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Opening Doors: Understanding Experiences of Dying

by

Gail P. Kulas

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ABSTRACT

What is dying? The phenomenon of dying can be understood in many ways and from many perspectives. This research uses a hermeneutic approach to understand the experiences of dying. This understanding was generated in conversations with five people. I think of these conversations, as doors that have been opened to help me see farther and to areas that were unknown to me. The metaphor of opening doors encourages being open to the mystery of life, the mystery of dying and all the possibilities in between.

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DEDICATION

This is dedicated to the five people who shared their stories and helped me understand the experiences of dying, and the experiences of living.

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Chapter One: The Doorways

*When experience is viewed in a certain way,
It presents nothing but doorways into the
Domain of the soul, and they are all formed in the present moment.
-Jon Kabat-Zin*

Understanding experience

What is dying? We all have notions and ideas about what this phenomenon includes and what it doesn't include. How did we come to these understandings? Is there more? How do our communities and our cultures influence these ideas? How do we understand our own mortality? How does another person's death affect this perception of dying? Although these questions may not be at the forefront of our thoughts they can be exemplars of an often-unconscious process. Both conscious and unconscious thought processes influence our understanding of this phenomenon and the world around us.

Understanding the idea of dying is complicated. Dying is not only something that occurs to our bodies, before our eyes, or to someone else. It is not only physical deterioration, pain or suffering. These instances often solidify our understandings because of their immediacy. They are in fact particular events that ultimately mesh into, dissolve into, and have a particular place in, the greater more expansive landscape of the phenomenon or experience of dying. In this research, experience incorporates more than the life events of any one person. The experience of dying in this research is a philosophical abstraction that reflects the multiple layers of how we understand this phenomenon.

Just as time is not static, how we understand the experience of dying is not static. "Coming to an understanding is not a mere action, a purposeful activity, a setting up of signs through which I transmit my will to others.... It is a life process in which a

community of life is lived out” (Gadamer, 1997, p.446). As Gadamer (1997) highlights, this process of understanding occurs moment by moment, constantly changing as we live our lives in relation to others. This research uses a hermeneutic approach to understand the experience of dying. For hermeneutics, knowledge is contained within, and emerges from, the meanings we generate in our everyday lives, and human experiences (Gadamer, 1997; vanManen, 1997). This hermeneutic process reflects the ways we as people constantly interpret, and generate meaning in our lives. When approached from a hermeneutic perspective the purpose is not to define what dying is, but to continually call into question what the experience might include.

Perspectives

Caregivers working with people who are dying use knowledge and skills that have developed from many perspectives. Yet it is my belief, that often understanding an experience from the individual’s perspective is underestimated, underutilized and undervalued. The Canadian Palliative Care Association (1994) described palliative care as,

[t]he combination of active and compassionate therapies intended to comfort and support the patient and family who are living with a life-threatening illness, during the illness and bereavement periods. Palliative care strives to meet their physical, psychological, social and spiritual expectations and needs with sensitivity to their personal, cultural and religious values, beliefs and practices (p.17).

Explicit in this definition is the need for holistic care. To achieve this ideal in practice, caregivers use many forms of knowledge in order to deliver safe, effective, and compassionate treatments and care (Engebretson, 1997). Yet health care services have been largely directed based on objective knowledge with a scientific perspective. Technical, medical and pharmacological breakthroughs made in the last decade were generated from

such a perspective (Engebretson, 1997). As a result of these developments, individuals with terminal illnesses can expect pain management, symptom control, and physical support during the dying process. The importance of these interventions should not, and cannot be underestimated. For example, knowledge about narcotics, opioid receptors, physiology, and pharmacokinetics, all contribute to pain management strategies, which are then applied to most people experiencing pain. The domains of physiology and biology teach us about systems and cellular changes associated with dying. This knowledge helps professional caregivers understand how a body reacts to a particular illness, what medications may alleviate symptoms, or how to know death may be near. But I believe they are only portions of how we come to understand the process of dying.

Our society is dominated by one scientific or medical perspective for understanding health, and illness in particular. Madison (1988) claims "The scientific conception must be recognized as a view of the world, a certain way of looking at it and dealing with it which serves certain purposes. The 'objective' world of science is but one interpretation of the world of our immediate experience" (p.4). As a nurse working in the area of palliative care, I am concerned by what seems to be the dominance of this scientific perspective to understand dying. Conscientious and professional caregivers often recognize the need to continually learn about treatments, pain management, procedures and how to effectively deliver good care. The types of research being done in this area reflect this emphasis. When caregivers work with the dying they intrinsically utilize types of knowledge that go beyond the explicit. As caregivers we cannot help but be absorbed and influenced by the situations and relationships with the people we care for. These relationships can also generate understandings as we talk with, care for, and are interconnected with people. "If what we

desire above all is to understand better...then the human sciences prove to be indispensable tools for attaining greater understanding” (Madison, 1988, p.47). I am interested in this subject because I am struck by the tension between how we currently understand death and dying, and how little this understanding reflects the perspective of the individual living the experience.

There is a tendency to believe we understand the experience of dying, not only when we examine specific portions of the process ‘scientifically’ but also when we attempt to say what the totality of the experience of dying ‘should’ be. Theorizing about the experience of dying gives the illusion of understanding and negates how individuals may interpret dying if it varies from what is predicted. “Modern theory is a tool of construction by means of which we gather experiences together in a unified way and make it possible to dominate them” (Gadamer, 1997, p. 454). My concern about commonly accepted constructions of dying is that they offer us again, only specific ways to understand this phenomenon. All societies have generalized theories to help people make sense of what it’s like to die (Kastenbaum, 2001). These theories can be useful and contribute to what we know, and can be identified as portions of the phenomenon. Fear of death is a common overt conceptualization (Copp, 1998; Kastenbaum, 2001; Mayer, 1989). ‘What a tragedy’, ‘that’s terrible’ are phrases heard when people discover someone they know has a terminal illness. This fear may be justified, and many people may hold this belief. My previous conversation with palliative clients challenges this assumption as being one perspective. One woman confided that she looked forward to death, she just didn’t want to go through the process! Another man was so strong in his religious convictions that he denied fearing death and dying, and was looking forward to being with his “Lord” and “Mary”. I do not

believe we have to travel beyond our communities and families to see how such generalizations cannot always be applied to individuals.

Virtually every aspect of a person's life is influenced by a terminal diagnosis. I travel through my day almost oblivious to my body and how it functions. I am not conscious of the pressure of each step on the pavement, or the sensation of air on my exposed skin. When a person is keenly aware of the finite nature of their life, maybe something changes. One man explained his cancer diagnosis as a toothache that never went away, he always thinks about it. I have always been curious about the ways that people choose to live after their diagnosis. I have seen people strive for cures and miracles, some people who alter their lifestyle and habits, some who turn to a sense of faith and others who turn away from faith. When people make such consuming changes in their life, I do not think we can assume that we know what it means for someone to live with a palliative diagnosis.

Sometimes, it is assumed that people do not wish to talk about their diagnosis or their impending death. Often this notion takes on a paternalistic flavor when we make the decision not to discuss a patient's own future beyond the medical jargon and rational discussions (Gadow, 1980). Some individuals may welcome discussions about their situation and the future. In The Death of Ivan Ilyich, Tolstoy (1981) paints the protagonist as a man who becomes isolated as he is dying. Everyone around him evaded discussion about his illness.

...and he was tortured by this lie, tortured by the fact that they refused to acknowledge what he and everyone else knew, that they wanted to lie about his horrible condition... He saw that the awesome, terrifying act of his dying had been degraded by those about him to the level of a chance unpleasantness (Tolstoy, 1981, p.103).

What could we possibly be communicating to people when we do not ask or are not open to hearing about their experience?

The research question

This research asks the question: What is the experience of dying? My curiosity with this question did not originate with this research. It was, and remains, a constant thought as I care for people who are aware that their life is nearing an end. In my practice, the ways that people make sense of terminal illness, and the ways in which they choose to live with these understandings, are important. How people understand their dying effects those involved in delivering care, their families, and anyone who listens. Gaining some understanding of how people make sense of their terminal illness also effects others. These conversations extend beyond the boundaries of a hospital room or bedside. Asking this question places people's experiences of dying forward to a place where they can be shared and heard. It continues this movement forward to understanding the phenomenon of dying, not only for them, but also for the world of which they are a part.

It becomes deceptively easy to segment the experience of dying into manageable portions where statistics and hypotheses can stake a claim to understand. I have chosen a hermeneutic approach to look at this phenomenon because practice has taught me that particular experiences and perspectives on dying also have much to teach about the phenomenon as a whole. Hermeneutics.

...differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it...and offers the possibility of plausible insights that brings us in more direct contact with the world (vanManen, 1997, p. 9).

This has significance for nurses and caregivers because people's health, illness and lives are the focus of our care. Our connection with the people we care for extends beyond tasks, and procedures.

Meaning and experience

For this research, people living with a terminal illness were questioned about the experience of dying. Knowing they were dying gave the participants a particular perspective on dying. Yet this experience does not 'belong' to them, nor is it only about them. "Experience always contains a *plus ultra*; it always means more than 'what is meant explicitly'" (Caputo, 1987, p.40). People cannot relate their stories or even talk about dying without the implicit and often entangled ideas about the topic that already exist. The experience of dying, therefore, is a phenomenon that encompasses more than particular interpretations (Caputo, 1987; Gadamer, 1997; vanManen, 1997). If we think about conversations about dying (or any subject) we realize we can only speak to, or speak about, something that already has certain meanings, that exists before and after these conversations. "We can learn something new only on the condition that we have already been appropriately oriented to begin with. We can understand only if we already pre-understand" (Caputo, 1987, p. 61). When we think about the experience of dying in this more global way, it becomes easier to understand how Caputo (1987) dares us to make explicit what is often implicit in the experience. The experience of dying is about: the neighbor in his eighties, our parents, our children, starvation, genocide, homicide, suicide, technology, quality of life, spirituality, culture, history, art, nature, loss, pain, prognosis, diagnosis, and the ultimately all other human lives.

“Experiences gather hermeneutic significance as we (reflectively) gather them by giving memory to them. Through meditations, conversations, day dreams, inspirations, and other interpretive acts we assign meaning to the phenomena of lived life” (vanManen, 1997, p.36). Constantly interpreting the world in which we find ourselves, making sense of situations, feelings and ideas in relation to other things and other people is our never ending work. It is in relationships and in relation to what is within and without that we find meanings in our lives. When we articulate experiences of dying, meanings develop through language and are shared with the world (Gadamer, 1997; Kvale, 1996; vanManen, 1997). Language exposes the meanings of human experience and helps us to make sense of the experience (Gadamer, 1997; Kvale, 1996; vanManen, 1997). Also, as we engage with texts or silently converse with ourselves, language gives substance to how we understand. “All understanding is interpretation, and all interpretation takes place in the medium of language that allows the object to come to words” (Gadamer, 1997, p.389). In this research the language, words spoken and unspoken in conversations, creates meanings. These conversations generated and co-created meanings as we entered into this relationship intent upon understanding the experience of dying. Language does not only account for how a person understands. When meanings in language are created, they ultimately connect the phenomenon being discussed and understood beyond the conversation.

For conversation is not just one of our many activities in the world. On the contrary, we constitute both ourselves and our worlds in our conversational activity. For us they are foundational. They constitute the usually ignored background within which our lives are rooted (Shotter as cited in Kvale, 1996, p.37).

Meaning is the result of contemplating, thinking, articulating, and understanding the experience of dying. Meaning is grounded in individual perceptions and is how we each

make sense of our world (vanManen, 1997). As people live with terminal illness they are continually trying to understand what the experience of dying means for them. The experience of dying has psychological, social, spiritual and physical dimensions. Within any of these areas of human existence, meanings can be found as people who live with impending death are making sense of their lives. When the physical body is overcome with pain, meanings surrounding this pain may be uncovered. Appreciating and respecting individual meanings not only for their unique perspective, but also for how they contribute to our common experience of dying, becomes imperative. These meanings do not exist independent of the encompassing phenomenon of dying. There is fluidity between how meanings are understood and how the experience of dying is understood. How I understand dying is not only about me. The stories of people who are dying are not only about them. Yet both are portions of how the universal experience of dying is understood. vanManen (1997) explains this relationship and reminds hermeneutic researchers to not only relate personal meaning but to take these a step beyond. "The interpretive examination of lived experience has this methodological feature of relating the particular to the universal, part to the whole, episode to totality" (vanManen, 1997, p.36). Likewise, the aim of this research is to explicate particular experiences of dying to at times compare but ultimately to weave and integrate these expressions into the universal phenomenon of dying. I have often used the terms "individual" or "particular" experience and "universal" experience to make it clearer which portion of the experience is being examined. In this research there is a process of looking narrowly at particular instances as well as broadening the gaze to better understand the of totality of an experience.

The meanings of dying will never be fully realized because of the infinite individual interpretations and the dynamic nature of the universal experience. "Essential to an experience is that it cannot be exhausted in what can be said of it or grasped as its meaning... its meaning remains fused with the whole movement of life and constantly accompanies it" (Gadamer, 1997, p.67). This should not deter researchers from attempting to understand people and the meaning of their experiences because all these perspectives comprise the phenomenon. Research that seeks to uncover and generate meanings evolves not from understanding using an objective detached approach, but by understanding in a subjective manner. By questioning people about the possible meanings of dying I hope to realize the experience of dying with a greater richness.

The point of phenomenological research is to 'borrow' other people's experiences and their reflections in their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience (vanManen, 1997, p.62).

Part of the purpose therefore, is not to establish new theories or generalizations of dying but to enter into relationships with the participants where more understandings are generated. By talking about life stories with people, new perspectives are emphasized and the doors to possible ways to understand dying are opened. This research also aims to show how these meanings are not independent in the world, but interdependent with the world, and are also portions of the expansive and ever changing experience of dying.

The metaphor of opening doors is loosely used throughout this writing because it has been my reminder to be open and not grounded in how I understand the phenomenon of dying. In life it can be easy to plant ourselves in the present, a place where we feel that we understand. This secure place is a deception. We are constantly pushed forward "in the

present moment' past the threshold of what we know to spaces and places beyond. My challenge has been trying to be conscious of this movement forward. This attempt at awareness helps me to see other vistas and move through the doors that others open. These openings create places within me where I understand dying differently.

Doorways give us access to particular places. Likewise, Chapter One has attempted to give readers an understanding of how I am approaching the subject, and why there is a need to ask: What is the experience of dying? Chapter Two accounts for my placement as a researcher and reviews relevant literature on the subject of dying. Chapter Three describes hermeneutics and offers some understanding of the philosophy and traditions that guided this research. The particular stories and voices of people who are dying resonate in Chapter Four. It is here that the research reflects some of the particular meanings that were created in conversations and as I interpreted the text. 'Opening doors' here symbolizes the new meanings and new possibilities for understanding the experience of dying differently. Chapter Five continues to generate meanings of dying and shifts perspective to consider the experience of dying from a more universal or encompassing perspective. Chapter Six elaborates how this research influences my perspective and details implications for nursing.

