a disjunction may develop. In discussing this emerging understanding with practitioners, they confirmed that the disjunction could be present and were interested in assessing whether understanding readiness for change would ease the situation. They found that re-framing the kin expectations in this way reduced their anxiety and eased tension for both patient and kin. Understanding the possibility of the presence of readiness for change has implications for the practice of both volunteer groups and general practitioner who work with terminally ill people. For hospice workers, whether in community or institution readiness for change could assist them in fostering hope without the common attendant anxiety that hope is unrealistic.

Implications of this study, in summary are:

- that the trends of patient-centred care are confirmed and encouraged. These should include creating space for the patient voice and avoiding the use of models as normative guides for patient's lives;
- that the difficult areas of suffering, handing over and the construction of post-death identity need exploration;
- that examining hope through the lens of readiness for change could positively influence practice;
- that questioning moral and practical understanding around the provision of support are issues for nurses and others to incorporate into practice.

The final word

This study began with the hope of understanding more about the experience of living with terminal illness through the eyes of patient, kin and nurse. The patient experience emerges as the key narrative, with the accounts of kin and nurse complementing and at times challenging the primary narrative. As the narratives are examined in transcript, through voice and in memory the patient experience shapes into three broad areas: fateful moments, living in suspended time, and handing over. However, these areas, and the items discussed in their fields, are artificially restricted. The reality is that apart from diagnosis and death, everything in between is individual to the patient and his life. For example, issues about body and personal identity are more and less important to various individuals, and more prominent at different times. Experiences with morphine are equally variable, though there were commonalities among two or three patients. Nevertheless there are things that can be summarised with confidence.

Being diagnosed with a life-threatening, certainly terminal illness and living toward death is immensely different from imagining, speculating or theorising about it. While this may seem self-evident, it should actually cause re-examination of existing interpretations that are written by not-living toward death persons. It seems that while the descriptions may not be entirely wrong they lack the authority of the engaged position.

Beginning morphine is a very significant event, with several concerns, and, like living toward death, our present understandings appear inadequate when measured against the patient experience.

Living toward death is active and on-going work, mostly difficult, for the patient. It must be undertaken in the way it presents and cannot be delayed or delegated.

The lasting impression from the experiences of the patient, and to a lesser extent, the kin and nurse is that of enduring. They must endure the experience and all the facets of it, the suffering, indignities and uncertainties. Enduring is both coping with negative events and living through them. The patient also seems to work on a sense of enduring that will continue through death.

The patient was steadfast in his enduring. Though he had no choice he still endured, got along with it, and persisted through the tribulations of his illness experience, displaying a kind of every-day courage that was more prosaic than heroic. In a sense this active work kept him in the world, compared with a more passive attitude which might have seen him as a bystander to his own life. It was by enduring that confidence in enduring grew further, and existential questions began to lose their urgency.

The ending

The end of the process is that there both is and is not an ending. This study has ended, and the patients lives have ended. The kin's temporal, visible, or physical relationships with the patients have ended. Yet the patients are still real in the lives of their kin and in the text of the study. They endure. The questions that arose from the study endure, though they too, will lapse. If the questions influence practice, research or knowledge then they will endure in new ways.

Had we lived, I should have had a tale to tell of the hardihood, endurance and courage of my companions which would have stirred the heart of every Englishman. These rough notes and our dead bodies must tell the tale.

Robert Falcon Scott, 1913
(Huxley, 1977, p. 256)

Though the patients are dead, their stories live: this is the tale of their enduring.

Appendix A

Key to transcriptions

<i>italic script, indented</i>	participant transcripts
bracketed words in transcripts (<i>what was this like?</i>)	interviewer's comment or question
(. . .)	data omitted
. . .	pause in conversation
A1 p3	people from set 'A', first interview, third page
<i>bracketed words within a participant transcript e.g. You (I) will get weaker. You (I) won't be able to do so much.</i>	words added to provide clarification



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Appendix B

INFORMATION SHEET

STUDY: AN EXPLORATION OF THE LIVED EXPERIENCE OF TERMINAL ILLNESS FROM THE PERSPECTIVE OF THE PATIENT, FAMILY CARE GIVER AND PALLIATIVE CARE NURSE

GENERAL INFORMATION

Researcher

This research is being carried out by Elizabeth Niven, a registered nurse who is a doctoral student in the Department of Nursing and Midwifery at Massey University.

Elizabeth can be contacted during work hours at 09-815 4321 extension 8320

Supervision

Supervising this thesis work is Dr Judith Christensen, senior lecturer, Department of Nursing and Midwifery, Massey University, who may be contacted during work hours at Massey University, Palmerston North. To call Massey University from Auckland, please call the Albany campus, 09-443-9700 and request the tie-line to Palmerston North.

The study

The study looks at the actual experience of the patient, someone who is closely sharing the illness experience, and the input of a specialist nurse providing care. Much research in the past has evaluated the patient's experience by interviewing the health professionals involved and observing the patient. In this type of research it is seen as more important to study the illness experience by starting with what the *patient* actually lives through, feels and experiences. The research plans to build up a picture of what it is really like to be coping with an illness which is usually terminal.

Four 'sets' of people will be interviewed; each set consisting of patient, family care giver and palliative care nurse.

