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Facing uncertainty: The lived experience of palliative care

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ABSTRACT

Objective: This qualitative research study listens to the narratives of people experiencing the dying process who attended the Otago Community Hospice, Dunedin, New Zealand.

Methods: Ten people, aged between 51 and 65 years old, were approached; two declined and one died sooner than expected. All were women (although this was not part of the original design), and all had carcinoma. Data for the study were sought through qualitative research interviews, considering the development of each participant's illness in relation to her perception of her embodiment in the palliative care setting, and concluding with questions about what she wants the people who care for and about her to learn from her experience. Consistent with this phenomenological approach, the method of analysis was thematic and interpretive.

Results: The main theme was the uncertainty that all participants felt throughout the diagnostic process and during treatment. Uncertainty, too, was a factor in how they managed their day, whether they would be able to sustain an outing or an activity or not, and whether they would be pain free. None were afraid of dying but hoped that when they did die, they would do so comfortably. The relationship with their general practitioners varied. Where fatigue or the effects of medication were not an issue, they could think clearly, but their bodies were experienced as letting them down and limiting their activities. The ideal of "living until you die" was not able to be fulfilled. The increasing approach of social death as they withdrew from their employment and social responsibilities affected them.

Significance of results: Whether one has a "good death" or not is determined not only by the progression and management of the disease process by health professionals, but also by the way in which one is perceived, by self and others. There are no guidelines for the dying role; everybody dies differently and individually.

KEYWORDS: Uncertainty, Palliative, Embodiment, Death and dying

INTRODUCTION

The original concept for this research developed out of listening to the stories of people experiencing an *injured* body and thinking about the losses in physical and social functioning that the injured person endures. As the idea evolved, this research aimed to listen to the voices of people experiencing a *dying* body and hearing about the losses in physical and social functioning that that person experiences. People with injuries have the expectation of being able to be healed; the person becomes whole again and able to pursue the things in life that provide meaning and purpose. People who are dying find that the process of becoming whole again means adapting to a new way of living in a world where health and wellness are celebrated, and death and dying hidden.

Illness has been defined in social science as "a state of disturbance in the 'normal' functioning of

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the total human individual, including both the state of the organism as a biological system, and of his personal and social adjustments. It is thus partly biologically and partly socially defined" (Parsons, 1951, p. 431). Sickness occurs at different levels, biological, psychological, medical, and social, in an integrated hierarchy of natural symptoms. The way an illness evolves over time is shaped first by social and cultural beliefs, then by scientific explanations that claim the person for itself in the medical encounter (Brody, 1987).

The social role of people who are dying does not fit into the pattern of sickness and return to wellness that either Parsons (1951) or Brody (1987) outline (de Spelder & Strickland, 1992). The social role of the dying is not well defined, yet the expectation of the people who are dying is that they act appropriately. They should follow a prescribed and regulated rite of passage to death passing through death expectations related to the timing of the forthcoming death (Glaser & Strauss, 1965). Dying people are urged to maintain a veneer of wellness as a way of presenting themselves to friends and family who are uncomfortable with the situation.

Death is part of nature's ongoing cycle, but the nature of the disease that kills people determines how they die (Nuland, 1993). Because of this and because death has become something not to be discussed, a way of dying has been created that takes place outside the home. The mythology that has developed around the process of dying is meant to be reassuring.

The language of medicine and illness behavior uses words, experiences, and feelings that describe the body as a creative source (Good, 1994). Good's hypothesis is "that narrative, the imaginative linking of experiences and events into a meaningful story or plot, is one of the primary reciprocal processes of both personal and social efforts to counter this dissolution and to reconstitute the world" (p. 118). He defined illness behavior as the way in which people monitor their bodies and take remedial action.

In the search for an explanation of what is wrong with them, people tell their story. The first part of the search can involve telling the story to themselves; developing an increasing awareness of their body as it changes. They then go on to tell their story to others, whether it be a friend, family member, or health professional. The way in which this story is told, and is interpreted, varies according to its intended audience. As the story evolves and becomes spoken, it takes on a life of its own. Doctors aim to diagnose a disorder; the patient attempts to find meaning and understand the illness. In the ritual of the medical encounter, part of these stories may remain unheard or even unspoken as that ritual unfolds into a process of diagnosis, treatment, and prognosis (Davey & Seale, 2002). Illness or disability disrupts life by altering the regularity and the routine of habitual behavior. These events are not predictable and require ongoing adaptation to new circumstances. People's sense of embodiment changes and they need either to adopt a new way of living or to adapt to a way of living that is thrust upon them (Frank, 1995).