Chapter Two: Standing At The Threshold And Moving

Interpretive inquiry is a form of self-exploration, but it is not 'just' an introspective journey. It is a journey outward into the fabric of human discourse in which my life is enmeshed. It is also an ecological journey into the textures of the Earth that sustain and surround human discourse in conditions of necessity, mystery and silence
(Jardine, 1992)

Standing at a threshold is an interesting position. We look forward to what may be revealed in the passages before us. Whether these doorways are new or not is often irrelevant. What becomes important is being cognizant of the travelling and learning, and that there is change from moment to moment. The thresholds are my points of beginnings. Places where I journey forward to see new perspectives. There is no one point where this story begins just as there is no one threshold over which I crossed to gain an understanding of dying. For within me there is no one understanding of dying. This chapter shows not only the view looking forward but just as importantly, where I have come from in order to get to this position – my thresholds. It is an introspective journey that examines my assumptions about dying, and the varying ways I understand dying. It is also an ecological journey that reviews some of the literature that has also influenced my notions about the phenomenon. A critical examination of these areas is necessary in order to understand where I am journeying.

Introspective journey

This hermeneutic research process is contingent upon self-exploration, being willing and able to interpret my assumptions, and understanding how my interpretations of dying have developed within my societal, familial, and cultural contexts (Gadamer, 1997). These assumptions need to be examined, challenged, and interrogated to achieve this

understanding. It seems artificial to locate myself within a particular discourse to explore the phenomenon of dying. It feels more appropriate to articulate my beliefs and those that impact my interpretations.

Since graduating as a nurse I have often worked in settings where dying and death were not always unexpected or surprising events. On medical units and a geriatric assessment unit, I gave people the care they needed as they faced the difficulties of dying. My move to Home Care opened my eyes and expanded my interactions with clients. Delivering care in a person's own home seemed very different from nursing in an institution. For example, when a physician prescribed a diuretic twice a day in the hospital there was very little movement with dosage times. As a Home Care nurse I quickly realized prescriptions often became flexible to meet individual needs and daily routines. Somehow, there is a shift when people return home, a shift of power where the people themselves took responsibility and made sense of the illness in their lives. My nursing practice changed as I increasingly respected the patient's wishes, the patient's autonomy, and the patient's right to control their life. I still wonder if there was a degree of control and domination in my relationships with clients. Nursing visits seemed to be preoccupied with tasks: adjusting narcotic dosages, assessing pain and symptoms, and asking the all too common 'How are you?' In looking back, I ask myself how much effort did I devote to understanding how this experience affected them? Was I so busy with medications, treatments, and routines that I sometimes missed seeing the person? "The diagnosing and prescribing comes from *our knowledge and our subjective perceptions* [italics added]. This may lead to premature closure to other possibilities, interpretations, and perceptions" (Munhall, 1993, p.128).

When I learned a person was dying, what did I miss, or what got left out? What could their stories teach me?

My understandings or beliefs about dying come from a multitude of influences. Consciously communicating my assumptions helps to identify my positions and interpretations of text. "The hermeneutically trained mind will also include historical consciousness. It will make conscious the prejudices governing our own understanding, so that the text, as another's meaning, can be isolated and valued on its own." (Gadamer, 1997, p.299). By thinking and examining my assumptions I hoped to recognize what may block my attempts to understand the phenomenon of dying. I do not espouse these to be truths rather they are my assumptions.

- * Living with a terminal illness is different than when an individual has not been given a terminal diagnosis.
- * The experience of dying will never be fully realized because of the infinite amount of individual interpretations and the dynamic nature of the phenomenon itself.
- * Individual experiences and particular meanings of dying need to be recognized as portions of how we understand the universal experience of dying.
- * People want to talk about the experience and portions of the experience can be communicated. In these conversations particular meanings can be generated and co-created.
- * I could write about this phenomenon in a way that is evocative and thought provoking for others. By writing about people's particular experiences and meanings of dying there could be change in the way we practice and work with clients.

- * Society has assumptions and beliefs about dying that serve to create a distance from individuals living with a terminal illness. This distancing is negligent and can be harmful to people who are dying.
- * Knowledge is dynamic and ever changing. New knowledge can be found and generated between individuals in conversations.
- * Dying individuals change how they perceive themselves, their bodies, their relationships and their lives.
- * Health care professionals are not meeting many patient needs because individual subjectivity is silenced in favor of generalized societal beliefs and assumptions.
- * I have a responsibility to challenge the status quo by examining how society influences our ability to understand the experience of dying.

When considering the direction from which to study the phenomenon of dying, I gave considerable thought and reflection to how I understood this experience, and how meanings are co-created within language. This is a requisite activity for hermeneutic researchers because “for the interpreter to ‘perform’ the text, he must have some pre-understanding of the subject and situation before he can enter into the horizon of its meaning” (Pascoe, 1996, p. 1311). Although there were no predetermined questions for the conversations, there were questions that were the impetus for my initiating this study. These questions developed as I reminisced about people I have known, and when I considered my own mortality. How does the presence of a terminal illness affect daily living? How does knowing that death is imminent affect personal relationships? How does a person feel about their physical body? Does a person’s religious beliefs or spirituality change? Do people give more thought to the idea of a soul, or afterlife when they are dying? What does dying mean to a person? What is

the experience of dying? I continue to wonder about many of these notions. While in conversations with people and when writing and interpreting I tried to be conscious of these ideas. They were in my thoughts, not because of my desire to justify my ideas, but instead to recognize that my interpretations could be swayed by my desire to have answers to the questions I live with.

In earlier parts of this research I aligned myself within the feminist and critical theory perspectives which grounded some of my assumptions and was a way of accounting for my interpretations. It feels wrong to do this now. This stems from how I have changed as a result of this research, and again as I have come to be changed in my understanding of hermeneutics. Feminism and critical theory more accurately reflect or align with aspects of who I am and how I might interpret text. A better approach is to detail for the reader what these ideas or notions are and how I believe they shape me. This accounting seems false at times because blatantly stating what I think changes as the days (and moments) go by. I can more accurately detail for readers what tenets or notions remain important to me.

My desire to understand dying is driven in large part by my beliefs about people, their lives and their stories. I consider myself a feminist and feel some of my opinions influence this research. Feminism goes beyond issues of gender. For me, feminism is a discourse that tries to expand how we see our communities, our society, and ourselves. Feminist literature points to the privileged nature of knowledge and power in our society (Allen, 1996; Allen, Maeda Allman, & Powers, 1991; Jagger, 1989; McCormick & Roussy, 1997). Feminism critically examines how power imbalances serve to marginalize those who do not fit within the parameters defined by the powerful. The powerful are often male, white middle class collectives which define 'norms' according only to their situation (Allen et al., 1991).

Flowing from this society in which we are embedded, there is a pervasive belief that knowledge is valued when it is objective, universal and generalizable. When this knowledge is applied to understand an experience, without consideration for how personal meanings contribute to the totality of the experience, these particular interpretations tend to be oppressed. In palliative care there remains an inclination to favor scientific ways of knowing the experience of dying. Venues for people to express their stories gives prominence not to vague generalizations, but rather to how we can learn from hearing the particulars.

Feminism as a discourse challenges these assumptions and advocates for a more inclusive perspective of power, knowledge and individual perspectives. This discourse also challenges what is omitted for the sake of generalizability (Griffin, 1982). For me, feminist discourses do not attempt to dampen the importance of objective knowledge, but to expose subjective personal interpretations as being comparable yet different ways of understanding our world. Feminism values and highlights the particular experiences of people free of the imposed norms. This act recognizes the multiple ways of knowing that are not limited to the empirical, positivist or objective positioning. These beliefs are tenets upon which this research is grounded.

The experience of dying is not exempt from these feminist issues because the phenomenon is not separate from the life that is lived by an individual. Dying does not occur away from people, communities and institutions, but is embedded within these contexts. When we consider the multiple meanings, and complexity of dying we need to critically challenge the social injustices that exist in society. These injustices occur when we favor only certain meanings. We see this occurring when we say what dying 'is' or

'should' be. When this is done it denies what living with impending death means for each person. I believe it is also an injustice when we discount the relevance of how people choose to live with terminal illness and oppress this human element to the complex concept of dying. When we examine the ways in which we interact and relate to people with life threatening illnesses we see that often medicalization equates to the objectification of people (Allen et al., 1991; Benner & Wrubel, 1989; Gadow, 1994). Care becomes purposeful, directed primarily towards the corporeal body. This disembodiment is sustained in the actions of caregivers that are preoccupied with nourishing the body, cleaning the hair and skin, controlling the symptoms, managing the pain and moistening the mouth. These tasks receive our dutiful care and attention. In doing these tasks we are helping, caring and loving. This is a deception that tactfully limits the way the experience is understood. We recognize the 'doing' while sometimes shunning the acknowledgment of 'being'.

It is my opinion that few health care providers, including myself, would like to acknowledge that they focus upon the physical person and maintain a professional distance. I was introduced to Mr. C. and prepared to turn him in bed. He did not respond to my introduction. It was obvious that he was drinking his last breaths of life. Mrs. C. and her son were in the room and their expressions and posture told me they were relieved that we would be doing the physical care. Mr.C. was now on his left side and appeared comfortable with the exception of the hoarse laboring respiration. The nursing assistant laid Mr.C.'s hand atop of the bedcovers and I saw his tattoo. My relationship with Mr.C. instantly changed as I recalled meeting him a week earlier at another hospital. I remember that he had a stoic demeanor, as he described parts of his life and explained where and when he had gotten his distinctive tattoo. Working in palliative care settings I have attempted to

keep the client as person, central to my work and care. It was my recognizing blue ink on the forearm of a man that awakened me to the reality that my care at times was distant and focused upon the physical needs of a person with little consideration for the person and meanings that dying holds for them.

I believe scientific knowledge, when viewed as the only viable way of knowing, can serve to distance the living from the dying. We push away from our mortality by calling or labeling people as dying. Feminist literature I have read has made me conscious of how often in our society we fragment ourselves from people based on the assumption that we are unlike them and their situations. We create an artificial divide between the 'us' and 'them' (Griffin, 1982; Jevne, 1994). On this playing field we remain distinct from people with terminal illnesses, able to impose professional power and control when we deem it is necessary, and also allowing caregivers to walk away when feeling too vulnerable. Often this distancing is unconscious, and my hope is to think about how dying is understood and see the phenomenon in a different light. "We assume we are knowledgeable about their bodies and their feelings and their souls. If we are open, these others whom we call 'patients' become our teachers" (Jevne, 1994, p.110).

It seems that critical theory shares some of the tenets of feminism. I find critical theory appealing because it extends beyond the identification of power discrepancies, and social injustices and challenges the status quo (Allen, 1996; McCormick & Roussy, 1997). "Critical theory attempts to articulate a comprehensive social theory and a critique of oppressive social structures based on hegemonic power relations. The goal of the various critical theories is emancipation from oppressive conditions that limit autonomy and responsibility" (McCormick & Roussy, 1997, p.269). Critical theory meshes well with the

principles of hermeneutics. Both call into question not only how we view the experience, but also how this experience relates to the social communities we share.

There are many ways to understand dying, and that understanding has many layers and depths. Society has assumptions and beliefs about death and dying which over time and with acceptance have established themselves as unwritten truths. These assumptions often remain unchallenged and can guide or restrict how we understand experiences. It would be negligent to generate meanings of dying without some interaction with the other layers or ways in which the meanings of dying continue to be created in society.

Ecological journey

Death and dying occur daily and are part of life. Just as no person can live isolated and insulated from the influence of people and environment, no person can die without these influences. How I understand dying, while personal and introspective, is also influenced by the environment in which I am entangled. This environment includes the varying sources and knowledge about the experience of dying. As a researcher there is a process of positioning, or grounding oneself in relation to other research studies. The researcher begins with a review of the literature, exposes what is already known on the subject, then examines and critiques relevant research studies. This often serves as an initial step, a 'digging into' the textures of the Earth, the textures that inform understandings. For me the process of understanding the experience of dying and the 'fabric of human discourse' were as Jardine (1992) suggests journeys that did not stop after identifying or justifying the placement and purpose of this research. It included questioning how we come to understand the experience, and questioning where these understandings originate.

So, the review of the literature was in some ways a starting point where I was able to stand at the threshold of understanding dying, but it was also more. When authors write about dying their interpretations keep me in the play and flux, and keep me thinking. Mortality is an inevitability of life and because it is so personal and inextricably linked with our lives, it has been a topic of discussion, in daily lives, philosophy, prose, art and literature since the beginning of man.

And who by the fire, who by water
 Who in the sunshine, who in the night time,
 Who by high ordeal, who by common trial.
 Who in your merry, merry month of May,
 Who by very slow decay
 And who shall I say is calling? (Cohen, 1974).

As Leonard Cohen (1974) asks of those who listen to his song, when people's lives end in so many different ways and so personally is it possible to label this phenomenon with the one word of death? Who shall I say is calling? Is God calling? Is there a world beyond that is calling? Is Mohammed beckoning? Is death calling? There are so many contexts of death. In order to understand the phenomenon of dying for this research it became necessary to focus the scope of the literature review, and perhaps more appropriately the topic of dying. The research that was reviewed was limited to the domains of nursing and allied health disciplines. The review was narrow in focus because of the extensive body of knowledge that has developed on the topic. The experience of dying incorporates the many ways a person may die or think about dying. The literature that was reviewed was narrowed to studies and sources that address dying as a result of illness. It is my assumption that living with, and dying from, a terminal illness is different than deaths that are the result of accidents, wars, murders and suicides.

Dying is a phenomenon with many dimensions each linked to our lives in some way. We all generate personal meanings about the experience of dying. Therefore the meanings are varied and diverse. The subjectivity of how dying is understood by individuals seems to complicate the foundations of understanding. Perhaps this is because personal narratives and perspectives generate a multitude of possibilities. Dying is something that cannot be definitively understood. It is interesting that the body of knowledge on dying and palliative care is dominated by literature attempting to tame the uncertain nature of the experience.

Medical research typically segments the experience of dying into particular aspects that can be analyzed and understood. There is emphasis on understanding cellular changes with diseases, pain management, symptom control, psychosocial needs, family dynamics, support, grief and bereavement. Research studies that seek to understand these processes are often generated in a scientific or objective manner where personal events and meanings are deemed irrelevant. In my practice the palliative resource Medical Care of the Dying, by the Victoria Hospice Society (1998) is often referenced and contains much of what the title implies. It targets helping health professionals in their delivery of care and includes sections on: cancer, pain principles, AIDS care, death and dying, and psychosocial care. Also included are sections devoted to gastrointestinal, respiratory, cardiovascular, orthopedic, genitourinary, neurological and dermatological systems as impacted by terminal illnesses (Victoria Hospice Society, 1998). When looking to understand the patient's perspective there is little enlightenment to be found. Included in the introductory chapter is information on: patient needs, dying with dignity, rights of patients and ethical aspects of care. Family support and grief support is discussed in the final chapters. Although there is mention of social, physical, cognitive and spiritual needs, these aspects still convey a medical

perception without emphasis upon what the experience of dying might mean for the person. This text is not unique or exceptional in its perspective. The experience of dying often becomes reduced to particular physiological and psychological problems as viewed by health care professionals. They place the phenomenon of dying in a medical context where it is often detached from the people themselves, from the context of their lives, and assumes a singular way to understand dying.