TAKING PART IN THE STUDY

Involvement from participants

Those who agree to take part in the study become participants. If you become a participant, the involvement from you will be as follows. I would like to interview participants four times. The first will be a brief interview to explain the purpose more fully, answer any questions and establish informed consent. The second interview will be about an hour and will be a discussion of what it is like to have this illness, cope with the changes it brings and how the work of the nurse specialist has influenced the experience. I would like to audio tape this and the following interview. The third interview will take up to an hour and will be a chance to contribute reflections prompted by the second interview; to update on life events; and to comment on the transcript of the previous interview. At the fourth interview you will have a further chance to comment on the printed record of the interviews and make any changes that are needed. If you are the close family member who agrees to be interviewed you will also have four similar interviews.

Time involved

Time involved is likely to be 15 minutes at the first interview; about 60 minutes at the second and third interviews; and about 20 minutes at the third interview.

Issues related to participating

You will receive no benefit from taking part in the study. The researcher is an experienced registered nurse who will not proceed with the study if you become tired or otherwise less able to continue. The researcher will ensure that willing consent continues at each interview.

Participant's Rights

If you take part in the study you have the right to:

- * refuse to answer any particular question, and to withdraw from the study at any time up to completion of data collection and analysis.
- * participate in the interview at times, and for periods of time, most comfortable to you
- * choose who will be present at the interview
- * ask that any part of the interview is not audio taped, or any or all sections be deleted from the tape
- * ask any questions about the study that occur to you during your participation
- * provide information on the understanding that it is completely confidential to the researcher. All information is collected anonymously, and it will not be possible to identify you in any reports that are prepared from the study unless you give express permission
- * participate in a discussion of emerging findings
- * be given access to a summary of the findings from the study when it is concluded

Patient Advocate Services

If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, PO Box 9983, Newmarket, Auckland, phone 09-638 9638

Use of information from the study

Information collected in the study will contribute towards the doctoral thesis of the researcher. Data will be stored in sets linked by codes, without using real names. Pseudonyms will be used in the final text, and in any reports. Transcription from audio tapes will be done by the researcher and all tapes, disks and transcriptions will be safely stored until no longer needed, when they will be destroyed.

Further questions

Please contact the researcher if you would like to know anything further about this study.

Appendix C.



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CONSENT FORM

STUDY: AN EXPLORATION OF THE LIVED EXPERIENCE OF TERMINAL ILLNESS FROM THE PERSPECTIVE OF THE PATIENT, FAMILY CARE GIVER AND PALLIATIVE CARE NURSE

I have read the Information Sheet for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I am free to withdraw from the study at any time up to the completion of the study, or to decline to answer any particular questions in the study. I agree to provide information to the researchers on the understanding that it is completely confidential.

I have been given a copy of the Information Sheet and this Consent Form to keep.

I wish to participate in the study under the conditions set out on the Information Sheet.

Signed: _____

Name: _____

Date: _____

References

- Abrams, M. H. (1981). *A glossary of literary terms*. (4th ed.). New York: Holt, Rinehart and Winston.
- Albom, M. (1997). *Tuesdays with Morrie*. New York: Doubleday.
- Allen, D. (1996). Hermeneutics: philosophical traditions and nursing practice research. *Nursing Science Quarterly*, 8, 174-182.
- Aranda, S. (1998). Palliative care principles: masking the complexity of practice. In J. Parker & S. Aranda (Eds.), *Palliative care: explorations and challenges* (pp. 21 - 31). Sydney: MacLennan and Petty.
- Aranda, S., & Kelso, J. (1998). The nurse as coach in care of the dying. *Contemporary Nurse*, 6(3/4), 117 - 122.
- Arend, A. v. d. (1997). Nurses' participation at the end-stage of life. In C. S. Fry (Ed.), *Quadrennial International Council of Nurses' Conference*. Vancouver, Canada: International Council of Nurses.
- Aries, P. (1974). *Western attitudes toward death from the middle ages to the present* (Patricia M Ranum, Trans.). London: Marion Boyars.
- Ashby, M. (1998). Palliative care as a medical specialty. In J. Parker & S. Aranda (Eds.), *Palliative care: explorations and challenges* (pp. 46 - 55). Sydney: MacLennan and Petty.
- Baker, C., & Diekelmann, N. (1994). Connecting conversations of caring: recalling the narrative to clinical practice. *Nursing Outlook*, 42, 65 - 70.
- Basile, C. M. (1997). Advance directives and advocacy in end-of-life decisions. *Nurse Practitioner: American Journal of Primary Health Care*, 23(5), 44 - 46.
- Becker, R. (1999). Teaching communication with the dying across cultural boundaries. *British Journal of Nursing*, 8(14), 938 - 942.