Keeping the body healthy becomes a project by which the social and cultural worlds are inhabited and little time is available to think about death. The human body at birth is a product of evolution, as much affected by social as by biological processes. As the body develops it is affected by and forms the basis for the construction of social relations. When the body refuses to be reconstructed, the prospect of death becomes real (Shilling, 2002).

Merleau-Ponty (1968) postulated that the body is a subjective experience of the world it inhabits rather than an objective experience. It is the perceived experience of the world that determines human experience. He finds that "being" is a body being looked at and a body looking, a body touched and a body touching. He sees language as the expression of life, the expression of thoughts and experiences and the way in which a body and world relationship is expressed and recognized. The phenomenological perspective is "being part of the world" (Merleau-Ponty, 1962), an interconnectedness as one moves through the social world that structures the day, and the life course. Illness prompts a feeling of disconnectedness as the focus changes from being in and part of the world to a turning inward in an attempt to negotiate and reconnect to a new world that is unfamiliar (Samson, 1999). Once this negotiation and reconnection have been mastered, there is further mediation as biomedicine reaches its limits and the move into palliative care is made.

Hospital practices around death and dying determine that the social organization of dying is embedded in the context of the organizational structure of the institutions involved. Death has been removed from the home, and the dying process has become medicalized with a dependency on professionals and institutions (Sudnow, 1967). In this way, dying has become a commodity. The person who is dying becomes a consumer of medical, palliative, and funeral services and yet death itself remains hidden in New Zealand as elsewhere in the Western world.

Studies involving doctors, health care workers, nurses, and social workers show a concern with ethical dilemmas in the hospice situation around patient autonomy and paternalism (Woodward, 1998; Csikai, 2004). Doctors identify tensions over the role of hospice and specialist terminal care services, the role

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of the general practitioner and ways in which practitioners might be better prepared to care for people who are dying (Field, 1998; MacLeod, 2001; Del Vecchio Good et al., 2004).

Communication is important in every aspect of patient care, especially in relation to decision making about care and treatment options (Weeks et al., 1998; Finucane, 1999; Yedida & McGregor, 2001) as are the roles of health professionals and access to them (Albayati et al., 2004). How people cope with dying can be determined by the things that give meaning to their lives (Kirk et al., 2004). Studies variously identify preservation of dignity and the need to remain in control (Seymour, 1999; Carter et al., 2004), good pain and symptom control and the aesthetics of the environment (McKinlay, 2001; Chochinov et al., 2002; Powis et al., 2004), fatigue (Potter, 2004), the ability to continue to manage one's life and relationships and understand the changes that are occurring (Singer et al., 1999; Daneault et al., 2004; Proot et al., 2004), and the importance of friends' roles in informal care and how women continue their caregiving role despite serious illness (Murray et al., 2003). Earlier intervention by palliative care services was described in a study by Rabow and McPhee (1999) and the experience of using services (Thomas et al., 2004) illustrated how the quality of palliative care service provision can be vulnerable (Cannaerts et al., 2004). Professionals sometimes need to abandon the role of expert and allow families to educate them about their experiences (Wright, 2003). Preparation for the end of life and the role of communication in understanding anticipated physical changes and spiritual changes involve the whole family. The way in which palliative care is practiced is important (Patrick et al., 2001; Steinhauser et al., 2001; Grumann & Spiegel, 2003). These studies all make the "missing" voices of the terminally ill audible (Rier, 2000).

This study explores the ways in which individuals live with dying by listening to their stories. People's lived experience of the process of investigation, diagnosis, and treatment determines the way in which these people understands their illness, how it is addressed by others, and how they perceive the changes that are taking place in their body. The specified aims of the study were to gather narratives of the lived experience of palliative care, to explore how images of embodiment function in social space, and to understand the ways in which these narratives might inform those involved in palliative care.