Theorists, researchers and writers often frame, construct, and communicate theories and ideas in manageable ways. They lead us to believe their construction is true, solid and unbending. These sources may assist our understandings about dying yet often give a false sense of comprehensiveness. These sources enlighten portions of dying, yet by their nature do little to help us grasp the meanings of dying for individual people.

When a person has a palliative diagnosis it becomes part of that person's day to day existence. It is an experience that cannot be only understood using objective, disassociated methods. Qualitative research methods attempt to learn from the subjective ways in which dying is experienced and understood. These vantages show the phenomenon of dying in a different light and teach different lessons.

A qualitative research study by Payne & Langley-Evans (1996) suggested there were differences between the hospice staff and patient's perceptions of a 'good' death. Patients described: dying in one's sleep, dying quietly, with dignity, being pain free and dying suddenly, as being ideal ways of dying. Interestingly, caregivers characterize a 'good' death as having adequate symptom control, family involvement, peacefulness and lack of distress. The study points to how often there are different values or qualities with dying and differences between the opinions of care providers and care recipients (Payne & Langley-

Evans, 1996). I think of the people who die with pain (which many do), or those patients I have cared for who hungered for each living breath. If there are tendencies to think that a person can have a 'good' death is it possible to have a 'bad' death? In our attempts to categorize, could we be missing part of the picture? Although this study uses subjective experience as a means of knowing, it falls short of interpreting these realities and in particular the realities as lived by people who have a terminal illness. In this study, the meanings of dying from these people are vague and limited to categories. We do not better understand what dying with dignity means for individuals. We do not better understand how a person lives with the threat of pain. In this research personal meanings also remain entwined in the medical landscape. A landscape that has been shown often to oppress and undervalue personal stories. It compares the perspectives of nurses and patients and while it points to differences in viewpoints, it limits the importance of the individual meanings that have been discovered. Comparing and contrasting viewpoints inadvertently leads readers to understand one perspective in relation to the other. This has me questioning what might be happening when we juxtapose professional and personal ways to understand dying. Frequently one perspective becomes more valid.

Postmodernism has influenced nursing research and there are studies that deconstruct how dying is conceptualized. Part of this deconstruction is a result of moving the focus away from the dominant medical narratives, and refocusing upon how dying is understood. In a case study, Jones (1993) uncovers the meanings of health that was generated for an individual who was dying. Understanding how a person lives with dying and perceives health challenges subtle medical narratives where there is an underlying assumption that dying is separate from health. Jones' (1993) approach to understanding a person's

experience emphasizes the need to search for meaning with patients in order to support healing, nurturing and improve the quality of patient's lives. Fryback's (1992) naturalist study also focused on people with a terminal diagnosis. In this study people expressed their beliefs about health in the presence of disease. Their beliefs about health encompassed more than the physical body. There were three domains of health described that included the mental/emotional domain, the spiritual domain, and the physical domain (Fryback, 1992). On a continuum of life, death and health have traditionally been at opposing poles. This research challenges the concepts of health and dying as not being dichotomous but rather integrated in the human experience.

There are few research studies utilizing a hermeneutic framework in the area of palliative care. Nevertheless, there are sources that relate stories of people, and similarly also challenge understanding, learning and thinking about the experience of dying differently. Powerful, telling and thought provoking books have been written about the event of dying. Such books include: Voices of Death (Schneidman, 1995), Final Gifts (Callanan & Kelley, 1992), Mortally Wounded (Kearney, 1996), and Dying Well (Byock, 1997). Sharing the aims of this research these books bring forth the voices of people that know their death is impending. These writings are also similar to this research because they recognize that individual experiences hold particular meanings and are part of the experience of dying. In his introduction Byock (1997) acknowledges the breadth of lived experiences and in his book he recounts stories that exemplify this scope. Although not stated in these words, the significance of individual experience is implicit.

The decisions people make to complete their dying days, or to help someone they love complete a life, are rarely easy.... Nevertheless, these end-of-life decisions

create opportunities for new experiences and discoveries that range from the fairly mundane to the frankly extraordinary (Byock, 1997, p.137).

Byock's (1997) narrative highlights not particular disease processes or treatments but the variety of meanings that the illnesses and impending death have for each individual.

Dying well does not always demand exceptional imagination and tenacity. Occasionally it is simpler and a little more private, although no less demanding.... Such was the case for Steve Morris, a Montana cowboy who typified the western culture of stoicism and deadpan reactions (Byock, 1997, p.139).

Knowledge about the process of dying is what Callanan & Kelley (1992) refer to as Nearing Death Awareness. This Nearing Death Awareness or process of dying is typically unrecognized and these authors invite caregivers, families and friends to relate to people with terminal illness where meanings can be understood. For example, they stress accepting and inclusive approaches when engaging in conversations in order to understand. "If you accept these messages you can then try to understand what the person is telling you, rather than looking for other explanations, such as medicine, hallucination, or loss of intellectual function" (Callanan & Kelley, 1992, p.96).

None of these authors espouse personal meanings as being more 'correct', 'right', or 'true'. Rather there is an understanding that these meanings and these stories are possibilities for the experience of dying, and are the realities of others. Finally, in each of these books the authors often acknowledge the interconnectedness of our lives and put forward these stories for particular reasons. Schneidman (1980) emphasizes this connection, "Occasionally, there may be voices that you will recognize from your own experiences, fantasies, dreams, or nightmares. When that occurs, then those voices will echo in your mind and you will know intuitively what they are saying"(p.xii). Our

understanding of dying is a process that continues as readers engage with these texts and find meaning as the stories are read and become part of our thoughts. Although a hermeneutic process does not guide these writings they exemplify how many caregivers intuitively do what hermeneutics makes explicit.

It would be negligent to talk about dying without acknowledging Dr. Kubler-Ross' research and contributions to the topic. Kubler-Ross' (1969) well known book On Death and Dying, defines five stages that a person with terminal illness experiences: denial and isolation, anger, bargaining, depression, and acceptance. It is interesting that Kubler-Ross' extensive work and writing about living with dying is frequently interpreted as being a conclusive way to sum up such a complex phenomenon. Her observations *also* challenge the dominance of medical perspectives, the ways we understand dying, and how the influence of culture and society are part of dying. These ideas seem to be lost in favor of understanding dying based upon the five stages. The fragmentation of Kubler-Ross' ideas speaks to how once again there are attempts to say we understand dying. These themes give a false impression that how a person makes sense of their dying can be understood when it fits within one or more of these themes.

Kubler-Ross developed these ideas of living and dying based upon years of clinical encounters with people who were at the end of life. Although personal stories were the sources of knowing dying, somehow these accounts become interpreted by caregivers as generalizable theories that can be applied to all people. Some people may have reactions that are similar to the steps outlined, but there should be caution from making the assumption that every person will interpret this process in a similar manner. What it means

to be dying when you're a mother of two children may be quite different than when you are homeless and dying of hepatitis.

Like many theories, Kubler-Ross' (1969) work emphasizes a particular way to understanding dying and has limitations. The five stages of dying may be useful but I would assert that they are useful only up to a point. People can feel anger when they realize life is obviously time-limited. This appears to re-enforce or fit with Kubler-Ross' (1969) theory. When we take this a step farther, when we question personal meanings and explore this reaction we come closer to realizing how this illness impacts the person and their world. Perhaps the anger stems from a feeling that dying is an injustice when a person has vigilantly upheld a healthy lifestyle. Perhaps a person is expressing anger at losing independence as their body physically deteriorates. Both are reactions of anger but the sources of anger and more importantly the meanings of this illness are very different. When we believe we understand dying as defined in categories or stages we are not open to new understandings of how this event affects them and is part of their life.

Nurses involved in palliative care often hear personal accounts of how illness and dying are part of people's lives. Hermeneutic research recognizes these accounts as being types of knowledge that can inform, and change how we understand dying. A hermeneutic research approach is able to "explicate the meanings as we live in our everyday existence" (vanManen, 1997, p. 11). Fundamental to this study is a desire to hear the person's story in order to understand dying differently. Although interest in this research approach is growing, palliative care literature revealed few studies, and none that sought to understand the experience of dying this way. Personal stories and the meanings created have been addressed in other studies and teach us about phenomena such as: caring and uncaring

encounters (Halldorsdottir & Hamrin, 1997); living with cancer and existential changes (Halldorsdottir & Hamrin, 1996); spiritual relationships between nurses and families (Stiles, 1994); the experience of meaning in suffering (Steeves & Kahn, 1987) and the meaning of being understood (McIntyre, 1997). These studies inform nurses about aspects of dying or living with illness where the knowledge was generated from conversations with patients. Each of these studies shared conclusions that beckon nurses to continue to recognize how knowledge and understanding the particular experiences of another occur in our relationships with patients. They also accentuate how nursing practice can improve as a result of these new understandings.

As the hospice and palliative care movement gains exposure and credibility within our society, we see a surge of different literature developing. Interestingly, it has been this interest on the part of consumers rather than providers of health care that has more readily given prominence to the experience of dying beyond scientific parameters. In keeping with the consumer interest, current literature and media are tending to present death and dying as part of, rather than separate from human experience. Books like, Tuesdays with Morrie (Albom, 1997), Cancer in Two Voices (Butler & Rosenblum, 1991), Twelve Weeks in Spring (Callwood, 1986), and In Lieu of Flowers (Cobb, 2000) are not resources that are hidden in medical libraries, or infrequently visited corners. They are easily found facing the public in any large bookstore. These sources do not typically fall within the domain of scholarly papers, yet I feel these permit a greater understanding of the meanings of dying often from the perspective of non-health professionals. Twelve Weeks in Spring (1986), poignantly accounts the true story of a woman dying of cancer, whose wish to remain at home to die was realized with the help and support of a network of friends. "It is not a

stretch of the truth to say that Margaret enjoyed her dying. While she was also angry and indignant that her life was ending, she basked in the kindness that surrounded her” (Callwood, 1986, Introduction). Basking in kindness are not words typically associate with dying yet the author stirs these words into the picture to make it more complete, more particular. These types of stories often poignantly expose the domain of dying through the eyes and the heart of others who are simply human.

We wanted to tell you our story.... A story about struggle and courage, even more than the part about sickness and death. A story about loss and the gifts it brings. We wanted to tell our story, finally, because this writing made us visible to ourselves as we were living it (Butler & Rosenblum, 1991, p. i).

The story of Butler & Rosenblum (1991) is one that includes lesbianism, careers, communication, coping, and living when one partner has breast cancer. Their story does not talk about hope, challenges, and physical changes in a detached manner but rather permits the reader to share in how the inevitability of death is lived and learned.

There are a lot of lessons that come with this disease, or maybe it's just that you learn to make them into lessons.... You can get courage to take larger risks than you ever have before. I mean, you're already sick, so what can happen to you? ... Cancer has released the courage in me.... [Cancer] can entice you into doing those things you have been postponing... Cancer actualizes you in that way, by not waiting (Butler & Rosenblum, 1991, p. 193).

These biographies and personal accounts detail the emotions, feelings, worries, fears, joys and sorrows that are a part of death and dying. Writing their stories gives life to the often-unheard voices. As these stories and voices describe dying they teach us about dying in ways that are distinct from research and theory. Although distinct they point to how particular experiences when communicated, can offer unique possibilities and new ways to understand the universal experience of dying.

This ecological journey should not be confined to the world of academia or even to the world of nursing. Although they are not factual or accurate in the typical sense, the depiction of dying illustrated in novels also teach us about the phenomenon of dying. The words are not bound to scientific limits, can be poignant and evocative. In the novel The Stone Diaries (1993) Shields offers an interpretation of dying, expressed through the protagonist.

Something occurred to her – something transparently simple, something that she had always known, it seems, but never articulated. Which is that the moment of death occurs while we are still alive. Life marches right up to the wall of that final darkness, one extreme state of being butted against the other. Not even a breath separates them. Not even a blink of the eye (Shields, 1993, p.342).

“Through a good novel, then, we are given the chance of living through an experience that provides us with the opportunity of gaining insight into certain aspects of the human condition” (vanManen, 1997, p. 70). The literature reviewed is not all encompassing but are examples that resonate with understanding. Novels where dying is illustrated not only spring forth from the imagination of the writer, but often echo images and notions found in our society and the culture in which authors are also embedded.

Passed. Departed. Left

But no. Not left. God damn it – dead

There. He had said it (Findley, 1997, p.31).

How often do we use euphemisms to express or describe death? Findley (1997) taps into an unspoken belief. The belief that not using words like death, and dying, is somehow easier, more tactful. Our use of language surrounding the dying experience is impacted by

what society assumes is most tactful or appropriate. In these few sentences the author makes clear the impression that words cannot mask, hide, or palliate the reality of death.

Good writers have an ability to draw readers into the stories. Critical thoughts are frequently suspended as we empathize with the characters and in a voyeuristic manner, experience the scene before us on paper (vanManen, 1997). Fictitious depictions of people who are dying convey possible events, possible worlds, and inform others about what the phenomenon of dying may include. Atwood (2000) does not gloss over or romanticize how a young daughter feels as she visits her dying mother.

I wasn't allowed to talk to her because (said Reenie) she was rambling. That meant she thought she was somewhere else. Each day there was less of her. Her cheekbones were prominent; she smelled of milk, and of something raw, something rancid, like the brown paper meat came wrapped in (Atwood, 2000, p.93).

This writing reminds me that dying is influenced by culture. A culture that assumes communication with people who are dying is pointless. The phenomenon of dying is also pulled to a sensual level. A level where the scent of a dying body is also part of the experience. Not all types of knowledge are able to teach us about dying on such a primordial level.

It becomes important to recognize how dying is pervasive within our world, in our studies, in our careers, in our leisure time and in our every day life. We absorb images and ideas about life and death so frequently that we can become ignorant to how they influence our perceptions, interpretations and understandings.

Chapter Three: A Way To Understand Dying

A hermeneutic process

Hermeneutics leads us: not to a conclusion which gives comfort but to a thunderstorm, not to a closure but to a dis-closure, an openness toward what cannot be encompassed, where we lose our breath and are stopped in our tracks, at least momentarily, for it always belongs to our condition to remain on the way" (Caputo, 1987, p.214).

This research uses a hermeneutic process to understand the phenomenon dying. A hermeneutic approach to research is concerned with interpretation. It espouses that interpretation is continuous, as on some level, we all seek to understand our world our everyday experiences and ourselves. It is assumed that knowledge can be generated in our everyday activities, as we attempt to make sense of these activities. Dying can be viewed as an experience, and experience holds many different meanings. Hermeneutics is not driven to find answers to the question, but rather to generate multiple possibilities to understand the experience of dying.

Hermeneutics is the research approach I chose to understand dying. The task of understanding dying and interpreting the research text is guided by the philosophical foundation of hermeneutics. With this philosophical approach, there is an understanding about how the research is conducted and how the researcher attempts to maintain the integrity of the research.