- Behi, R. (1997). Ethical issues in spiritual care: *Quadrennial International Council of Nurses' Conference*. Vancouver, Canada: International Council of Nurses.
- Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing Practice*. Menlo Park, Ca: Addison-Wesley.
- Benner, P. (Ed.). (1994). *Interpretive Phenomenology*. Thousand Oaks: Sage.
- Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness*. Menlo Park, Ca: Addison-Wesley.
- Benoliel, J. Q. (1994). Death and dying as a field of enquiry. In I. D. Corless, B. B. Germino & M. Pitman (Eds.) *Death, dying and bereavement* (pp. 3 - 13). Boston: Jones and Bartlett
- Benzein, E., Norberg, A., & Saveman, B.-I. (1998). Hope: future imagined reality. The meaning of hope as described by a group of healthy Pentecostals. *Journal of Advanced Nursing*, 28(5), 1063-1070.
- Berger, A. A. (1997). *Narratives in popular culture, media and everyday life*. Thousand Oaks: Sage.
- Berger, K. (1988). *The developing person through the life span*. (2nd ed.). New York: Worth.
- Berns, R., & Colvin, E. R. (1998). The final story: events at the bedside of dying patients as told by survivors. *American Nurses Association Journal*, 26(6), 583 - 587.
- Bill of Rights Act (1990) New Zealand Government.
- Bondi, R. (1999). Acquainted with death. *Christian Century*, 116(25), 906.
- Bottorff, J. L., Gogag, M., & Engelberg-Lotzkar, M. (1995). Comforting: exploring the work of cancer nurses. *Journal of Advanced Nursing*, 22, 1077 - 1084.
- Bottorff, J. L., Steele, R., Davis, B., Garossino, C., Porterfield, P., & Shaw, M. (1998). Striving for balance: Palliative care patients's experiences of making everyday choices. *Journal of Palliative Care*, 14(1), 7-17.

- Boyle, D. M. (1997). Cultural awareness: The cultural context of dying from cancer. *International Journal of Palliative Nursing*, 4(2), 70-83.
- Bradbury, M. (1999). *Representations of death*. London: Routledge.
- Brenneis, D. (1996). Telling troubles: narrative, conflict and experience. In C. L. Briggs (Ed.), *Disorderly discourse: Narrative, conflict and inequality* (pp. 41 - 52). New York: Oxford University Press.
- Brody, H. (1987). *Stories of sickness*. New Haven: Yale University Press.
- Brooker, S. (2000). God is no divine sadist! *The Anglican*, September 6.
- Broom, B. (1997). *Somatic illness and the patient's other story*. Bristol: Free Association Press.
- Brown, M.-A., & Stetz, K. (1999). The labor of caregiving: A theoretical model of caregiving during potentially fatal illness. *Qualitative Health Research*, 9(2), 182- 198.
- Buckman, R. (1993). Communication in palliative care: a practical guide. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (pp. 47 - 61). Oxford: Oxford Medical Publications.
- Callahan, D. (1993). *The troubled dream of life: Living with mortality*. New York: Simon & Schuster.
- Campbell, K. (1984). *Body and mind*. (2nd ed.). Notre Dame: University of Notre Dame Press.
- Cardy, G. (1997). The beauty of living. *The Announcer*, May 1-2.
- Carson, M. G., & Mitchell, G. J. (1998). The experience of living with persistent pain. *Journal of Advanced Nursing*, 28(6), 1242-1248.
- Cassidy, S. (1994). *Light from the dark valley*. London: Darton-Longman & Todd.
- Charmaz, K. (1999). Stories of suffering: subjective tales and research narratives. *Qualitative Health Research*, 9(3), 362-383.

- Christensen, J. (1990). *Nursing partnership: a model for nursing practice*. Wellington: Daphne Brasell Associates.
- Clandinin, D. J., & Connelly, F. M. (1995). Personal experience methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 413-428). Thousand Oaks: Sage.
- Clark, D. (1993). *The sociology of death*. Oxford: Blackwell
- Cohen, M. Z. (1987). A historical overview of the phenomenological movement. *Image*, 19(1), 31 - 34.
- Cole, S. (1979). *The sociological orientation*. Chicago: Rand McNally.
- Copp, G. (1998). A review of current theories of death and dying. *Journal of Advanced Nursing*, 28(2), 382 - 390.
- Corless, I., Germino, B., & Pittman, M. (Eds.). (1994). *Dying, death, and bereavement: Theoretical perspectives and other ways of knowing*. Boston: Jones and Bartlett.
- Corr, C. A. (1992). A task-based approach to coping with dying. *Omega*, 24(2), 81-94.
- Coward, D. D. (1997). Constructing meaning from the experience of cancer. *Seminars in Oncology Nursing*, 13(4), 248 -251.
- Cowles, K. V., & Rodgers, B. L. (1991). The concept of grief: a foundation for nursing research and practice. *Research in Nursing and Health*, 14, 119-127.
- Croatto, J. S. (1984). *Biblical hermeneutics* (Robert R Barr (1987), Trans.). Maryknoll, NY: Orbis Books.
- Crotty, M. (1996). *Phenomenology and nursing research*. Melbourne: Churchill Livingstone.
- Crotty, M. (1998). *The foundations of social research*. Sydney: Allen and Unwin.
- Crowell, S. G. (1997). Neighbours in death. *Research in phenomenology*, 27, 208-224.