METHODS

The research proposal was approved by the Health Ethics Committee of the Otago Region. Once ethical approval had been granted, the inpatient rounds of the hospice and the following clinical meetings were attended by the primary researcher over the data collection period. The outpatient clinic was also attended during the active recruiting phase.

Participant Recruitment

Participation was sought from people diagnosed with a terminal illness who were receiving palliative care from the Otago Community Hospice, Dunedin, New Zealand. Participation was entirely voluntary. Ten women were approached with a view to participating and provided with an information sheet by their clinician. (In the study design, it was anticipated that five men and five women would be approached; however no suitable men became available during the recruitment period.) Two declined and one died sooner than expected (the day before the interview was due to take place). The participants were aged between 51 and 65 years. All had been diagnosed with various forms of carcinoma. Four were married, one single, and two divorced. The length of time from diagnosis to the interview ranged from 4 years to 6 months. All seven had died by the time of writing, including five who died within several weeks after the interview.

Informed and written consent was obtained at the commencement of the interview in keeping with standard research procedures. The primary researcher was a graduate student in Health Sciences and was supervised by a palliative care physician and a medical anthropologist.

Interview Process

Data for the study were sought through qualitative research interviews. The interviews were semistructured and face to face. The initial part of the interview considered the development of their illness and their perception of the changes that had taken place in their bodies followed by their experiences within the palliative care setting. The interview concluded with questions about what the participants wanted the people who care for and about them to learn from their experience.

Analysis

The method of analysis used in this research was thematic and interpretive. Interpretive understanding explores how action becomes meaningful, within an ethical commitment to respect the subject's life world (Schwandt, 2000). Researching lived experience involves a phenomenologically based way of gathering information as both researcher and interviewer interrelate with each other. In the lived experience

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of emotionally charged issues such as illness and dying, each person affects the other in a reciprocal way. The task of phenomenological research is to "construct a possible interpretation of the nature of certain human experience" (Schwandt, 2000, p. 41) or, in other words, investigating experience as it is lived. Recalling the experience gives it meaning and structure (Van Manen, 1998).

The transcripts were read and reread in their entirety to establish the narrative of the whole story while bearing in mind the framework of the questions that were asked. Major themes were identified as "The Illness Experience," which included embodiment and social roles and responsibilities, and the experience of "Palliative Care." The transcripts were read again to look for subthemes within these main categories and a further analysis was made of these. This analysis was then transformed into a meaningful description of the experiences of the participants.

RESULTS

The Illness Experience

Prior to establishing the certainty that they were dying, all participants experienced protracted uncertainty. First, they needed to establish what was wrong with them. Most had had symptoms that they initially considered to be relatively benign: "I thought my endometriosis had returned because I sort of felt some niggles. . . . It was intermittent and related to cycle so it wasn't pursued." This insidious onset of the disease process masks a growing fear that may be sufficient to seek medical advice or may be counterproductive: "My self-diagnosis of course was that maybe I had asthma because there is a lot of asthma in the family, . . . so I just struggled through. . . . My breathing was becoming more and more difficult so I went back to the doctor." Second, there is the uncertainty of diagnosis while undergoing medical examinations and tests to establish what is wrong with them: "Just to know what was wrong with me, it would make life a bit easier." The way in which participants described being told about their diagnosis was important. Two general practitioners told them by phone: "He [GP] phoned me up all upset and I said no I haven't, no I haven't, I went into full denial. Cancer was never an option as far as I was concerned".

Finally there is the uncertainty about what treatment option is best and, indeed, whether treatment is going to provide a cure at best or at least control and manage the symptoms. In this respect treatment seemed to the participants to be haphazard: "I had two sessions [of chemotherapy] and at this point we are uncertain whether to have any more. . . . My quality of life became such that there wasn't much point in being alive really. I would much rather be well for a shorter length of time." The body comes under medical and personal surveillance as the progression of the disease and the effects of treatment are duly noted within the cultural constructs of effective medical management.