The philosophical tradition

The hermeneutic tradition aims not to understand something completely but to understand a thing differently (Caputo, 1987; Gadamer, 1997). This philosophy is based upon ontological and epistemological beliefs that questioned what it means to be a person, and how people gain knowledge and understanding. Hermeneutics emphasizes that there

are multiple realities. As people are unique, so too are their perceptions and interpretations of the world around them (Caputo, 1987; Gadamer, 1997). Knowledge is not attained from the simplistic notion of being taught or reading. Philosophy delves deeper into examining knowledge. Hermeneutics is based upon the idea that we as humans are learning, interpreting and integrating knowledge continually as we experience life. "Philosophical hermeneutics does not consider understanding as a way of knowing but as a 'mode of being'" (Annells, 1996, p.708).

Hermeneutics as a research approach is governed by this hermeneutic philosophy. There is a greater focus upon the process of understanding than upon a method prescribed to obtain this knowledge (Gadamer, 1997). Understanding the hermeneutic research process, for me, hinged upon an understanding of the philosophy. Reading and synthesizing the hermeneutic ideas of prejudice, fusion of horizons, the flux and uncertainty, and language developed this understanding. Taking these elements, conceptualizing and (more accurately) feeling the interconnectedness of these notions placed my interpretations of dying into a hermeneutic process or 'hermeneutic circle'. The hermeneutic circle is grounded in the idea of movement between what is commonly understood in the large context of the world, and portions of the experience which we have knowledge of as a result of understanding the particular.

Fundamentally, understanding is always a movement in this kind of circle, which is why the repeated return from the whole to the parts, and vice versa, is essential. Moreover, this circle is constantly expanding, since the concept of the whole is relative, and being integrated in ever larger contexts always affects the understanding of the individual part (Gadamer, 1997, p.190).

In this research, conversations about particular experience of dying create knowledge about dying. These accounts do not tell us what dying is, but rather are portions of how dying is

understood. No one commentary on the phenomenon of dying is 'correct', 'complete', 'true', or 'right'. But each narrative broadens the boundaries of what we know when these meanings are placed back to what is generally known about dying. As we understand one, we better understand the other. The relationship is reciprocal. Knowledge of the particular is not only what the person with the terminal illness says it is, but also what I as a researcher, nurse and person believe this to be. As I place these meanings of dying out for critique, and examination into the hermeneutic circle, I gain a greater understanding.

Prejudice

Heidegger's philosophy is grounded in the assumption that persons are connected with the world that they seek to understand. Objectivity is a condition that can never be achieved because we cannot detach ourselves from our being-in-the-world (Caputo, 1987). For this reason, interpretation is influenced by the history, culture, conscious and unconscious assumptions of the researcher as intricately as it is for the subject of study. These pre-understandings or prejudices then need to be acknowledged in the hermeneutic circle and the research process. Contrary to scientific traditions, which believe in objective, dispassionate observers, the hermeneutic process neither sees this as a good or bad influence. Rather it includes this influence in the rigors of accounting for why certain interpretations have been made. "A person who is trying to understand a text is always projecting. He projects a meaning for the text as a whole as soon as some initial meaning emerges in the text. Again, the initial meaning emerges only because he is reading the text with particular expectations in regard to a certain meaning" (Gadamer, 1997, p.267).

To understand personal insights, impressions and potential projections I have recorded my thoughts during various stages of the process in a journal. This was to

facilitate interpreting data, which was undoubtedly influenced by my participation in the process. Self reflection and journal writing are means I have used as a researcher to examine my assumptions, impressions, beliefs, and what I believe dying to be. This process placed my pre-understandings of dying in a position where they created meanings and at times accounted for why and how I thought about dying. Excerpts from my journal writing and honest commentary about my assumptions throughout this work also helped to account for my interpretations. Interpretation is not merely recounting verbatim themes but instead is part of a diligent process of thinking, postulating, questioning, wondering, surmising, comparing, including, and questioning again (Caputo, 1987).

Fusion of horizons

With feet planted on the sandy beach you look forward to see the setting sun. The picture contains the meeting of the sea and sky, a fusion of horizons. You understand the sea and the sky in relation to the other. This is how I understood Gadamer's (1997) metaphor for understanding. I could understand another person's particular experience of dying set against the backdrop of my prejudices and ideas. "A person who has no horizon does not see far enough and hence overvalues what is nearest to him. On the other hand, 'to have a horizon' means not being limited to what is nearby but being able to see beyond it" (Gadamer, 1997, p.302). Playing and looking at where our horizons and perspectives meet could generate new meanings of dying.

The hermeneutic process seems at work in every aspect of this research, not just how I perceive dying but also how I perceive this hermeneutic 'method'. Questioning, questioning and questioning lead me to wonder if the fusion of horizons could be more. As

I read Gadamer's (1997) words my seaside picture suddenly becomes more developed, more containing, and more telling.

The concept of 'horizon' suggests itself because it expresses the superior breath of vision that the person who is trying to understand must have. To acquire a horizon means that one learns to look beyond what is close at hand - not in order to look away from it but to see it better, within a larger whole and in truer proportion (Gadamer, 1997, p.305).

The seaside picture also contains the boats, the swimmers and the cracked shells only meters from my feet. From the location on the beach the aperture can change and move, at times focussing onto small objects, at times peering to the distance, at times stepping back to see all that is contained in the picture. It is only as I step back that I am able to see and understand how a person can make sense of something by situating the phenomenon against a bigger backdrop of understanding. The interpretation of dying is not only focused upon one or even five particular experiences of what it is like to die. A step backwards shows that it also contains assumptions, stereotypes, cultural beliefs, societal values, and how this experience is perceived in the bigger picture of life experiences. The experience of dying has many layers, vantages, perspectives, and therefore many meanings. The process of understanding is always changing and moving. Gadamer's (1997) fusion of horizons urges us to move our vantages, uncover the layers, and generate new meanings.

The flux and uncertainty

John Caputo (1987) adds to the traditions of hermeneutics by accentuating the dynamic motion of understanding. Influenced by the work of Derrida and Kierkegaard, Caputo (1987) expands Heidegger's philosophy of hermeneutics. He expresses this idea of dynamic understanding in the notions of the flux, and the play. "What I mean by hermeneutics in its radicalized mode has all along been this willingness to stay in the play,

to stay in the flux, without bailing out at the last moment” (Caputo, 1987, p.198). The flux represents the fluidity of time, events and life. It represents the ups, the downs, and the uncertainty from moment to moment. Think of all the energy that we spend to avoid uncertainty. We ponder, hypothesize, measure, record, plan, map and attempt to prepare for what lies ahead of us. How much of our life is directed towards conquering or finding what we don’t know? We feel secure and comfortable when we understand. Caputo (1987) cautions against this false sense of security and cheers us toward the uncertain. It is within this flux, within what we don’t know, within what we think we know, that we might move our margins and create room for new ways of understanding. So as I define, sum up, describe or conclude I am challenged to stop. Challenged to look beyond these conclusions for what I might be missing, to listen for hidden meanings, to see different perspectives or to feel how a person’s story of dying can be different. The flux and the play throw me back into the process of interpretation and the hermeneutic circle to think again. Perhaps notions about dying box in and limit that dying could be? What could they be saying? What else does dying include? As I follow this flux or wave of understanding I felt its motion. At times it seems I tap new meanings to understand dying in a different way, then at other moments I feel defeated and blocked by this uncertainty. It seems easier, to say I understand dying.

Language

Language expresses and gives substance to the meanings we create as we make sense of our lives and the world. Hermeneutic research that seeks to understand human experience is necessarily dependent upon language – like any understanding. We can only understand something because of our ability to know what something is or might be

(Gadamer, 1997). Language gives us this ability. It is the medium that expresses all experience and meaning (Gadamer, 1997; Kvale, 1996). Experience 'comes to life' and becomes illuminated through language. "For language is by nature the language of conversation; it fully realizes itself only in the process of coming to an understanding" (Gadamer, 1997, p.446). Language includes the words and silences that shape our thoughts as we read, think, and converse with others. We cannot think, just as we cannot have conversations - without language.

In this research people who are living with terminal illness shared what the experience of dying means for them. In the collaborative and interactive process of conversation meanings about death and dying are generated. Meanings do not 'belong' to the researcher or to the participant but rather are co-created as both individuals attempt to understand. "Reaching an understanding in language places a subject matter before those communicating like a disputed object set between them (Gadamer, 1997, p.446). The experience of dying becomes realized and understood as we speak to, and speak about the subject of dying. The words and ideas expressed become the source of interpretation and understanding.

Hermeneutic interpretation requires sensitivity to language. This sensitivity relates to how ideas are expressed in conversations, thinking, and writing. "The phenomenological method consists of the ability, or rather the art of being sensitive -- sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak" (vanManen, 1997, p.111). Questioning and wondering about the words and phrases spoken is necessary because they tell us something specific about the experience as a whole. Why does he describe dying in this way? If a person says they are afraid of dying,

what might this tell me about their experience? Likewise, in silences and what is not said about dying meanings can develop.

Hermeneutic writing

“Writing leads to careful attention to the details of experience carried in words to a kind of contemplation. Such careful attention in turn leads to a deeper awareness of the profound interconnectedness of everything, and to a mode of insight more in line with what might be termed ‘mystical appreciation’” (Smith, 1992, p. 255). One of the greatest challenges for me has been this task of placing my notions, ideas, and interpretations in the permanency of ink. Perhaps this is because I feel a sense of responsibility. I feel a responsibility to the people who shared portions of their lives, and a responsibility to be true to my interpretations by expressing what might not have been said. And perhaps most weighing is the responsibility to write in such a way that will stimulate readers to think about dying differently. For me, it seems it is this task of dissemination for which I plod slowly. Writing an idea, paying attention to the way I use words, pointing to possibilities, constructing these ideas, I become bogged down and lose my momentum. At other times, this process of writing seems cathartic and revealing. Where did this idea come from? It seems to capture my thoughts. And after placing momentary value on this one idea, I am reminded of the flux and the play. Perhaps this captured thought is only one of many. I must think again, and write again. As though writing is a different way of thinking.

I see now how the hermeneutic process is never ending as there is repetition and a constant circling, and reworking of what we think we know. I then move to a place of questioning this process. Where does it end? How can we learn from notions that are constantly moving and changing? Is it possible to stop this process, to give permanence to

ideas about dying that are evolving? Part of me doubts the false sense of pinning down the flux, the play, the uncertainty, and the mystery.

Openness to the mystery

“We are all bound together by the mystery of our mortality and by midnight shadows” (Caputo, 1987, p.288). For me, being open to the mystery helps me put my notions and ideas of dying into perspective, remembering that any new understandings are not new answers but rather new possibilities. Possibilities that extend what is known and add a degree of breadth to how I come to understand the experience of dying. It pushes me to remain open, always seeking difference in the commonness of an experience such as dying. “All that is asked is that we remain open to the meaning of the other person or text. But this openness always includes our situating the other meaning in relation to the whole of our own meanings or us in relation to it. Now, the fact is that meanings represent a fluid multiplicity of possibilities” (Gadamer, p. 268).

The hermeneutic tradition like understanding ‘remains on the way’. It seems to be continually stretched by writers, philosophers, researchers and people who are open to the multiple possibilities of what hermeneutics could encompass. Likewise research done with a hermeneutic approach can be equated to a never-ending journey of discovery it may stop us in our tracks, but it then changes and moves. New meanings can continually be created and develop with reflection, revisiting, and the passing of time. It is difficult for me to separate the research process from the research itself. It is only possible to express how I understand hermeneutics today, and portions of how I believe I came to these understandings. Doing hermeneutic research is not a linear process with the tasks of data collection, analysis and interpretation all separate and segmented. These processes overlap,

mesh and are done almost simultaneously. My understanding of hermeneutics flows and changes as does my understanding of the question: What is the experience of dying?

Placement of the researcher

My understanding of hermeneutics has developed in large part through engagement with the writings of Gadamer (1997), vanManen (1997) and Caputo (1987), and as I come to understand dying, hermeneutics and myself. My process of learning echoes the process of understanding my participants, and the texts. Each weaves and combines with the other elements to integrate into a momentary understanding from which I move forward and backward into the unknown. Researching the Lived Experience (1997), by vanManen and Truth and Method (1997), by Gadamer were texts which started me on the road of hermeneutics. From these texts I have taken portions, and returned to portions of their writing. Yet as I continue in this hermeneutic process, I find the writing of Caputo (1987) to be most appealing, and it has me questioning my beliefs about the experience of dying. It moves my thinking and continually reminds me to be open to the mystery of dying. The process of hermeneutics challenges many parts of my being. It challenges how I look, how I interpret and how I communicate. This process is frustrating, as I so desperately want to define dying. There is anxiety and impetuosity, which restricted what I see within the text. As I release to the uncertainty and flux I feel different. I am reminded to release my desire for answers, for the uncertainty of my own thoughts and interpretations. Instead of concluding and summarizing, constantly playing, moving with ideas and staying in the uncertainty is my challenge. To communicate this openness to the mystery and facets of dying is my purpose.

Integrity

There is no one way to judge the integrity of hermeneutic research. This does not infer that integrity is not something that can be achieved or that rigor cannot be applied to this research. Indeed the issue of integrity is fundamental to this research if it is to serve the purpose of expanding what is known about the phenomenon of dying. Koch (1996) states that in qualitative research “an inquirer needs to engage in this literature and select or develop the most appropriate criteria for their particular study” (p. 178). There are many indicators and notions about how to ensure the integrity of qualitative and hermeneutic research in particular. Plager (1994) outlines three factors that contribute to the rigor of hermeneutic research, the examination of the retrospective and historical nature of the phenomenon, the time-consuming need to study the participants in the context of their everyday situatedness, and finally by being committed to interpreting the text. Sandelowski (1986) looks at the ‘truth value’, ‘applicability’, ‘consistence’ and ‘neutrality’ as indicators to evaluated qualitative research. The criteria of ‘credibility’, ‘fittingness’ and ‘auditability’ are indicators that Beck (1993) includes in qualitative research.

Ensuring the integrity of this research is not only an academic requirement. It is important to me, as a nurse, a researcher and a person. For me, maintaining the integrity of the research is fundamental from writing the proposal, during the conversations and to the final product. I tried to keep in mind Koch’s (1996) observations that “while there is a lack of consensus regarding the idea of rigor, legitimacy for knowledge claims are dependant upon demonstrating that the research study is trustworthy and believable” (Koch, 1996, p. 178). This trustworthiness and believability is maintained with attention to ethics governing qualitative research and the integrity. Ethical parameters included the principles

of confidentiality, accurate reporting, informed consent, and preventing deception (Ramos, 1989). The integrity of the research is dependent upon my ability to explain or account for how my interpretations have been made, by showing how I enter into a hermeneutic circle in order to critically and continually challenge how I understand (vanManen, 1990; Plager, 1994). As a novice to the research process, I initially found it unsettling and difficult to account for the integrity of this particular research, given the variety of theories and criteria espoused by different researchers. My aim is not only to understand the experience of dying, but also to account for how I have come to interpret the text. "A trail of the decisions, theoretical, philosophical, and methodological, has the potential to clarify the research process and establish trustworthiness of the study" (Koch, 1996, p.178).

The fundamental principle, by which the investigator attempts to ensure the integrity and legitimacy of this research, is my adherence, and commitment to the process of the hermeneutic circle. The hermeneutic circle is grounded in the assumption that meaning and understandings are processes that are connected and weave and circle together (Gadamer, 1997). This notion of a hermeneutic circle parallels Caputo's (1987) flux and play in its commitment and necessity to continually interpret the text, looking for possibilities and understanding how these possibilities are generated.