- Culbertson, P. (2000). *Caring for God's people*. Minneapolis: Fortress Press.
- Cutcliffe, J. R., & McKenna, H. P. (1999). Establishing the credibility of qualitative research findings: the plot thickens. *Journal of Advanced Nursing*, 30(2), 374-380.
- Daly, J. (1995). The lived experience of suffering. In R. Parse (Ed.), *Illuminations: The Human Becoming Theory in Practice and Research* (pp. 45 - 60). New York: National League for Nursing.
- Davis, B. D., Cowley, S. A., & Ryland, R. K. (1996). The effects of terminal illness of patients and their carers. *Journal of Advanced Nursing*, 23, 512 - 520.
- Davis, P. (1982). Health and health care. In P. Spoonley, D. Pearson, & I. Shirley (Eds.), *New Zealand: Sociological Perspectives* (pp. 119 - 142). Palmerston North: Dunmore Press.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (1995). *Handbook of qualitative research*. Thousand Oaks: Sage.
- Dickinson, E. (1970). *The complete poems*. Boston: Faber and Faber.
- Diekelmann, N. (1983). Behavioral pedagogy: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in baccalaureate nursing education. *Journal of Nursing Education*, 32(6), 245-252.
- Diekelmann, N. (1992). Learning-as-testing: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in nursing. *Advances in Nursing Science*, 14(3), 72-83.
- Dilthey, W. (1961). *Meaning in history: W Dilthey's thoughts on history and society* (P Rickman, Trans.). London: George Allen & Unwin.
- Dirksen, S. R. (1995). Search for meaning in long-term cancer survivors. *Journal of Advanced Nursing*, 21, 628 - 633.
- Dluhy, N. M. (1995). Mapping knowledge in chronic illness. *Journal of Advanced Nursing*, 21, 1051-1058.
- Donne, J. (1959). *Devotions*. Ann Arbor: University of Michigan Press.

- Douville, L. M. (1994). The power of hope. *American Journal of Nursing*, December, 34-36.
- Dunker, P., & Wilson, V. (Eds.). (1996). *Cancer through the eyes of ten women*. London: HarperCollins.
- Dunlop, R. (1998). *Cancer: Palliative care*. London: Springer-Verlag.
- Dunniece, U., & Slevin, E. (2000). Nurses' experiences of being present with a patient receiving a diagnosis of cancer. *Journal of Advanced Nursing*, 32(3), 611-618.
- Edwards, J. N., Herman, J., Wallace, B. K., Pavy, M. D., & Harrison-Pavy, J. (1991). Comparison of patient-controlled and nurse-controlled antiemetic therapy in patients receiving chemotherapy. *Research in Nursing and Health*, 14, 249-257.
- Eifried, S. (1998). Helping patients find meaning: a caring response to suffering. *International Journal for Human Caring*, 2(1), 33-39.
- Eliot, T. S. (1938). *Murder in the cathedral*. London: Faber and Faber.
- Eliot, T. S. (1944). *Four quartets*. London: Faber and Faber.
- Ellingson, S., & Fuller, J. D. (1998). A good death? Finding a balance between interests of patients and caregivers. *Generations*, 22(3), 87-92.
- Erikson, E. H. (1963). *Childhood and society*. New York: Norton.
- Exley, C. (1999). Testaments and memories: negotiating after-death identities. *Mortality*, 4(3), 249-268.
- Fagerstrom, L., Eriksson, K., & Engberg, I. B. (1998). The patient's perceived caring needs as a message of suffering. *Journal of Advanced Nursing*, 28(5), 978-987.
- Fielding, H. (1987). *Amelia*. New York: Penguin.
- Foucault, M. (1973). *The order of things: An archaeology of the human sciences*. New York: Vintage.

- French, M. (1998). *A Season in hell*. New York: Alfred A Knopf.
- Fridfrinnsdottir, E. (1997). *Quality of life: the lived experience of women living with cancer*. Paper presented at the Nursing at the threshold of the 21st century: connecting conversations of nursing practice, Palmerston North, NZ.
- Friedman, M. M. (1981). *Family nursing: theory and assessment*. Norwalk, Conn: Appleton-Century-Crofts.
- Gadamer, H.-G. (1994). Truth in the human sciences. In B. R. Wachterhauser (Ed.), *Hermeneutics and Truth* (pp. 25 - 32). Evanston, Illinois: Northwestern University Press.
- Geanellos, R. (1998a). Hermeneutic philosophy. Part 1: implications of its use as a methodology in interpretive nursing research. *Nursing Inquiry*, 5, 154-163.
- Geanellos, R. (1998b). Hermeneutic philosophy. Part 11: a nursing research example of the hermeneutic imperative to address forestructures/pre-understandings. *Nursing Inquiry*, 5, 238-247.
- Giddens, A. (1979). *Central problems in social theory*. Berkeley, California: University of California.
- Giddens, A. (1991). *Modernity and self-identity*. Cambridge: Polity Press.
- Gilligan, C. (1982). *In a different voice*. Cambridge, Mass: Harvard University Press.
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. New York: Aldine Publishing.
- Glaser, B. G., & Strauss, A. L. (1968). *Time for dying*. New York: Aldine Publishing.
- Goffman, E. (1959). *The presentation of self in everyday life*. London: Penguin.
- Gorer, G. (1955/1965). The pornography of death. In G. Gorer (Ed.), *Death, grief and mourning in contemporary Britain*. London: Cresset.