All but one of the participants described a sense of abandonment after being discharged from active hospital treatment. Because they had had very little to do with their general practitioners after being referred to the hospital services, they identified a gap where they felt a lack of follow-up. This may, in fact, reflect a discomfort about not being able to do anything to halt the progression of the disease by the doctor. There was evident confusion about who to turn to in the event of a variation of health: "We didn't know who to turn to, because I had been in and out of hospital. . . . Because there are so many people involved it became a bit confusing as to who dealt with what and who knew about what was going on. We kind of felt quite lost." One participant was unhappy with the information she received from her surgeon and another with the lack of information that was available about her particular form of cancer. This contributed to the overall sense of uncertainty the women felt. All agreed that a follow-up phone call from either their general practitioner or their practice nurse on receipt of the hospital discharge letter would have been valuable in ascertaining who and when to contact, at least to reemphasize the information that may have been provided but not always adequately absorbed.

Embodiment

Embodiment, or the sense of being in a body, is about how that body occupies its social space. There is a sense of body image functioning in physical space connected to an environment of exchange and reciprocity (Turner, 2000). One of the main aims of this study was to find out how participants experienced their dying body. With the current dominance of the expectations of society in maintaining health, body image may be perceived to be important, but at this stage in their lives all had gone beyond worrying about how they looked: "I think my body has deteriorated quite markedly. . . . I can see my face has changed, I have had to have my dentures realigned because the tissues in my mouth have shrunk. . . . I have got this swelling on the stomach, that's nothing, it doesn't bother me, . . . that's not important in the scheme of things, so your body image changes." What was more important to them was to be able to function in comfort with as little pain as possible;

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all had developed strategies to be able to do this. How they look may be different for people at an earlier stage of cancer in an attempt to normalize the sick body where the signs of illness need to be masked and hidden. Indeed the nature of the cancers experienced by all the participants kept the women hidden, except for family occasions and hospital visits, despite a preference for being able to do things out in the community.

All the participants felt they had taken care of their bodies during their lives; paying attention to their diet and exercise and how they looked was important to them. Until the growth of tumors became evident on the outside, looking at these women physically did not reveal any sense that they were seriously ill, and, indeed, for two of them with abdominal tumors, one might think they were pregnant: "I wouldn't feel proud of showing off the body to anyone. . . . I have always been very thin between my midriff and that has become very distended and that was the hardest thing out of the lot to cope with. . . . I sort of feel like a pregnant woman, what I imagine a pregnant woman would feel like." Until treatment marks them as having cancer, such as losing hair and losing limbs or breasts, people can continue to look well. The body becomes broken down not only by the disease but also by treatment. The way in which these women experienced their bodies and the way in which their deteriorating bodies were managed and controlled by themselves, their nurses, and their doctors was important, because this process allowed them to function in their social and physical world: "There are days when I put makeup on and days when I don't. . . . That's the thing I have noticed now though, if I am not well, I don't care about putting makeup on."

None were able to tolerate being touched because of the sensitivity of the nerve endings and various levels of pain such touching caused, which had a severe effect on intimacy with their husbands and partners. "We haven't been able to sleep together because of my op, I just couldn't stand anything rocking." Another, who was single, said "I wouldn't feel proud of showing off the body to anyone. . . . Like it must be a worry for partners as well because I wouldn't even like to—because of the nerve endings and all those sorts of things around there, I wouldn't really want to be touched."

Is dying a matter of peeling away the layers of the social structure in the world in which a person operates, as well as the physical structure within embodiment? The outer layer maintains the illusion of wellness, and people do maintain the illusion of being well to a point. Often they look well and, where fatigue is not an issue, continue to function: "I need to transplant my functioning head on to a functioning body." This woman had all her mental faculties and could think clearly and logically. Her body, on the other hand, was perceived by her as letting her down and limiting her activities.

People who are dying experience the ultimate threat to their bodily integrity through the changing ways in which their deteriorating bodies allow them to live. This integrity is also threatened by treatment. The participants in this study tended to disembody *themselves*, rather than *their cancers* by describing their tumors as something "other" using terms like "grotesque" and "obscene." One stated that "the tumor" made a limb feel like it was not part of her: "The tumor is sitting on a nerve that goes down the leg so my leg doesn't feel part of me. It is like it is just a piece of wood or something that I am carrying along with me." How another participant was able to function in her world was determined by what "the cancer" did to her.