... which means a constant moving back and forth between our experience and theirs, assimilating their experience within our horizons, revising our horizons on the basis of their experience, even as they on their part do the same-until finally some point of convergence and fusion can be reached (Caputo, 1987, p.45).

Integrity is evaluated based upon the researcher's ability to evidence how the elements of this circle have been considered in this study. Included in this circle are the concepts of language, fusion of horizons, prejudices and hermeneutic writing.

Adherence to ethical considerations

Prior to commencing this study approval was received from the Faculty of Nursing Research and Scholarly Development Committee which serves as the faculty level ethics review committee for the University of Calgary General Faculties Council Committee on the Ethics of Human Studies. Approval was also obtained from the Mistahia Bioethics Committee. Participants were recruited from a northern Alberta area through the local Home Care program. The intent of the research was discussed with Home Care nurses and coordinators. At this meeting, the staff identified potential participants. After this process, the Home Care nurses distributed copies of the Letter to Prospective Participants (see Appendix A). Given the small number of participants needed, letters were only distributed to five individuals. Each of these five individuals agreed to participate in the research study, and communicated this via their Home Care nurse who then contacted me. I then arranged a convenient time for the conversation.

Individuals with a life threatening illness are often considered a vulnerable population with sensitive issues. I do not feel that this is reason alone to exclude them from research studies. I do assert that researchers need to be alert and sensitive in their approach and interactions with vulnerable client populations. Ethical implications include upholding confidentiality, accurate reporting, ensuring informed consent, and lack of deception (Ramos, 1980)

Confidentiality was upheld in strategies such as, omission of names from documents, changing names in transcripts and the thesis, and locking the written and audiotaped information in a secure location. I used alias names in the thesis to disguise the participant's identities. This was done after the consent was signed and the new names appeared on the

transcripts and all written material following. As the researcher did all the transcriptions only I knew the false identities. The original name appears only on the consent forms and remains intact. The consents will be destroyed when the final report has been completed and approved by the thesis committee. The audiotapes will also be destroyed when the research is completed. The transcripts of the conversation will remain in the possession of the researcher in a locked cabinet for three years before being destroyed. This practice is in accordance with standards to ensure the validity of any future publications.

The issue I feel needs highlighting for this particular study is emotional security for the participants. Dying can be a sensitive topic because it points to our vulnerability, mortality and fears (Kastenbaum, 2001). Researchers can often be viewed in positions of power. We are educated, have greater medical knowledge than most people, and hold inherently a position of privilege (Gadow, 1980, 1994). For this reason I needed to relinquish 'control' in the conversations and permit the people to determine the issues they felt comfortable talking about. Process consenting was one means to safeguard against doing harm to participants. Process consenting assessed the individual's consent throughout the conversation not just upon initiation when the consent form was signed (Hutchison, Wilson, & Wilson, 1994; Ramos, 1989). "The respondent is kept informed as to his vulnerability to potential dangers, and the investigator and participant make research decisions as a team. The depth of the research relationship makes this possible" (Ramos, 1989, p 61). Participants were aware they could opt out at any time in the research process. During the conversations one participant became emotional and requested to stop the tape. The researcher respected the person's wishes and halted the audiotape, then resumed taping when indicated by the participant. A second participant also requested that a portion of the

conversation not be recorded. The participant was not unwilling to share his particular experience of dying, rather that portion of the conversation was focused around the story of another individual and was not appropriate or necessary for the research.

Generating knowledge about experience

Recruitment and selection of participants

In order to understand the experience of dying for palliative clients it was necessary that the research had a purposive sample (Polit & Hungler, 1995). The sample needed to be comprised of people who had been diagnosed with a terminal illness, as the aim was to study their meanings of the experience. This method of sampling assumed that these individuals had a particular knowledge about the meaning of dying. Terminal illness is random and non-discriminating. Each person's story has the potential for new meanings to emerge. Participants in the research had a palliative diagnosis, and were aware of this medical diagnosis. The individuals were all over eighteen years old, were able to communicate in English and be understood. It was not my intention to draw attention to differences based upon demographics, rather I hoped to present people's stories in a purposeful way where the particular meanings of the experience can teach us, while remaining true to the spirit and soul of each person. For this reason, as a researcher, I choose not to be made aware of any demographic information such as people's age, religious beliefs, or diagnosis. As a nurse I often had this information prior to initial nursing visits. This information, although basic, had me making assumptions about the people I was meeting. As a researcher, not having this information facilitated openness within myself where my assumptions were lessened. Conversations with these people frequently touched upon the topic of diagnosis and the specifics of their illnesses. This occurred when the

participants choose to share this information with the researcher when discussing the experience of dying.

Just as there is no recipe for hermeneutic methods, there is no definitive answer to the required number of participants. "Subjects are initially selected because they can illuminate the phenomenon being studied.... Sample size cannot, therefore, be predetermined because it is dependant on the nature of the data collection and where those data take the investigator" (Sandelowski, 1986, p.31). Some claim that adequate sample size is attained when there is 'saturation' of the data. My aim was to understand the phenomenon of dying with a degree of depth. This depth was achieved as I understood the data and as I reached data 'saturation' from the conversations. Five people agreed to be in the research project. Each participant was interviewed twice with the exception of one individual who was unavailable for the second interview. Unlike quantitative studies, qualitative studies attempt to understand particular experiences and saturation of the data occurred with this small number of participants (Sandelowski, 1986, 1995).

Conversations

"The deeper goal, which is always the thrust of phenomenological research, remains oriented to asking the question of what is the nature of this phenomenon as an essentially human experience" (vanManen, 1997, p.62). The primary means of understanding this human experience of dying was in conversations with the participants. "Conversation is a basic mode of human interaction. Human beings talk with each other - they interact, pose questions, and answer questions. Through conversations we get to know other people, get to learn about their experiences, feelings, and hopes and the world they live in" (Kvale, 1996, p.5). I intentionally chose to gather information in the context of conversations

because I felt that conversations place emphasis upon the relationship between the researcher and the participants where both individuals contributed and together construct the meanings about the experience. This process also attempted to nurture a reciprocal interaction and to limit the power imbalances that often exist between researcher and participant. These conversations were audiotaped with the written consent of the participants (see Appendix B). The consent was reviewed and read with the participant by the researcher prior to the conversations. All the participants signed the consent, were in agreement and were willing to participate in the study. The length of the conversations were determined by the participants with sensitivity given to the stresses often felt by people with terminal illness such as: pain, daily routines, disease processes, emotional and physical pressures. It was important to me that the participants felt comfortable and secure in the environment where the conversations took place. Conversations occurred in people's homes, and in an acute care hospital. Each participant determined the location of the conversation.

I minimized the structured nature of the interviews by reflecting upon the phenomenon, yet not preplanning the questions. "To conduct a conversation, says Gadamer, means to allow oneself to be animated by the question or notion to which the partners in the conversational relation are directed" (vanManen, 1997, p.180). After establishing the purpose and rationale for the interview both researcher and participant entered into a conversation, with few walls or boundaries, where the meaning of dying were more freely constructed. Although the research question was to understand the experience of dying, there were conversations where the question was never posed to participants in those words. Conversations were about, how the person felt about the life threatening

disease, how they cope, how they are felt at that particular moment, and often the conversations veered from the topic of dying. Portions of the conversations where dying was not discussed still told me about the experience and frequently contained messages which communicate ideas more poignantly than words on the subject.

I did not have predetermined opening questions. Conversations were initiated by reviewing the purpose of the study. These conversations often spontaneously occurred when there was discussion about the diagnosis, treatments and history. In order to generate meanings of dying I questioned the participants about what the diagnosis means to them, or how it affected them. My nursing practice has taught me that was a useful place to start discussions about dying.

Tact

The conversations with the participants addressed a very sensitive issue. Talking about dying can be uncomfortable and is often fraught with a multitude of emotions. For this reason I attempted to be sensitive to the nature of this topic. Although words such as 'palliative', 'terminal', 'dying' and 'death' may appear bold, I felt that often the use of these words and this language was appropriate. "One can say something tactfully; but that will always mean that one passes over something tactfully and leaves it unsaid, and it is tactless to express what one can only pass over.... thus tact helps one to preserve distance" (Gadamer, 1997, p.16). The intent of this research was to address the issues of dying, so often covered, hidden and oppressed by a society that encourages distancing, tact, and leaves many things unspoken. As I had anticipated the people were not intimidated by use of words or language, rather they themselves often spoke in a frank manner. It is interesting that, although committed to talking about dying in a candid and honest manner, there were

still times when I was taken back by the people's forthrightness. As I wrote about these instances I began to wonder how ingrained my thinking was and how, out of respect and politeness, I believed 'skirting' the issue was required. I slowly discovered that not everyone felt or expressed the experience of dying using tactful or sensitive words. Indeed it lead me to question where or why I may believe that tact or sensitivity were prerequisites to discussions about dying. This notion added to the information and beliefs I had about dying and how to discuss the subject.

Listening

The aim of this study is to gather information not only by asking particular questions about the experience of dying, but also by hearing the responses of the individuals from a different perspective. This is not a simple exercise when I consider how the act of listening shapes how I come to understand things in the world.

We can hear only what we want to hear, or what we already know and believe; we can hear nothing different, nothing new. There are some things we can hear only with great difficulty, only with great pain. There are some things we need to hear, but probably never will. There are some things we would like to hear, but we are also too afraid to listen (Levin, 1989, p.19).

When I initially considered my research question, I was interested in a person's relationship with their body when death was expected. I was drawn to the ideas of hope, embodiment, spirituality, and existentialism. As I considered these ideas I questioned how I might listen to people's stories, and possibly hear what I wanted to hear. Before the conversations I wondered if maybe the words of participants would confirm my notions and suspicions. I tried to resist directing the conversations in these areas and when I was in the conversations I attempted to listen not to my thoughts and ideas but to what the people had

to tell me. The impetus for opting for a broad research question helped me to listen to the viewpoints of the participants.

For me, one way to understand the depth of another's experience, is to listen differently. Levin (1989) develops the idea of listening.

[Listening] involves the entire body, the body, that is, of felt experience. It is a listening structured not by the intentionality of conceptual grasping, but rather by the body's felt sense of the saying it is a listening attune through feeling. This way of structuring the listening situation allows the words to resonate: it gives the words the auditory space of a listening that has refrained from restricting them to the field of a subject-object structure (p. 21-22).

By listening in this way my attempt was not to clarify, test, or confirm any preconceived notions, but to learn from being in the conversation.

Chapter Four: Opening Doors

Doors often show us passageways beyond where we are standing. The stories of the people who lived knowing they were dying also served as passageways. The stories of Christine, Frances, William, James and Hank generated new meanings of dying as they recounted their lives, feelings, emotions and particular experiences. As I wrote about these people, clusters of ideas or notions developed. Wanting to present these ideas coherently and in an orderly fashion consumed, and periodically stopped, my writing process. I now realize that like life, and the hermeneutic circle, the ideas of dying are not neat, orderly or precise. Rather they weave, overlap, surface, repeat, and reemerge in different sections of the writing. I choose to keep these ideas often where they developed in order for the reader to perhaps gather some understanding of how my questions, musings, and ideas changed and were emphasized. As I focused upon my writing about the people who shared their stories, I came to wonder if these conversations not only facilitated the development of themes or notions about dying, but also emphasized how I come to understand the experience. They made me think about how we talk about dying, how I learn from another person's experience, how my assumptions block what I hear, what is said and not said about dying, and how the phenomenon of dying has many layers and complexities.

I think of those conversations, as doors that have been opened for me to help me see farther and to areas that were unknown to me. As each participant opened their doors to me, they also opened themselves to sharing their lives, vulnerability, pains and joys. This metaphor also reminds me to be open to the mystery of life, the mystery of dying and all the possibilities in between.

The doors William opened

I was buzzed up to the apartment and marched up the stairs to see a head peering from the open doorway. He seemed worried that I might not find his apartment. His quiet voice welcomed me and he stepped backwards to allow me to enter his apartment. He was friendly yet timid and I sensed gentleness about his man. From my vantage I saw the bedroom, kitchen and living room. Only the bathroom escaped my glance. The rooms seemed sparse, minimal furniture and only a few pictures donning one wall. He asked me where we should sit as though it were my domain. I encouraged him to make himself comfortable in his well-worn reclining chair. He patiently waited and said little as I reviewed my purpose and he signed the needed consents. He didn't smile and he didn't frown. His pale blue eyes seemed fixed upon me yet never were glaring or intent. We were about to begin our conversation and he seemed ready.

William spoke with a quiet clear voice and he rarely embellished upon an idea. His comments were brief and well considered. Although William was aware of the purpose of my meeting him, he seemed to have little interest in talking about dying. I wrote in my journal after this first interview, "He denied feeling uncomfortable about talking about dying yet I interpreted clues as being contrary. Or were they? He rubbed the table with his hands and his fingers rode along the ninety-degree angle that the corner made. His answers were abrupt and he denied thinking about dying, at least he limited his thoughts about dying. As I think, I wonder if I almost felt that he was bored" (personal journal, 2000). I had expected to hear certain stories about what it is like to be dying. I anticipated hearing about how a person's body slows down, possible fears or worries about the dying process, spiritual beliefs and possible discussions about heaven, hell, or places beyond this world.

William did not engage in any of these types of discussions. At times I felt anxious because when he did talk, much time was devoted to conversations about William's role as caregiver for his parents, his life farming, and his contributions to the community. Very little time seemed devoted to his account of his experience of dying.

I had started this research with an assumption that people want to talk about dying. Yet discussions reflecting upon his immediate situation did not seem to interest him. I realized that there are many people who do not share my interest in the issues of death and dying. What I had not considered until this moment was the possibility that people who were dying may not be interested in the subject. I explicitly stated as one of my assumptions that people had a desire to talk about this experience and that often their stories were silenced by general notions and ideas about the experience. Could it be that William did not think others would want to hear about dying? Could talking about dying and thinking about this future be a way of hurrying it up? I wondered if perhaps talking might be a way of moving to this place or space in a person's life prematurely. It made me question my assuming need to talk about dying when William did not express a need. At this point I started to question my own motivations for wanting to understand the experience. Was my desire to understand dying voyeuristic? What claim did I have to touching this spot in a person's life?

I returned to examine our conversation and how I was listening. Why did I assume I would hear a certain story? For me, there was a distinction between narratives about dying and narratives about living. We expect specific elements in each type of story, as if dying and living are mutually exclusive. Yet it is impossible for dying to occur without life, or life to occur without dying. I also began to wonder if I had placed dying in the forefront of a

person's life when it may be an aspect that sits the shadows. Something that is part of the living yet it does not assume a pivotal role in day to day existence. At times I had the impression that for William the experience of dying was not a 'big deal'. It's as though this process was like another of life's phases. "It's going to end. You just don't know when, but no use hurrying it up" (William #1, p.29).