- Gregory, D. M. (1994). *Narratives of suffering in the cancer experience*. Unpublished PhD, The University of Arizona, Arizona.
- Gubrium, J. F., & Holstein, J. A. (1998). Narrative practice and the coherence of personal stories. *Sociological Quarterly*, 39(1), 163-188.
- Haddock, J. (1996). Towards further clarification of the concept 'dignity'. *Journal of Advanced Nursing*, 24, 924 - 931.
- Hallam, E., Hockey, J., & Howarth, G. (1999). *Beyond the body: death and social identity*. London: Routledge.
- Hanks, P. (Ed.). (1990). *Collins concise dictionary plus*. London: Collins.
- Harden, J. (2000). Language, discourse and the chronotype: applying literary theory to the narratives in health care. *Journal of Advanced Nursing*, 31(3), 506-512.
- Harvey, J. H. (1996). *Embracing their memory: Loss and the social psychology of storytelling*. Needham Heights, MA: Allyn & Bacon.
- Health and Disability Commissioner Act (1994) New Zealand Government.
- Hegedus, K. S. (1999). Providers' and consumer's perspective of nurses' caring behaviours. *Journal of Advanced Nursing*, 30(5), 1090 - 1096.
- Heidegger, M. (1962). *Being and time* (John Macquarrie & Edward Robinson, Trans.). Oxford: Blackwell.
- Henderson, V. (1966). *The nature of nursing: a definition and its implications for practice, research, and education*. New York: Macmillan.
- Holmes, C. (1996). The politics of phenomenological concepts in nursing. *Journal of Advanced Nursing*, 24, 579-587.
- Holmes, H. B., & Purdy, L. M. (Eds.). (1992). *Feminist perspectives in medical ethics*. Bloomington: Indiana University Press.
- Holmes, P. (2000). Paul Holmes talks about his cancer. *New Zealand Woman's Day, March*.

- Hosking, M. (2000). *Fighting spirit*. TV One. New Zealand.
- Howarth, G., & Jupp, P. C. (Eds.). (1996). *Contemporary issues in the sociology of death, dying and disposal*. New York: St Martin's Press.
- Hoy, D. C. (1993). Heidegger and the hermeneutic turn. In C. B. Guignon (Ed.), *The Cambridge companion to Heidegger* (pp. 170 - 194). Cambridge: Cambridge University Press.
- Hudson, R., & Richmond, J. (1994). *Unique and ordinary*. Melbourne: Ausmed.
- Husserl, E. (1973). *Cartesian meditations* (Dorion Cairns, Trans.). The Hague: Martinus Nijhoff.
- Huxley, E. (1977). *Scott of the Antarctic*. London: Weidenfeld and Nicolson.
- Irvine, B. (1993). Developments in palliative nursing in and out of the hospital setting. *British Journal of Nursing*, 2(4), 218-224.
- Jacob, S. R. (1993). An analysis of the concept of grief. *Journal of Advanced Nursing*, 18, 1787 - 1794.
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243-248.
- Johnston, M. (2000a, Thursday, September 28). Doctor 'put too much faith in ultrasound'. *The New Zealand Herald*, p. A5.
- Johnston, M. (2000b, 31 July). Nutritionists challenge writer's anti-dairy line. *The New Zealand Herald*, p. 11.
- Jones, A. (1998). 'The awful rowing toward God!': therapeutic conversations with a woman following major surgery. *Journal of Advanced Nursing*, 28(6), 1195-1198.
- Jones, A. (1999). 'A heavy and blessed experience!': a psycho-analytic study of community Macmillan nurses and their roles in serious illness and palliative care. *Journal of Advanced Nursing*, 30(6), 1297-1303.

- Jung, C. G. (1961). *Memories, dreams, reflections* (Richard Winston & Clara Winston, Trans.). New York: Random House.
- Kalish, R. A. (1979). *Death, dying, transcending*. New York: Baywood.
- Kanitsaki, O. (1998). Palliative care and cultural diversity. In J. Parker & S. Aranda (Eds.), *Palliative Care: Explorations and Challenges* (pp. 32 - 45). Sydney: MacLennan and Petty.
- Kearney, M. (1996). *Mortally Wounded*. New York: Touchstone.
- Keats, J. (1991). *Lyric poems*. New York: Dover.
- Keizer, B. (1996). *Dancing with Mister D*. London: Doubleday.
- Killilea, A. G. (1988). *The politics of being mortal*. Lexington: University of Kentucky Press.
- Kittel, G., Friedrich, G., (Eds.) (trans. G. W. Bromiley), (1985). *Theological dictionary of the New Testament*. Grand Rapids, Michigan: William B Eerdmans.
- Knepfer, G. (1994). Palliative salvation. *Australian Nursing Journal*, 2(3), 24-25.
- Kolf, J. C. (1999). *Comfort and care in a final illness*. Tuscon, Az: Fisher.
- Kübler-Ross, E. (1969). *On death and dying*. New York: Collier.
- Kylma, J., & Vehvilainen-Julkunen, K. (1997). Hope in nursing research: a meta-analysis of the ontological and epistemological foundations of research on hope. *Journal of Advanced Nursing*, 25, 364 - 371.
- Lawler, J. (1991). *Behind the screens*. Melbourne: Churchill Livingstone.
- Lawler, J. (1998). Phenomenologies as research methodologies for nursing: From philosophy to researching practice. *Nursing Inquiry*, 5, 104-111.
- Lewis, C. S. (1940). *The problem of pain*. Glasgow: Collins.
- Lewis, C. S. (1976). *A grief observed*. San Francisco: Harper.