The embodiment debate is embedded in the Cartesian dualism of the mind/body split. The way participants perceived their bodies varied from this classic dualism "head-wise I am fine" to separating their cancers from their body. Such separation objectifies and disembodies the cancer as something alien that was threatening the integrity of their body and the ability to do the things they wanted to do. The pain from the cancer was one constant reminder to them that it existed.

Social Roles

The experiences of all the women reinforced Cassell's (1991) concept of "personhood" in that disease made the performance of their social roles difficult, if not impossible, especially in relation to their occupations. Their roles as family members, such as mothers, wives, grandmothers, sisters, and daughters, did not change, but the way they fulfilled those roles did.

The women who had husbands and families carried on managing their household as much as possible. Often husbands had to change their jobs or take leave to be available to take over household responsibilities. The women grieved for things like not being around for their children's life events such as marriages, graduations, and having babies. Having been independent all their lives, they were also independent in the way they managed their death: "Sometimes it is hard to actually allow yourself to be taken over like that and it was probably good when I first went in there [hospice] that I was really not well." The woman who was single looked on her impending death with relief that she did not leave a husband and children grieving for her. It is the patient and their carers, whether it be family or

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not, who are dealing with the day to day reality of living with the dying process. Those innermost worlds of thoughts and feelings that occur in the night remain unexpressed in the clinical setting unless something happens as a catalyst.

They all had to determine how family and friends were confronting the reality that their lives were going to be shortened and negotiated these relationships accordingly: "They all want to help greatly; one close, close friend we actually had to stop her coming for a while and that was really, really hard. I think she misunderstood—her idea was the moment I got home from hospital, she would come and sit beside my bed and hold my hand all the time. . . . The friends one is quite difficult."

A sense of burden contributes to an individual's state of being with the focus on alleviating burden by whatever means are available. This context implies that it is something a person would desire to shed, but ignores the fact that most family members do not consider giving care a burden. Although this study did not explore this with family members, other research found that caregiving is based on motivation and behavior, and the positive aspects of mutually reciprocal relationships (Clapton, 2004). How the women viewed themselves as burdensome was more related to what their expectations were of what dying would involve. The nature of relationships changed for some of the women, surprisingly so for them, in that some of the people they expected would be open about their dying were not, whereas others they had not thought would cope did. One woman talked about her husband "pushing her into dead" before she herself was ready. Some relationships were strengthened, other relationships disintegrated.

All of them experienced and expressed an intense sense of loss in all sorts of ways, including loss of health, loss of friendships, loss of family, loss of community, and loss of creativity. Their lives had contracted down to whatever they could manage: "I can't do the things I thought I would be able to do. . . . I heard one of the doctors say, 'You are never going to be any better than you are now,' so where I am at is the best I am going to be. I would like to be better." "Everybody sort of said to me go out and live your life, and live your life until you die, but because of all these other things, I have had a chest infection which knocked the stuffing out of me so that's been—that's really knocked me around a bit, and there have been times when I thought I was dying already."

Although they had to withdraw from their employment earlier than anticipated, more because of the nature of the treatment they received than the disease, they attempted to maintain their social responsibilities as much as possible. They were all pleased to be with people and have people around them but did describe a need to be able to spend some time alone: "You need time alone especially in those initial—well I found I did—you need time just to come to terms with it all and they sort of think that you need to be with people—well you do, I mean I love people, I like people around me, but you do need space just to get your head around everything and to come to terms with it and just quiet time to cry because you don't have that time—I mean you are with people you love and you can cry but sometimes you just need to cry, really cry, really let it go."

What was also important was that they have as good a quality of life as possible. How this is defined is unique to the individual. Some of the women interviewed talked about the environment in which they lived, but more about how people were important to them and how they were important to people: "I was by myself just sitting on my front veranda there one night, about three o'clock in the morning and I was thinking about—you know how you usually think about how much we like people and it was about how people liked me and it was quite an interesting concept, never thought about it before in my life."

The unpredictability of symptoms contributed to the uncertainty the women experienced, not knowing whether eating certain foods was going to upset their digestion or not knowing what was going to happen next: "I am living with whatever I get, whether it be vomiting and diarrhea, what else do I get—I get the sweats, I get various pains in my tummy and all sorts of different things pop up." Weakness and fatigue also dictated how they managed their days with feeling well on one day and feeling exhausted the next: "It is a bone-crushing sense that reduces me to sleep wherever I am." The importance of pain control was paramount but the side effects of medications limited activities. They did not know when they embarked on a project whether they would have the stamina to complete it before they died.