His statements about his illness, and his future seemed terse and matter-of-fact. I asked him if he talked about the future with his close friends, he replied, "we don't bring up the future that much because there might not be that much there" (William #2, p. 17). His words struck me as being very rational and pragmatic. They acknowledged the reality and inevitability of dying and yet left very little room to think about this process. It was as though dying was something that everyone would face and there was no point in talking about it. On one level I could not deny that this might be the case. Dying can be viewed as a reality for all things alive. But I wondered how when we have this discreet impression of the process we run the risk of missing the uncommon elements in the universal experience. I seemed torn between how William presented his story and how limiting I thought this perspective was. Maybe my perspective was limiting.

I began to wonder if William didn't think about dying because it was too emotional. Facing mortality for many people including myself can stir up emotions and expose a person as being vulnerable. Yet to say that William was unaffected or unemotional does not seem to capture all that he was saying. He did not deny he was nearing the end of his life, but neither did he focus upon this. He seemed aware and in touch with the changes that were happening in his body and in his life. It was as though William believed, like his cattle

and the changing seasons of farming, the cycle of life continues. There was a time to live and a time to die. He was not scared of dying. He had grown into this stage in his life.

I began to see that there was no one story of a person. Rather there were layers and depths to a story that continually gave it shape and flexibility. I found that I gained different insights into William's experience when I released my desire to question, probe and seek answers. William's true story seemed to emerge when he expressed to me the stories and anecdotes of things that were important to him. These narratives at first seemed distinct and separate from William's experience of dying. He talked about the subjects of family, community and farming. I came to wonder if the stories weren't still telling me something about dying.

For William, could it be that dying and living were so entwined that they were almost indistinguishable? I would say that instead of learning about the experience of dying, I was told about how William's life had been lived. He described his connection to others, and relationships with the people who entered and exited his life but who forever touch him. William talked about the stresses of being the youngest child in a family who assumed he was responsible to care for elderly parents. When he ventured into this topic I wondered about how we arrived here. As he continued I seemed to sense that perhaps this story was telling. It seemed to exemplify the potential in William's life. I had a sense that William would always be left to wonder about how life could have been different if he was not responsible for his parents. As we talked about caring for his parents William comments that he becomes depressed by the thought. I asked why this thought made him feel depressed. He responded "sometimes just thinking about things I could have been doing otherwise. More enjoyable than looking after those folks" (William #2, p.11). He

commented that he may have traveled, but quickly dismissed this thought as frivolous because time cannot be altered. He talked about the activities that consumed his life, his farming, and involvement in community organizations. I thought at first these were things that William enjoyed doing but as I look at the words I see this was not quite true. To seem more accurate to say that this was a reflection about how William had spent the years of his life, encompassing the good with the bad, the special with the ordinary. This seems to me to be such a reasonable and realistic picture of life where there was a perusal and evaluation of his existence. It was as though he found more pleasure at looking at the path he had traveled in life with the turns and dips, than looking forward to the shorter path into the unknown and dying.

The doors Christine opened

I waited patiently after ringing the doorbell as the shuffling figure made it's way to the entrance. A screen door and a wooden door separated us. She peered through the window to see her visitor. She opened the solid front door, as I opened the screen door. We smiled as we did this and met in the middle.

Christine's home smelled clean but old. I scanned the living room noticing the displayed antiques and treasures of the past. She made me feel welcome and we chatted briefly about some furniture I admired. I enjoyed my conversations with Christine and I frequently thought that I was helping her understand the experience of dying as much as she was helping me. This was different than many other discussions I have had about dying.

This idea was interesting because it told me something about the nature of conversation, particularly about discussions of dying. I did not think I was afraid to talk

about dying. As a nurse many people expect these types of conversations of me: people who are dying, people with life threatening illnesses, other health care providers, and friends. It was disturbing to realize how I have absorbed assumptions about dying that influenced my interactions. When I thought about how conversations with Christine were different, I started to look at these assumptions. Conversations about dying are different than conversations about the weather, entertainment, politics and even religion. Although people may not agree, and discussions can get passionate, they do not invoke emotions quite like the topic of our mortality.

Often we intellectualize death and place it out of our immediate reach. When broadly talking of death, we talk of grandparents or parents who have died, or we hypothesize about our destiny, still being somehow protected by the veil of disbelief that death will happen to us. (I'm not certain it is even possible to talk about our dying with a degree of sincerity until we are face to face with the inevitable). But I see a difference between talking about dying when we are well and when we are dying. When people receive a palliative diagnosis, or when they are faced with their own death, my conversation and interaction with these people changes.

Discussions about dying often take a solemn tone and I find I am sensitive to the mood and emotions of the other person. Perhaps this was the difference in my conversation with Christine. Her reactions were not what I would have anticipated. She was reflective, and thoughtful. She was able to articulate how the experience affected her, and engaged with our questions and musings. Dying was not relegated to something outside of her reach but was accepted as being part of her life and her reality. "It just gradually keeps getting worse... I just don't pay any attention to it... it comes on slowly and you get used to it... you

have to accept it" (Christine #2, p.5). She was not fearful of dying and I sensed that dying was an insignificant experience in the grand scheme of her living. She seemed to give little consideration to the moment of death and events that happen before and after. She had such a strong faith in the life beyond this world that the event of dying was almost unimportant. Like a door or a means to an end it is a transition.

Christine talked with love as she described meeting her husband and family members in heaven. She had spent time considering her mortality and integrating these ideas with her spiritual beliefs. For Christine these spiritual beliefs helped to shape how she thought about death. We started on this topic when we discussed the death of her husband. I had asked her about his death believing that previous events in a person's life influence how they interpret their lives. She told me she believed her marriage did not stop with her husband's death, and they were married for 'time and eternity' She believed she will meet him again in heaven as his wife. "When we go to heaven or wherever we go, we will be together as a family again... It's a great comfort to me. And I think about it so often. It is a comfort to me just to know that our marriage didn't end when he died. I'm still his wife. That's a great comfort to me" (Christine #1, p.7).

For Christine death was potentially a journey to where she would be reunited with her husband, a place she could not go to while she was clinically alive. Thinking about dying as a transition, to a world where Christine would be reunited with people she loved, helped her to not fear death. Somehow, this belief made dying easier, more comfortable for Christine. In a world focused upon empirical data, facts and provability this seems an irrational belief. Maybe the experience of dying is not rational or about objectivity. If anyone else had told me dying was comfortable because they anticipated meeting loved ones I may have

doubted them. But Christine had a way of telling her story that had me absorbed and convinced of her belief. I have assumptions that dying can be an arduous process for people and affects them mentally, spiritually, and physically. Christine's story challenged my understanding. She described how she was comforted in this process of dying. She was comforted by her faith, and by beliefs that could not be substantiated, proven or measured. For her the dying process became less ominous. At times her words lead me to believe that dying was welcomed.

Beliefs do not have to be rational and only to a bystander could they seem "irrational". "The usefulness or nonusefulness of a belief, however, is dependant on the judgement of an observer and the context in which the belief arises" (Wright, Warson & Bell, 1996, p.22). It seems to me, to judge beliefs as being rational or irrational, useful or non-useful misses the point. Perhaps it is just as productive to invest energy to understand what particular beliefs mean for the person, and how these philosophies work in a person's life (Wright et al., 1996). So although some may wonder about Christine's belief in the after-life, for her this meaning was part of how she perceived death and life.

Christine's story also included how she integrated her illness and limitations into her daily life. She lived with illness, and made accommodations and changes because of its presence. She described how at times she was frustrated by how dominant illness was in her life. "Like little things too. If you want to open a jar you can't because you're not strong enough. And there's just all kinds of things you can't do. But you have to accept it, that's the way it is" (Christine #2, p.5). It must be frustrating not to be capable of performing simple tasks. How would it feel to be dependent on others to open jars because your body no longer was able to do a once easy task? Yet Christine has somehow come to terms with

this reality. Maybe accepting this change was not significant for her when compared to other challenges, and changes that dying had imposed. Christine went on to express the idea that she did not become consumed by activities she could not do. She accepted the limitations as a reality and moved beyond frustration to a place where she coped, and accepted illness in her life. Christine's dying demanded a place within her; it's limitations difficult, even impossible to forget. Christine had chosen one of many possible ways to cope with her illness and dying. She had chosen to live with her failing heart and body.

Many of the ideas that have risen from the conversations gave me the impression that Christine, like myself, was changing and creating an understanding of what dying meant for her. She also gave me the impression that this evolution did not start when we entered into our conversations. Living with dying it seemed was not something done all at once, but was something that she grew into. She comments "You know it's coming but you don't know when" (Christine #1, p.5); "I just thought, go on as long as you can" (Christine #1, p.25); "Just comes on slowly and you get used to it" (Christine #2, p.5); "Well I've had this problem for a while... I've had it for years it just gradually keeps getting worse" (Christine #2, p.4). Christine helped me to understand how slow changes in a person's life can move them to a place where dying becomes expected and inevitable. Her comments lead me to wonder if her physical limitations and the disease process were catalysts in this progression. When a person's heart is failing and the disease keeps getting worse, would it seem like a relief if death was coming sooner rather than later? Christine also made me wonder about how age affects our perception of what dying means. I hesitate to make this assumption because I believe that ageism can limit how we understand the experience of dying. We hear how a person should expect or accept death because they are of a certain age.

Nevertheless, Christine herself comments “I know how old I am and I (laughing) know it’s coming” (Christine #2, p.2). Her comments strike me as being practical and I wonder how she came to hold the view that dying is acceptable at a certain age. So often, dying is an acceptable process only for people who are aged or debilitated (Gadow, 1996). Dying becomes manageable, expected, and acceptable for the bystanders when this ideology is believed to be true.

Then I wonder if she was telling me one of the realities of dying. People who grow old move closer to the end of their lives and often they know this. So this place was not a place where Christine was twenty years ago. This place was also not a place that she was prior to our conversations. Christine’s understanding of dying was evolving day by day and maybe even minute by minute. Perhaps this evolution prepared Christine for the inevitability of her death and dying.

The doors Hank opened

The door was identical to all the other doors along the long narrow hallway of the seniors residence. I found the number and rapped firmly on the door. ‘Come in’, yelled a voice from inside. I opened the door and entered the apartment while Hank’s voice commanded me towards the bedroom. He seemed to be talking from the moment I knocked. He jumped into conversation, as his wife sat silently by the door and I settled into a chair by his bedside. He was reclining with one arm bent behind his neck, propping his head forward so he could survey the room. His words and his posturing gave me a clear sense that he was comfortable in this environment, and also that he felt in control.

Hank spoke with a clear, loud voice that seemed to ring with crispness. This voice in many ways seemed to echo his story, which at first appeared clear and defined. When Hank

spoke he tried to be frank about his story. I was taken back by his forthright comments. "That's up to you...this is going to help me get the cure...it's cancer...definitely....that's all there is to it....I have to do something about it myself....[crying] don't help....Just take things as it comes" (Hank #1, p. 14). It was as though he was driven by his need to teach me, to tell me what he knew, as though everything was ordered and defined. Perhaps he had an expectation of what would happen in our conversations and how he should act. As though telling me his story, articulating the required words and aspects would complete his purpose and mission. Yet at the same time I wondered if he was so eager to tell his story in a particular way that moments of chit-chat or idle conversation would stall his desire to tell someone what was happening to him. It was also possible that Hank, knowing the purpose of our conversations and having consented, only wanted to get it finished. If Hank felt uncertain or scared about the future maybe talking about dying was not a task he would relish or enjoy.

Still, I was pleased to be getting what I thought was valuable research data. I had feared that talking about the experience of dying might be difficult. My history taught me that the topic of dying was not always comfortable and the subject of the conversations can be quickly changed. So when Hank jumped into the conversation and described how he was preparing to die, I was eager to start the tape recorder. The gears in my mind clicked as I tried to think about what he was telling me. I heard what I thought was something too difficult for a person to express. He was saying the things I had hoped to hear. This pleased me, and I began to wonder why I would feel an emotion like pleasure. Perhaps I was hearing what I thought Hank would tell me, as if he was proving my theories and assumptions. It seems satisfying when we have people confirm what we think we know. On

the other hand, I also felt a deep sense of privilege at finally being given the opportunity to spend time listening to the stories of people who were dying. Another point was how pleasing I found the neatness of Hank's narrative. He had a way of telling his story in a decisive and convincing manner that was clear, crisp and well defined, with very few grey areas.

Hank had an interesting perspective on his illness and his hopes for the future. In one instance he would talk about the fact that he was dying, and then moments later soliloquize about how herbal treatments had cured other people with advanced cancer. It was only when I reviewed the audiotapes that I heard Hank contradicted himself. It was my feeling that this was an important piece about how he experienced dying. These contradictions did not suggest to me that what Hank said was untrue, rather they point to the multitude of tensions a person may be feeling. I sensed Hank was living with the reality of his illness, yet maintained positive hopes for a cure. When I met Hank for our second conversation he still told stories of hope but it seemed to me they were different. No longer were his hopes 'full', rather the stories repeated words that had lost meaning and relevance to him. The stories concluded with "in my situation I think it's so far gone that it's too much... I hope I'm wrong" (Hank #2, p.5). It seemed like hope still lived within him but no longer held the spotlight that it once had. His hopes were tentative. He no longer appeared certain he would be cured. He hesitated and even built into the conversation the possibility he would not be cured. I wonder about this because before he had such conviction and faith in actions that would rid him of the cancer. As he made these comments in our last interview the hopes seemed less obvious.

Each of us lives with hopes and dreams, whether articulated or not, for our children, our friends, our careers, our happiness and our future and our lives. These hopes, often unconscious, can motivate and move us beyond where we are today (Lamm, 1995). People like Hank who have a terminal diagnosis, also live with hope. I wonder if we see these hopes as being different. I question this because, as I listened to Hank's story, I recognized two interesting assumptions I have about hope. Firstly, as I have been taught, I believe hope is an important presence in a person's life and that sustaining hope for people with a palliative diagnosis is therapeutic and beneficial. My second assumption was difficult to realize. Although I believe hope is a positive influence in a person's life, I found that while I listened to Hank's story I thought his hopes for a cure were unrealistic.

I had the impression that Hank would do almost anything that would better his odds of curing his cancer. At first I wondered if this was his way of bargaining or grasping to life, but in my heart I don't believe this was his intention. All his actions seemed to be prefaced with a 'just in case' or 'it won't hurt' attitude. This way Hank was able to know that he had done all that was possible of him. He had tried all the options available to him and if one worked, and gave him health then it was worth it. His hopes also seemed to give him a sense of purpose and control. Instead of placidly sitting and letting the cancer run his life Hank was taking charge.

One of his first statements in our meetings was "I'm getting everything all set and ready in case I die" (Hank #1, p.1). Later Hank commented, "So your life is fulfilled then your ready to go, in that respect, because you have done all you can for your friends and family. You know and you're happy with that" (Hank #2, p.12). As I heard this statement it seemed to flow from how Hank had directed his recent actions. His actions seemed focused

upon preparing to die. Here it seemed he was at a place where his tasks had been accomplished. He no longer had things to be done. They were finished. I wondered if at our second meeting, Hank might feel a sense of satisfaction or accomplishment. Satisfaction because he had arranged his funeral, sorted out his legal and financial affairs and believed he was leaving his family with a lessened burden. Might it be that Hank understood that his family will be distressed and emotional with his death but he has helped lessen their burden? Now they will not be consumed with challenging financial matters or bureaucratic paperwork when they are vulnerable and mourning his loss. I think it must be a pleasurable feeling to know that you are still able to help others when you are gone. I think of how, if these matters were unresolved, a person may feel guilty or feel a need to fix things before dying. On the other hand I wonder if Hank told me that a person can never be completely ready to die. I wonder if he told me that arranging financial and legal affairs was a part of a process that moved him closer to death, but did not make him wholly accepting of this fate.