- Lingus, A. (1998). Fateful images. *Research in Phenomenology*, 28, 55-72.
- MacLeod, R., & Carter, H. (1999). Health professionals' perception of hope: understanding its significance in the care of people who are dying. *Mortality*, 4(3), 309-318.
- Macquarrie, J. (1955). *An existentialist theology*. London: SCM Press.
- Macrone, M. (1995). *A little knowledge*. London: Pavillion Books.
- Madden, E. (1993). *Carpe Diem: enjoying every day with a terminal illness*. Boston: Jones and Bartlett.
- Madjar, I., & Walton, J. A. (Eds.). (1999). *Nursing and the experience of illness*. St Leonards, NSW: Allen & Unwin.
- Manias, E. (1998). The interface of palliative care and technology in critical care. In J. M. Parker & S. Aranda (Eds.), *Palliative care: explorations and challenges* (pp. 238 - 249). Sydney: MacLennan & Petty.
- Manning, P. K., & Cullum-Swan, B. (1995). Narrative, content, and semiotic analysis. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 463 - 477). Thousand Oaks: Sage.
- May, C. (1995). "To call it work somehow demeans it": the social construction of talk in the care of terminally ill patients. *Journal of Advanced Nursing*, 22, 556 - 561.
- May, K. A. (1991). Interview techniques in qualitative research: concerns and challenges. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 188 -201). Newbury Park: Sage.
- McCaffery, M., & Ferrell, B. R. (1996). Correcting misconceptions about pain assessment and use of opioid analgesics: educational strategies aimed at public concerns. *Nursing Outlook*, 44(4), 184-190.
- McCorkle, R., Robinson, L., Nuamah, I., Lev, E., & Benoliel, J. Q. (1998). The effects of home nursing care for patients during terminal illness on the bereaved's psychological distress. *Nursing Research*, 47(1), 2 - 10.

- McHugh, P. R. (1999). Dying made easy. *Commentary*, 107(2), 13-18.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis*. (second ed.). Thousand Oaks: Sage.
- Molen, B. van der (1995). Dyspnoea: a study of measurement instruments for the assessment of dyspnoea and their application for patients with advanced cancer. *Journal of Advanced Nursing*, 22, 948-956.
- Monk, G., Winslade, J., Crocket, K., & Epston, D. (Eds.). (1997). *Narrative therapy in practice*. San Francisco: Jossey-Bass.
- Morse, J. M. (1989). Strategies for sampling. In J. M. Morse (Ed.), *Qualitative nursing research* (pp. 127 - 145). Newbury Park: Sage.
- Morse, J. M. (2000a). Denial is not a qualitative concept. *Qualitative Health Research*, 10(2), 147-149.
- Morse, J. M. (2000b). Researching illness and injury: methodological considerations. *Qualitative Health Research*, 10(4), 538-547.
- Morse, J. M., Bottorff, J. L., & Hutchinson, S. (1994). The phenomenology of comfort. *Journal of Advanced Nursing*, 20, 189-195.
- Morse, J. M., & Carter, B. J. (1995). Strategies of enduring and the suffering of loss: modes of comfort used by a resilient survivor. *Holistic Nursing Practice*, 9(3), 38-52.
- Morse, J. M., & Proctor, A. (1998). Maintaining patient endurance. *Clinical Nursing Research*, 7(3), 250 - 275.
- Moules, N. J., & Streitberger, S. (1997). Stories of suffering, stories of strength. *Journal of Family Nursing*, 3(4), 365-378.
- Munro, J. (1996). *The story of Suzanne Aubert*. Auckland: Auckland University Press.
- Muzzin, L. J., Anderson, N. J., Figueredo, A. T., & Gudelis, S. O. (1994). The experience of cancer. *Social Science and Medicine*, 38(9), 1201-1208.

- Narayanasamy, A. (1996). Spiritual care of chronically ill patients. *British Journal of Nursing*, 5(7), 411-416.
- Neill, M. (1997). *Issues of death: mortality and identity in English Renaissance Tragedy*. Oxford: Clarendon Press.
- Neimeyer, R. A., & Brunt, D. v. (1995). Death anxiety. In H. Wass & R. A. Neimeyer (Eds.), *Dying: facing the facts* (pp. 49 - 82). Washington: Taylor and Francis.
- Netherlands, Department of Population (2000). *Population, Stock and Flow*. The Hague: Netherlands Government.
- New Zealand, Department of Statistics (2000). *Mortality figures*. www.govt.nz.
- Nichols, J. (1999, 27/28 August). *Standing at the crossroads*. Paper presented at the Haematology/Oncology Nurses Conference, Waikato, New Zealand.
- Niven, E. (1996). *The ethics of qualitative research*. Paper presented at the Bioethics Summer Seminar, Dunedin.
- Nuland, S. B. (1993). *How we die*. London: Chatto and Windus.
- N.Z.N.O. (1995). *Code of Ethics*. Wellington: New Zealand Nurses' Organisation.
- NZPA. (2000, Friday, September 29). Medical review aims to win back patient trust. *The New Zealand Herald*, p. A5.
- Ogden, J. (1994). Voluntary benefits. *Nursing Times*, 90(25), 64-68.
- Panek-Hudson, Y. (1998). From cure to palliation in a bone marrow transplant unit. In J. Parker & S. Aranda (Eds.), *Palliative care: explorations and challenges* (pp. 250 - 258). Sydney: MacLennan and Petty.
- Parker, J., & Aranda, S. (Eds.). (1998). *Palliative care: explorations and challenges*. Sydney: MacLennan and Petty.
- Parkes, C. M., Laungani, P., & Young, B. (Eds.). (1997). *Death and bereavement across cultures*. London: Routledge.