In common with other studies (Murray et al., 2003; Proot et al., 2004), this study also found that women continued their caregiving role to others as best they could, especially in making arrangements for the family to continue functioning without them. All participants had made preparations to a greater or lesser extent for their funeral, "A couple of things I found hard to deal with—he [husband] said to me had I written out a list, and I said a list? What's a list? He said a list of things you want sung at your funeral." Another had specified how she wanted her coffin to be, "I want a painted coffin. I mean I won't paint it but I love beautiful, beautiful wood and I think it is such a shame to put that beautiful wood in the ground or cremated or whatever and I just said to

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[husband] it can be painted." One woman saw her funeral as a way of helping others to grieve. "My friends asked me if I had sorted out my funeral and I said well no, because I don't think it is for me to sort out. I think the funeral is for the people who are left behind to sort out."

The dying role has no guidelines that determine people's behavior, and everybody dies differently and individually. Whether they have a "good death" or not is determined not only by the progression and management of their disease process but also by the way in which they are perceived by the people around them. For the participants in this research, palliative care provided the resources for them to continue to live their lives.

Palliative Care

The hospice became a refuge from mainstream health care, a respite from the medical system and other people while they were being taken care of. The community perception of what the hospice does is important. It is perceived as being "the end of the line"—the place to go to die. It is a place that will be there when people need it, in some instances a place to be feared as well as a place to be embraced: "I think [specialist] is desperately trying to get me there; I told him I will go when I am ready. I am comfortable at home and they are not going to do anything different for me. When I am ready I will know."

Lawton (1998) discusses how hospices provide a space for the sequestration of the body as it decays, thus setting it apart from the mainstream society, enabling accepted ideas about living to be maintained. The handing over of one's disintegrating body to hospice care was seen by all the participants in this study as something they could do to protect their families from witnessing their deterioration: "It was quite early in the piece when the hospice became an option—was offered; . . . it was explained 'just come, get to know the place,' . . . that it wouldn't be such a shock. . . . The family just made the arrangements and basically had me committed." The hospice is a place where time stands still as people who are dying gradually relinquish themselves to the dying process. It protects the living from the dying and the dying from the living.

The relinquishment of control to professional caregivers seemed to give the women interviewed the energy to control other aspects of their lives. Yet as dying moved closer, the ways of maintaining control for themselves diminished until they reached the stage where they simply "let go" and withdrew completely. At the time of the interviews, preservation of identity and dignity was not something that was discussed in depth, more something that it was hoped would happen within whatever setting it was that their dying took place: "I guess it is going to be just a gradual like the lights going down in the factory, and they just slowly turn off. . . . It is not as scary as people think. . . . I will be quite ready when it is time just to be quietly slipping away." In terms of their experience of palliative care, they felt supported and empowered. After being told by her surgeon to "go home and wait to die," one woman was delighted to be told by the palliative care specialist that she could do the things she wanted to do. She felt this reinforced her decisions to do things for herself.

None of the women expressed a preference for earlier access to palliative care services. Although there was still the sense of uncertainty, especially about the appropriate time of contact with the hospice, some felt it was something to be investigated later rather than sooner. However, given the extent of the uncertainty experienced by the women, earlier access to palliative care may have been helpful to them.

DISCUSSION

It is easy to make generalizations about the dying process in an attempt to idealize ways to die by constructing the "right" way to die (Pattison, 1977). What this research has shown is that, in common with previous research, generalizations about the way people confront dying changes from a presupposed model of coping to one where individual difference is recognized. People need to tell their stories as they experience them, and dying becomes a mutually reciprocal process (Wright, 2003).

This study confirmed the findings of previous studies where the ability to direct a person's own life and well-being was helped or hindered by the way in which needs were met. The ability of the women to do the things they wanted to do very much depended on how they were feeling on any one day, and that was influenced by not only the level of pain relief and comfort they had, but also by how they were regarded by the others around them. One woman talked about visitors coming "with the look of death in their eyes," that made her uncomfortable.