Perhaps this preparation is one portion of dying. I wonder how Hank would determine a fulfilled life. When he reflected on his life, did he get a feeling of having achieved dreams, reached goals, or fulfilled his potential? If this was true was Hank saying it was easier to die? As I think about this idea I wonder how a person feels when they are disappointed with what life has held. Would there be regrets? Would this feeling change how dying was interpreted?

The doors James opened

The smell of coffee was one of the first things I noticed as I stepped into the modern and comfortable mobile home. Both James and his two small dogs greeted me with a sort of

friendly apprehension. The dogs wagged their tails and barked. As he unlocked the door and brought me in from the wintry day outside, James smiled yet eyed me curiously.

As I entered James' home I was nervous yet attempted to appear comfortable and confident. I wonder if at times I was trying to be so friendly that I might not be perceived as threatening. For some reason I felt my presence was threatening. An outsider who was going to peer in, or perhaps just a person who was upsetting a usually planned and organized day. James was pleasant and smiling but I also had the impression he was shy and reserved. James seemed comfortable with his wife present and it was she who seemed to fill the moments of silence and hesitation, even in our initial introductions. At the start of our introductions she left briefly to hang wet clothes outside on the line. James seemed anxious while she was away and the friendly conversation felt stilted as he looked for his wife's return.

James' wife remained for the conversations. I had a number of feelings and responses to her presence. Often she seemed to answer for James and she was giving her story of James' illness. I was a little hesitant as my objective was to explore the meaning of dying not from the perspective of observers, health care providers, or family members, but with the person living with the terminal illness. I wanted to hear his story and his expression of what living with this illness meant to him. But I did think about how often our stories are constructed with the reactions, interpretations and input from those that we love and who are close to us. I thought about how it was likely that the story of James' experience was relayed to family, friends and health care workers through his wife. As we were talking I wondered how perhaps the wife's story was part of James' story. It was as though she had assumed, or taken up, this role before I entered their home. Perhaps this was how he reacted

and communicated to others most often. James did talk and shared in the conversation but he also allowed his wife to tell his story, and rarely did he contradict her. Experience often seem to be momentarily captured when we say the spoken words. Perhaps part of the meaning for James was understood when his wife articulated it. As though there was an obvious co-creation of James' experience between his wife and himself. I thought that the presence of James' wife would comfort him and facilitate the conversations. I was fearful of his not wanting to talk to me, and of how we both may be uncomfortable. It is interesting that I might have thought this. That James would somehow be incapable of comfortably sharing his story with me. It is interesting how I wanted to ensure James' comfort to somehow make the story of dying more comfortable for a person. Can it ever be comfortable? Can it ever be uncomfortable?

It seems ironic that I felt so uncomfortable. Ironic because I enjoyed my conversation with this family and because after the recorder was turned off, we continued to talk in this same rhythm we had developed. James and his wife lived an hour from my home in a rural farming community, so I accepted their invitation for lunch as the three of us continued to talk and share, about illness, our career, our families, and life in general for two more hours. As I transcribed the tapes I was concerned again about the role of James' wife and was a little distressed at her exceedingly large contribution to the whole of the transcripts. What was interesting though was as I focused upon James' words I had the sense that although the words were few, that the content and meaning of these words spoke volumes. I remain surprised at how these few words have moved my understanding of dying so much.

Often, when I talked to James, I felt he was telling me a particular story, something that was at times distinct from the reality that was happening to him. "You learn to live

with it, and crying about it doesn't make life any easier" (James #1, p.1). I had the impression when James said this that he was telling me what he thought I wanted to hear. As if he felt someone who starts a conversation by detailing their own trials, challenges and discomforts were inappropriate. I also had the impression that he had determined appropriate responses to his illness. As though he directs himself towards understanding his illness on a rational level as opposed to understanding what the emotions might mean. His words suggest that he believed crying was purposeless and will do little to change the future. This may be true, but I wonder what it does to a person when they believe that emotions don't make life easier.

Later in the conversation, he openly cried and also at times discussed how he was limited physically by his weakness and lack of energy. Looking at the whole of the conversation, I quickly saw what I started to believe were contradictions in his story. I started to wonder are they contradictions? Could it be that James' feelings changed so dramatically from moment to moment that each statement was true and real at that instance? It seems funny that I should assume that a person must have a defined understanding of their experience when my understandings also seem to change and move from moment to moment. Maybe I was just seeing how variable the meanings of dying were for James' as well. Could this be one way of understanding a story that seemed to contradict itself? Perhaps it would be too difficult to jump into the true experience of dying. Insinuating in a matter of fact tone that everything was all right could make it manageable. If every time a person questioned about the ability to cope, perhaps a person's defenses and sensitivity would always be heightened and leaving them vulnerable. Instead James' statement may suggest that you move and continue as before, only now accompanied by an

illness that must be lived with. I am not certain that James understood or thought about living with his illness, although that was how I interpret his words. Living with an illness can be quite different than forgetting about an illness. At first, I interpreted his statement in that way, that he might be ignoring or forgetting that he was living with a terminal illness. Perhaps James was denying (at least outwardly) his palliative diagnosis. But I do not think this is the case. I would guess that James was very aware of his mortality and his diagnosis, and at times in the conversation this became more apparent. "What do you say to, you know a man with a bad heart, he's facing a smoking gun. He's in the same shape as I am. He don't know what move he's going to make and that's going to make and that's going to be his last. Say, what makes cancer so much worse? I know there's pain with it, but as I said we all die" (James, #1 p.18). He may have been attempting to make sense of this reality and somehow understand how it fits in life, as he knew it. He questioned me about what makes cancer worse, as though he was trying to understand what this experience might be like, what the future might hold. He has heard it was worse, but worse than what? Other ways of dying? The words that follow this question make me wonder if he even wanted an answer to his question. "We all die" is a very closed statement that cannot be denied but that offer little room for understanding how people's individual experiences can be different. Instead it sums up the fact that we all will be in James' position with the same fate awaiting us. Again I feel some tensions between how he understood dying and how he lived with his dying.

I began to pursue this research with a desire to understand how people experience dying. I wondered, what do they think about? How does life change? What happens to people when life becomes finite? What is the experience of dying? I am coming to realize

there are many aspects to this complex question. It is a complex question because a person's interpretation of dying is partially shaped by what they see, what they hear or say, how they feel, the reactions of others, the emotions a person feels, the conscious and the unconscious. Many of my questions about James' situation were answered tersely; "You just learn to live with it"(James #2, p.5), "There's nothing you can do about it"(James #2, p.5) and "It doesn't make it any worse" (James #1, p.1). As I listened it seemed as though James had everything well in hand. But was I listening? At the time I believed we were both grounded in the same understandings of our words. Now I am not as confident. These brief words exploded with different possibilities when I questioned what 'it' could mean for James. Was James talking about, living with cancer, or living with the physical changes that cancer often causes? Is there no use worrying about what today holds, or no point worrying about dying? Does his illness, his knowledge that death is near, not change things or does it make it worse? Each of these questions opens up different meanings and these are the questions that I continue to ponder after James' brief comments, and expanding the possible interpretations. What did 'it' mean for James? Was he referring to the cancer, the changes in life, a diagnosis, his illness or impending death? As I think about these possibilities I also wonder if it could include all these notions.

I had the impression that James viewed his illness and the cancer as being a distinct entity separate from him. As I thought about this idea I began to think that this might affect James in many ways. At times this distinction seemed to create a distancing, perhaps a buffer zone, with James planted firmly and the illness being at arm's length away. He was close enough to be aware of it, yet far enough that it did not invade his person and who he was. Sometimes I also wondered if this separation of illness and self permitted a splintering

of his experience. If James perceived the illness as separate, maybe it was how James could talk openly of his tests, procedures and clinical aspects of his illness. “In fact it’s clear but I still keep taking medication for it. Because what has happened the way I understand it they have to keep the protostrogen and androgens down because that’s what is feeding the cancer” (James #1, p. 5). Perhaps this notion of illness as ‘other’ allowed James to see this portion of his experience in an open manner, with his feelings and emotions separated and buffered from the same public scrutiny. I think about this possibility, and it seemed James was comfortable talking about the illness yet uncomfortable talking about how the illness affected him. It makes me think how often we can skirt issues of experience when we become narrowly focused on treatments and interventions. It seems to me that James has made a choice to understand his illness in these terms. He talked of his hormones and the relationship with his spreading cancer using technical terms. He mistakenly referred to progesterone, or progestogen as protosterogen making me curious about his level of understanding. And could this medical reasoning possibly extend the gap between self and illness?

The doors Frances opened

Frances’ door had a floral bag and a name marker telling me she lived there. These were the only indicators in a passageway that was filled with doors that looked the same. I recall thinking that although the doors looked the same, they each were passages to different people, different lives and different stories. When I was face to face with Frances’ door I wondered about the story I may hear.

Frances was approached by her Home Care nurse and agreed to be part of the research. She had read and signed the consent, and it was not until we were well into the

conversation that I realized that Frances had not been diagnosed palliative by a physician. I was about to stop the interview believing she did not meet the 'criteria' for this study. Before I could interject Frances continued on to tell her story, a story that I soon saw, needed to be told. A story about how she believed she was dying. When I determined the recruitment criteria I was unaware of my assumptions about how and when a person was dying. I assumed physicians and health care workers were the ones who drew the line in the sand defining who stepped over the threshold to the dying. Frances drew this distinction herself. She called herself dying.

"The doctor found it at home, just a lump about here, which I knew was there but which I didn't tell her because I thought we'll just let her find out for herself" (Frances#1, p.9). She spoke as though the cancer was more important to the physician than to herself. As though she was playing a harmless game where she found the cancerous lump, yet it still was hiding from the doctor. This game of hide and seek made sense to Frances. Perhaps the confirmation of the cancer scared her, and until it was identified by a doctor its presence was hidden or imaginary. Maybe for Frances it was a game where she snickers as she played along with what medicine dictates, already knowing what medicine has not told her yet. This seems but one way to create a space for herself in a medical system that overpowers, dictates and dominates people (Gadow, 1996). Instead of choosing conflict she created a reality where she placated the medical establishment by letting them think they know about her and about her illness. Frances' physician had not even told her she was dying. Yet she knew she was. Perhaps dying is not inextricably linked to a diagnosis. It was as though Frances herself was at a point of looking at dying. "So he said I have good news and bad news for you.... The good news, I don't know what the good news was. But the

bad news was that it was aggressive.... And the good news was what the heck was the good news? I think it hadn't spread into the lymph glands" (Frances #1, p.9). Can there be good news? Because cancer had not spread to lymph glands was a person supposed to feel better about having cancer? It seems to me that a person would still be affected by the diagnosis and that it would be difficult to see the good side. As though again it was good for the doctor, good because of the prognosis, good because of the physiology of the cell growth. But was it any better for Frances? She had difficulty remembering the good news; the news of the cancer being present in her body was primary in her thoughts.

Frances was admitted to acute care and then long-term care during the course of this research. Because Frances was no longer in her own home I was required, as previously determined, to request access to her to continue with the research process. This approval was asked of physicians who assumed the role of primary caregiver in institutional settings. In an attempt to request continued conversations with Frances, I was told by the doctor's nurse that the physician was 'not too pleased' with my research. He never permitted me to follow this patient. Frances and I only had one conversation.

This upset me and continues to leave me feeling guilty and helpless. I wonder if I should have been more assertive in my requests. I questioned why I might be denied access. I questioned the authority of a physician to deny a patient's story. What were his issues about talking about dying? What were his assumptions about control? What were mine? It was easier for me to assume the physician could deny me access than to defend my beliefs in this research, and what the research means. I rationalized I had enough data, yet that placed little value on the relationship I had with Frances.

Is a person not dying or palliative until a doctor says they are? Instead of pointing fingers, or questioning the physician's motivations, I think this circumstance still can be examined within a larger context, a context that concerns the power of words. The physician did not encourage my discussions about dying with Frances. Could it be he was uncomfortable talking about dying? Could he have been concerned about the feelings, and emotions that may come up for Frances? At times we carelessly utter phrases, sentences and greetings to which we give little thought, underestimating their power. Then at times we are sensitive to the power or lasting effects that words have. What about dying makes people fear talking about it? As though talking about dying should only occur at certain moments in a person's life? Perhaps by avoiding discussions of dying we continue to be oblivious to our mortality. Or perhaps not talking allows us to skirt around things that are difficult. But does this make it any less difficult for the person who lives knowing the end of their life is near?

Part of dying for Frances involved her physical being. She had undergone many surgeries that forever changed her and her body. She would not die with the body she was born with. Rather she had tissue removed, a breast cut away, and a steel rod placed in her thigh "in case my leg broke" (Frances #1, p.3). It was a challenge to know how these illnesses affected Frances when she was first told of them, now they seem secondary. As though they were small tokens to pay to remain alive. When a person is told they have a terminal illness maybe losing parts of a body is less scary than losing your life.

Frances was not oblivious to how the health care system works. Like others she focused upon what is done, 'to fix her'. She told how she recently had five or six radiation treatments, and how years before she had twenty-nine radiation treatments for the same

cancer in her breast. She had been tested, probed, had radiation, surgeries, therapy, been fitted for support braces, yet she commented that as far as the cancer “they can’t do much”. Perhaps we pass on to people the grand lie. The lie that tells how everything can be fixed. Broken bones can be set, amputated limbs can be replaced with prostheses, failing hearts can get new vessels to pump blood. “They did a lumpectomy on the right... I was sorry afterwards that I didn’t have it all off... then it spread over here... and then they found a spot above my knee here. And they operated and put a steel pipe inside my thigh bone” (Frances#1, p.1). For Frances it was as though the cancer was invading her body. Moving from one part to continue and invade another limb. She mapped the traveled route in her body. As though these were places and not parts of who she was. It becomes about how a person is able to distance themselves from their bodies. Perhaps it is this separation, this perspective that permits a seemingly objective account of the experience. I question how she could be objective yet her words still show her attempts: “it spread over here”. The “it” is cancer yet why does the name not come up? With the word cancer, like the word dying, the prognosis, treatments, images, negative thoughts and emotions surface. With Frances, it was as though not saying the word cancer might perhaps keep the demons at bay.

This was how she made sense of what was happening inside her, in the spaces and places she could not see. There is an invisibility to cancer. Frances would never see “it”, her enemy, her invader, her cancer. It starts on a microscopic level before the human eye, or medical equipment can detect cancer’s presence. Now that it was within Frances she used terms and words that make sense for her. I would doubt if she knew what her tumor looked like, if she could recount the position and placement of the tumor, if she has ever seen a

cancer cell. Yet she grasped the severity of her reality, what was happening in her body, if only metaphorically.