- Paterson, R. A., Rees, N. W., Czarniak, P. A., Reiss, B. S., & Evans, M. E. (1993). *Pharmacological aspects of nursing care in Australia*. Melbourne: Nelson.
- Pattison, E. M. (1977). *The experience of dying*. New York: Simon and Schuster.
- Pearce, S., & Richardson, A. (1994). Fatigue and cancer: a phenomenological study. *Journal of Clinical Nursing*, 3, 381-382.
- Pears, D. (1971). *Wittgenstein*. London: Fontana Collins.
- Peck, M. S. (1997). *Denial of the soul*. London: Simon & Schuster.
- Pellino, T. A., & Ward, S. E. (1998). Perceived control mediates the relationship between pain severity and patient satisfaction. *Journal of Pain Symptom Management*, 15(2), 110-116.
- Pierce, S. F. (1999). Improving end-of-life care: gathering suggestions from family members. *Nursing-Forum*, 34(2), 5 - 14.
- Pitkeathley, J. (1989). *It's my duty, isn't it?* Trowbridge, Wiltshire: Souvenir Press.
- Pollock, S. E., & Sands, D. (1997). Adaptation to suffering. *Clinical Nursing Research*, 6(2), 171-186.
- Purdy, L. M. (1992). A call to heal ethics. In H. B. Holmes & L. M. Purdy (Eds.), *Feminist Perspectives in medical ethics* (pp. 9 - 13). Bloomington: Indiana University Press.
- Quint, J. (1967). *The nurse and the dying patient*. New York: MacMillan.
- Rasmussen, B. H., & Sandman, P. O. (1998). How patients spend their time in a hospice and in an oncological unit. *Journal of Advanced Nursing*, 28(4), 818 - 828.
- Reynolds, W., Scott, P. A., & Austin, W. (2000). Nursing, empathy and perception of the moral. *Journal of Advanced Nursing*, 32(1), 235-242.
- Richardson, L. (1990). Narrative and sociology. *Journal of Contemporary Ethnography*, 19, 116-135.

- Robinson, K., & Austin, J. K. (1998). Wife caregivers' and supportive others' perceptions of the caregivers' health and social support. *Research in Nursing, 21*, 51 - 57.
- Rogers, J., & Niven, E. (1996). *Ethics: a guide for New Zealand nurses*. Auckland: Addison Wesley Longman.
- Rorty, R. (1989). *Contingency, irony and solidarity*. Cambridge: Cambridge University Press.
- Russell, B. (1998). *The problems of philosophy*. (2nd ed.). Oxford: Oxford University Press.
- Sacks, O. (1984). *A Leg to stand on*. London: Picador.
- Sakalys, J. A. (2000). The political role of illness narratives. *Journal of Advanced Nursing, 31*(6), 1469-1475.
- Samarel, N. (1991). *Caring for life and death*. New York: Hemisphere.
- Samarel, N. (1995). The dying process. In H. Wass & R. A. Neimeyer (Eds.), *Dying: Facing the Facts* (pp. 89 - 116). Washington, DC: Taylor and Francis.
- Sampson, E. E. (1989). The deconstruction of self. In J. Shotter & K. J. Gergen (Eds.), *Texts of identity* (pp. 1 - 19). London: Sage.
- Sandelowski, M. (1999). Time and qualitative research. *Research in Nursing and Health, 22*, 79-87.
- Sandelowski, M. J. (1996). Truth/story telling in nursing inquiry. In J. F. Kikuchi, H. Simmons, & D. Romyn (Eds.), *Truth in Nursing Inquiry*. Thousand Oaks: Sage.
- Sartre, J-P. (1956). *Being and nothingness*. New York: Simon and Schuster.
- Schmidt, D. J. (1997). What we owe the dead. *Research in Phenomenology, 27*, 190-199.

- Schumacher, K. L. (1996). Reconceptualizing family caregiving: family-based illness care during chemotherapy. *Research in Nursing and Health*, 19, 261 - 271.
- Schwartz, M. (1996). *Letting go: Reflections on living while dying*. London: Pan.
- Seale, C. (1998). *Constructing death: The sociology of dying and bereavement*. Cambridge: Cambridge University Press.
- Secomb, L. (1999). Philosophical deaths and feminine finitude. *Mortality*, 4(2), 111- 122.
- Sheehy, G. (1995). *New passages*. New York: Random House.
- Sherson, S. (1998). The inevitability of death: some personal reflections. In J. Parker & S. Aranda (Eds.), *Palliative care: explorations and challenges* (pp. 139 - 147). Sydney: MacLennan & Petty.
- Sherwin, S. (1992). Feminist and medical ethics: two different approaches to contextual ethics. In H. B. Holmes & L. M. Purdy (Eds.), *Feminist perspectives in medical ethics* (pp. 17-31). Indianapolis: Indiana University Press.
- Sicola, V., & Hall, J. (1997). "I wouldn't want to live": the myth about attitudes of terminal patients. *Journal of Nursing Law*, 4(4), 31-43.
- Sitzia, J., & Wood, N. (1998). Patient satisfaction with cancer chemotherapy nursing: a review of the literature. *Nursing Studies*, 35, 1-12.
- Smith, A. (1995). An analysis of altruism: a concept of caring. *Journal of Advanced Nursing*, 22, 785 - 790.
- Smythe, E. (1998). *Being safe in childbirth: a hermeneutic interpretation of the narratives of women and practitioners*. Unpublished PhD, Massey University, Palmerston North.
- Snell, C. C., Fothergill-Bourbonnais, F., & Durocher-Hendriks, S. (1997). Patient controlled analgesia and intramuscular injections: a comparison of patient