One thing the participants in this research were certain about was that they were dying. How they negotiated the rest of their lives depended upon a number of things, such as how they were treated by their health care professionals and how they were regarded by their friends and family, reflecting Glaser and Strauss (1965, 1966) in their discussion about death expectations and the awareness of dying.

Aspects of suffering were addressed by hospice staff, but the source of that suffering was not always adequately identified or, in some cases, assumptions

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were made that were unfounded. Certainly for the women themselves, what they expressed in terms of suffering was in relation to the losses they experienced as their worlds collapsed around them. This reflects Cassell's (1991) definition of suffering in the ways in which suffering is created through the experience of a disease that threatens everything a person lives for and the relationships a person has.

The illness experience has, in itself, been the subject of considerable discussion as to how individuals and those around them respond to episodes of chronic and acute illness. Issues of making choices, patient autonomy, and involvement in decision making were important to the participants of this research. However, priorities of these changed as the person drew closer to death and withdrew into themselves, relinquishing control to the point of "whatever was best" for themselves and for the others in their families.

The overriding theme of the dying experience was the sense of uncertainty that all the women felt, not only during the diagnostic process, but also their description and experience of apparently haphazard treatment and uncertainty about what that treatment would achieve. Embodiment, to them, seems to revolve around a sense of being able to function in comfort, as pain free as possible. People who are dying lose everything (Craig, 2004); they lose not only their hopes and plans for the future but also their relationships and independence as they, and everyone around them, struggle to come to terms with a new reality. There can be the best palliative care services available, but there are still those quiet times in the night when, lying awake, they reflect on what it is they can best hope for. They should be enabled to die in a place of their own choosing surrounded by the people and things they enjoy. Western society has come to rely on other people to provide expertise in health care and on science to provide a cure. People who are sick want an explanation for what is happening to them and why. People who are dying want to die a "good" death: "Just to let go and get on with it."

This study aimed to investigate the experiences of people living with terminal illness, how they viewed the ways in which their body was being affected, not only by the disease process but also by treatment, how they negotiated their social roles, responsibilities, and relationships while living with terminal illness and what they wanted the people around them, their friends, families, and health professionals to learn from their experience.

What was found was that the ways in which their bodies were affected by the disease process and by their treatment determined how they lived their lives. They all had a sense of uncertainty about their lives and lived in the expectation that, whatever happened, they would deal with it somehow. Body image was no longer important to them. What was important was being able to function in comfort with as little pain as possible.

Their social roles in terms of their relationships with family changed as they became more dependent on family to look after them. They maintained a sense of needing to protect their family from the "business" of dying and this, along with their experiences in the hospice, influenced their choice of a place to die. In terms of their roles and responsibilities in relation to their employment, they all had to resign from their jobs sooner than expected due to the effects treatment regimes were having on them. Their roles in friendships changed too in that they needed to determine how their friends were responding to their illness and adapt to that.

What they wanted the people around them to know is best expressed in their words for family and friends: "I have cancer, but I am still me." "Some days I look really horrible and feel fine." "They don't need to be forever sad." "Life is for living, you can't be mucking around." What they wanted their health professionals to know was more complex but predominantly related to communication. Although information was provided to them, they needed time and help in absorbing it all and to come to terms with their prognosis.

This study gives voice to those living the experience and adds to the growing amount of literature gathering those narratives. A limitation, as with all such research, may be the way in which the narratives are interpreted in an attempt to understand how a person's social world contracts and adaptations are made under uncertain circumstances. The reality, certainly for the participants in this research, involved coming to terms with deteriorating health and enduring the rigors of treatment. Any sort of traveling meant having to put alternative plans in place should they deteriorate more rapidly than expected while away from their home. Life contracts down to managing what is important to each person and mustering the resources available to be able to do that.

Educating people about palliative care and hospice services remains problematic, as none of the participants in this study were fully aware of what hospice did. Their experience was based on having had friends die there or donating to hospice fundraising activities. This may reflect the current social attitude about keeping death and dying hidden or it may simply be that more resources need to be put into funding such hospice education programs.

Because all participants were recruited from within the hospice programme, the results may well be biased by this location and the way these

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participants interpreted their own experience. Although this need not undermine the validity of these results, because it places the research within the hospice context, it points out the need for further research to be carried out in other settings in the community.

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