- pain experiences and postoperative outcomes. *Journal of Advanced Nursing*, 25(4), 681-690.
- Spence, D. (1999). *Prejudice, paradox and possibility*. Unpublished PhD, Massey University, Palmerston North.
- Spiegelberg, H. (1994). *The phenomenological movement*. Dordrecht - Boston - London: Kluwer Academic Publishers.
- Spiers, J. (2000). New perspectives on vulnerability using emic and etic approaches. *Journal of Advanced Nursing*, 31(3), 715-721.
- Street, A. (1998). Competing discourses with/in palliative care. In J. Parker & S. Aranda (Eds.), *Palliative care: explorations and challenges* (pp. 68 - 81). Sydney: MacLennan and Petty.
- Streubert, H. J., & Carpenter, D. R. (1999). *Qualitative research in nursing: Advancing the humanistic imperative*. (second ed.). Philadelphia: Lippincott.
- Tarnas, R. (1991). *The passion of the western mind*. London: Pimlico.
- Telegraph. (2000, Monday, October 30, 2000). Near-death tales may point to independent life of 'soul'. *The New Zealand Herald*, pp. A11.
- Temmink, D., Francke, A. L., Hutten, J. B. F., Zee, J. van der, & Abu-Saad, H. H. (2000). Innovations in the nursing care of the chronically ill: a literature review from an international perspective. *Journal of Advanced Nursing*, 31(6), 1449-1458.
- Thomas, J., & Retsas, A. (1999). Transacting self-preservation: a grounded theory of the spiritual dimensions of people with terminal cancer. *International Journal of Nursing Studies*, 36, 191-201.
- Thorne, S. E. (1999). The science of meaning in chronic illness. *International Journal of Nursing Studies*, 36, 397-404.
- Tilley, S., Pollock, L., & Tait, L. (1999). Progress's pilgrim: a critical narrative of research in progress. *Journal of Advanced Nursing*, 29(5), 1221-1227.
- Tillich, P. (1952). *The courage to be*. New Haven: Yale University Press.

- Timms, S. M. (1999). The origins of St Joseph's Mercy hospice. *Newsletter*.
- Van Manen, M. (1990). *Researching lived experience*. New York: State University of New York.
- Van Manen, M. (1997). From meaning to method. *Qualitative Health Research*, 7(3), 345 - 369.
- Van Manen, M. (1998). Modalities of body experience in illness and health. *Qualitative Health Research*, 8(1), 7- 25.
- Van Tholen, J. (1999). Surprised by death. *Christianity today*, 24(19), 57-60.
- Walter, T. (1993). Modern death: taboo or not taboo. In D. Dickenson & M. Johnson (Eds.), *Death, Dying and Bereavement* (pp. 33 - 44). London: Sage.
- Walter, T. (1996). Facing death without tradition. In G. Howarth & P. C. Jupp (Eds.), *Contemporary issues in the sociology of death, dying and disposal* . New York: St Martin's Press.
- Warburg, T. L. (1988). *A voice at twilight*. London: Peter Owen Publishers.
- Ward, S. E., Berry, P. E., & Misiewicz, H. (1996). Concerns about analgesics among patients and family caregivers in a hospice setting. *Research in Nursing and Health*, 19, 205-211.
- Wass, H., & Neimeyer, R. A. (1995). *Dying: Facing the facts*. (Third ed.). Washington, DC: Taylor & Francis.
- Weenolsen, P. (1996). *The art of dying*. New York: W B Saunders.
- Wellard, S. (1998). Constructions of chronic illness. *International Journal of Nursing Studies*, 35, 49-55.
- Wenneberg, S., & Ahlström, G. (2000). Illness narratives of persons with post-polio syndrome. *Journal of Advanced Nursing*, 31(2), 354-361.
- Widera-Wysoczanska, A. (1999). Everyday awareness of death: a qualitative investigation. *Journal of Humanistic Psychology*, 39(3), 73-96.

- Wilkes, L. (1998). Reflection on the good death and the nurse in palliative care. In J. M. Parker & S. Aranda (Eds.), *Palliative Care: explorations and challenges* (pp. 115-125). Sydney: MacLenan & Petty.
- Williams, J. (1995). *Transcendence as a human response to life threatening illness: description and understanding through narratives*. Unpublished PhD, University of Rhode Island.
- Wilson, S. (1991). The unrelenting nightmare: husbands' experiences during their wives' chemotherapy. In J. M. Morse & J. L. Johnson (Eds.), *The illness experience: Dimensions of suffering* (pp. 237 - 314). Newbury Park: Sage.
- Wood, P. J. (1996). The sick child, humanitarian narratives and the getting of hospitals: an historical research brief. *Nursing Praxis in New Zealand*, 11(3), 50 - 54.
- Woodruff, R. (1999). *Palliative medicine*. (third ed.). Oxford: Oxford University Press.
- Yates, P., & Stetz, K. M. (1999). Families awareness of and response to dying. *Oncology Nursing Forum*, 26(1), 113 - 120.