She used words that have been bestowed upon her as she needed to understand cancer. It became part of her and she needed to make sense of it. 'Lumpectomy', 'spot'. how did she come to use these words? She has assumed this information from people who help her interpret what is happening inside her body. No longer did she have sole knowledge of her body. Radiologists, nurses, physicians, chaplains, therapists, and unit clerks interpret her reality. They have given it a name, a name that has particular meaning for each person. For the chaplain it may mean another visit, for the physician it may mean a poor prognosis, for the nurse another patient, the therapist a reminder of her uncle's death. Each has a perspective and an interpretation, unique and common. We share the language with patients and clients and teach them our professional diction. We instruct as though these words were the only way to make sense of what is happening.

Chapter Five: Seeing Other Vistas

The experience of dying

It is only possible for me to detail some of what might be included in the experience of dying. These notions are not just the products of my beliefs and history, but come from the meanings created in conversations with the five people who had terminal illnesses.

These people shared openly and helped me better understand what might be going on for people in this stage of life. At present, like Caputo (1987) encourages, I am in the flux and the play. This is not an easy place to be as I doubt and question my assumptions, the people's stories, and how dying can be understood. It is particularly challenging to write these interpretations in ways that will enlighten and expand how we think about dying, and to see these interpretations as being possibilities for others. Part of this task includes framing these views within the generalized ideas about dying that society holds. The societies in which we are embedded influence and affect the experience of dying.

Understanding these influences helps us see bigger horizons. In order to write this in a coherent fashion, I will present themes about what may be part of the dying experience.

Conversations about dying often circle and overlap back into conversations about living because living and dying are in constant motion. They are perpetually pivoting and flowing together. When one assumes foreground the other slips to the background. As one is elevated to the spotlight the partner is close but hidden. They are more alike than different. How can we understand living without dying? How do living and dying co-exist? How does a person live with the knowledge that they are dying? Are living and dying separable? Can they be separate? The stories people told me exemplified the delicate dance.

We talked about dying and death, we talked about living, and we talked about the spaces between living and dying.

Inevitable destiny

“It’s something we all get to face. No way out of it, but a couple of words is - inevitable destiny” (William #1, p.29). When William first said these words I gave them very little thought and moved quickly to the question that was ready in my head. It is in some ways disappointing not to be able to ask William more about this idea of inevitable destiny and what meaning it holds for him. As I continued with the other conversations I was surprised at how often I returned to these two simple words. The term inevitable destiny nicely captures different aspects of dying. Dying can be an experience, which is common to all humans – life’s inevitability. And within this common experience for those that appreciate, and look for the difference, the individual destiny for people can also shed light on what it means to be dying. They are different vistas from the same room.

Few of us relish thinking about the moments of our dying and death. At times we may ponder our dying and even romanticize how it may occur. I say romanticize because our thoughts can only be suppositions about what may occur in our final moments. Movies and television often portray the dying in unthreatening ways where the pain of dying is masked, and conversations leave nothing unsaid (Kastenbaum, 2001). I think of this because although we may think about dying, I wonder how reasonable or telling these thoughts can be. We live in a society that may outwardly discuss dying but below this surface can still be found fears, worries, and foreboding about this life event (Berfman, 1991; Kastenbaum 2001). As stated earlier, I have even come to wonder if we can question our personal deaths until we are placed in the context of dying. There seems to be a

temporal distancing, though often unconscious, that make us think our brief glances are enough.

I continue to fall into this trap of security by believing this research is about five participants or something that happens to other people – but it is not. If there is an unspoken distinction, or distancing of people with a terminal illness, William's words seemed to pull them back into the fold of humanity. He reminded me that there can be no distinction, we all have the same fate and we all will face death. Distance from understanding dying does not evade, but only postpones the inevitability of facing this reality for ourselves.

With the development of science and technology has also come a false sense of power over dying (Kastenbaum, 2001). Our society has expectations surrounding medicine, health care, and about fixing our bodies and medicine's ability to heal us. We go to doctors to relieve symptoms, to eliminate discomfort, and to make us healthy again. We have expectations about the power of blood tests, X-rays, MRIs, CAT scans, medicines, and treatments. These expectations speak more to evading disease and illness than understanding how it affects our lives and the meanings they hold. I do not suggest this is wrong, rather acknowledge how this frame of mind influences our perceptions of dying. William reminded me that medications, chemotherapy, radiation, herbal treatments, prayer, exercise, healthy diets and regular medical check ups will not prevent our death. There is no way out of dying. When we so intricately evade the notion of dying with these expectations of medicine, what happens when we are told there is no cure – told your death is inevitable?

When we talked about dying, Frances also told me, "It's something that's inevitable" (Frances #1, p.14). Inevitable, this word says little about the nearness of fate. I have an assumption that knowing you will die soon is different than the knowledge that death is inevitable. As I sit and think I have many ideas about death and dying. Yet for me, there remains a gap between thoughts and my reality of death. I am cognizant of this as I think and write yet I was not aware of this subtle belief until I listened to the conversations again and again. What I found interesting was how often the participants expressed these statements to me in tones that suggested I might not have assumed this to be true. "For goodness sakes we can't live forever you know." said Frances (p.10), and I wonder if my questions inadvertently distanced me from them, or assumed I would not be in their position. I was asking the questions about dying as though I had no knowledge about what this might be like. Don't I bring a perspective about dying? The participants seemed to narrow this gap between the 'us' that are living and the 'them' that are dying. It again reiterates the perhaps-false line that we impose between people. Interestingly they do not see or respect this line in the sand.

To say that the experience of dying is inevitable or ordinary seems contrary to how I have come to understand or relate to people who were dying. It has been my assumption that dying, like birth, is a unique and special moment. I feel it is a privileged position for me, a nurse, to be present during the moment of death. Yet as I write this, I see this perspective leans towards romanticizing the experience. Dying can be painful, smelly, uncomfortable and a distressing experience for individuals. And perhaps by romanticizing this idea of dying I am closing off to all that dying can be, by highlighting the 'nice' parts, the 'good deaths', the 'good conversations'. Does romanticizing dying somehow make it

easier for observers? Why does it make it easier for me? Does it deny the difficulty? We shy from the difficult. We like to understand, predict, and control. It is difficult to see physical debilities, smell the odor of the body, or feel the dampness of the feverish skin in dying. Caregivers offer care that is palliative in nature and as the word palliative suggests, we cloak, alleviate, and ease the severity of this pain and disease (Webster, 1979). Do we also inadvertently cover or hide portions of what a person may be feeling because of our zealous efforts to palliate? We bandage ghastly wounds, we bathe and powder sweaty bodies and dying seems more neat, orderly, and manageable. Dying is not neat, orderly, or manageable.

“One thing about having cancer, nobody can do anything much about it... It is something that’s inevitable” (Frances #1, p. 13-14). Frances herself placed the emphasis on her dying. She was able to make sense of her illness and her fate by placing it within a context where death was not unexpected, or feared. Frances interpreted the reality of her situation in a way that made sense for her. Again, it seemed so easy to believe that Frances was denying the severity of her illness. This is ironic, when it was Frances (not the physicians or nurses) who believed she was palliative and dying.

“Well you know there are millions of people on this earth and they are all going to die everybody does it. Some sooner, some later” (James #2, p.26). James made sense of his dying by believing his death was inevitable and also predetermined. This way of looking at life in some ways freed him of responsibilities or ownership. Not that he was uninvolved or accepting but instead he may lessen feelings of guilt or responsibility because of his belief in destiny. The belief in destiny was not random it was purposeful and gave him choices about how to live.

- James: Life is important but you have to be realistic too...you have this. You're going to die. Well I say I'm sixty-seven years old.
- Gail: That's when it's okay to die, at sixty-seven?
- James: Huh?
- Gail: Is it okay to die at sixty-seven?
- James: Lots of people do.
- Gail: Yes. Do you think its different if your twenty-seven?
- James: That's the span of years that you are allotted and that's all you're going to get.
- Gail: So do you believe that somebody has our date upstairs?
- James: I believe that the minute you are conceived that your date is set. How long you are going to be here, what you are going to do. I believe in that whole-heartedly (James #2, p.20).

Dying for James was a destiny, a predetermined fate from which he could not escape. Indeed he does not try to escape or alter his course in life. For him, it was a part of dying. "You don't want to go through it. Just like you don't jump off a ten story building.... You don't know how long you'll last that's the secret. Nobody knows what's in store for them so why cry about it" (James #2, p.26). James placed dying outside of his grasp, in a context beyond his control and I wonder if there was passivity towards his fate. As though he gives control (and with it the requisite responsibility) to a higher power. It could also be that for James this attitude was realistic when fate his fate was uncontrollable.

Spirituality is a theme that seemed to be woven into the narratives of dying. For Christine it was represented as a devote faith in a God. for James it was less defined, like an abstract being that controlled the lives and claimed the souls of humans at its discretion. For James his spirituality has now been diverted from what is taught in traditional Christian religion. He said "I believe there is a greater being in control of us, but so much that's preached in church and that, I've got second thoughts of it" (James, #2, p.27). When the idea of spirituality emerged it seemed to be linked somehow to this sense of destiny: a belief in some higher power that determined a persons fate and life expectancy. Like

science, religion and spirituality fall under the analyzing gaze of critics. "Faith makes its way in the dark, seeing through a glass darkly, and it is genuine only to the extent that it acknowledges the abyss in which we are all situated, the undecidability and ambiguity which engulfs us all" (Caputo, 1987, p.281). In Caputo's view spirituality often attempts to stabilize the uncertainty of life. In the context of living and dying, spirituality risks offering answers to mortality in terms that exclude all other forms of knowing and claims to illuminate these dark and unknown phenomenon.

When the topic of God or spirituality was discussed in conversation I remembered Caputo's warnings (1987). James in particular seemed to live this ending of his life with passive attitudes. As though his belief in a high power absolved him of the responsibility of dying. His date was already set and there was nothing he could do that would alter this destiny. I do not suggest this was wrong, but is rather another example of how meanings of dying are variable. James' story emphasizes how not all people see death as something to be combated, or confronted. Perhaps faith in a higher power affects dying. Maybe with convictions of faith, dying is interpreted as an event without being met by resistance.

Reflecting on a life that has been lived

Death and dying are frequently placed in the metaphorical circle of life. Where seasons, generations and lives are understood as travelling from birth with its newness and anticipation, around to the inevitable process where this season, this generation, and this life ends (Kastenbaum, 2001; Kubler-Ross, 1969). The cycle continues as new seasons, new generations and new people enter into this never-ending circle. I have shifted my understanding of this perpetual motion. It seems more appropriate to say that a person's life involves a circling and re-circling and re-circling. We are not limited to one turn of this

wheel. Dying involves living and living involves dying. It is said that we cannot turn back the clock and live again. Perhaps this is pragmatically true. The conversations I have had with people who are dying challenge not only how living and dying are interconnected but also how it is possible to re-live in different ways.

Each conversation that I engaged in had portions devoted to the person's family, interests, and history. At first I relegated these notions to superfluous commentaries. When I became submerged in the data I began to see, these expressions could not be ignored. They were detailed, passionate, and looked to be connected to each person. Telling about our daily lives, our past, and our dreams is part of dying (Benner & Wrubel, 1989; Callanan & Keiley, 1992; Kleinman, 1988). It seems difficult to imagine a person would change completely when they were faced with their nearing death. Our past and our history help to shape what we are, and how we understand. This notion may not be new. Still these impressions, although seemingly obvious, did not come quickly or simply for me. I may have thought them at different moments, but it was only after being with, mulling over, sorting out, and making sense of all the stories that I returned to this possibility.

People's narratives have been receiving attention, as there is a move toward a postmodernism ideal that values understanding human perspectives (Frank, 1991, 1995; Kleinman, 1988; Young-Mason, 1997). When a person articulates their stories, they open and create meanings that disease and illnesses have in their lives. "The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering" (Kleinman, 1988, p.49). In my practice I have heard such stories and, as I anticipated, the five participants also recalled stories where meanings of dying were exposed. But their stories also had portions that appeared

segmented from the meaning of dying. As we entered into conversations about past lives I wondered how or if these stories spoke about the dying experience. In order to make sense of these stories I needed to reposition my thinking and my listening. At times I heard in the life stories, very little about dying. Kleinman (1988) explains how the elderly in particular,

... frequently weave illness experiences into the apparent seamless plot of their live stories, whose denouement they are constantly revising. In the terminal phase of life, looking backward constitutes much of the present. Things remembered are tidied up, put in their proper place, re-thought and equally important, retold, in what can be regarded as a story rapidly approaching its end (p.50).

My interpretation of these stories is subtly shifted from the perspective suggested by Kleinman (1988). Perhaps this explains my concern as I read transcripts that seemed irrelevant. I do not believe these stories reflect just a remembering or rethinking of life for the purpose of understanding dying. They dealt with people's histories and lives too passionately. Relevance became obvious when I understood that dying and living were not separate.

Histories of people's lives were dominant aspects of every research conversation. Christine talked of how she and her family moved from the United States, slowly abandoning heavy possessions like sewing machines, and how cattle and horses were lost on the long journey to northern Canada. She remembered the details of how her younger sister was buried along the trail, and how years later the grave was not found, because it had grown over and become part of the prairies. Hank told of the difficult years as a newlywed, when a fire destroyed their family home. He continued to explain how shortly after he erected the new home it was again destroyed, this time by a tornado. James and Frances told stories of their careers and family, also set when they were younger.

In William's case, storytelling served to solidify his role and contributions to the community. As though by telling the stories he would live on. It could be that not just William but the stories about his homestead, his family, and his life as a younger man, would live on. The stories were situated in the distant past and made me wonder if William was reliving the years that had gone by. He did not seem to long for these times, but rather basked in the life the stories held. And he seemed content to hear his voice and know that someone was hearing him, hearing the stories. Stories and traditions have lost a place in today's society. We are motivated by the shiny, by the modern, by the fast, fit and recent. Yesterday's news interests few, as we move towards what is new today. Technology has made immediate access an expectation. We no longer wait to hear news from relatives, we 'log on' and our messages arrive in moments. As we move forward, the past, and the old are being forgotten. We live a pace that has no time for stories only information.

With dying it seems important for people to tell the stories of their lives. As though it defines and solidifies who they were, who they are and who others will perceive them to be. Could dying be a phase in a person's life for reflection? It may be part, but it seems to have a greater role than merely an accounting for the past. Perhaps history defines the experience of dying as much as the present. As humans we are constantly evolving, growing and changing. This process does not stop with a terminal diagnosis. Part of who we are is included in our past and our history. The storytellers change and evolve as well, as we retell the past and the stories, creating new meanings. Each person seemed eager and at ease when they told these stories and I questioned how many people had actually listened to them. So often stories of the past are quickly passed over, or ignored in favor of the here-and-now details. I expected to hear the here-and-now details of dying. I struggled because I

had expected to hear about dying placed in the context of the present. My notions about the experience of dying did not place the same emphasis upon the past. Somehow history has its own place in the story of what it means to be dying today.

Is it possible that I looked at dying as an experience that was separate from living, separate from our history and who we were? This assumption is difficult to face as I now see my perspective was often narrow, and didn't encompass the bigger horizon of a person's history. Have I come to understand dying without truly accounting for the history that moved a person to this point?

In the process of dying people are still in the process of redefining themselves, understanding who they are, and how they live. This idea of reminiscing and storytelling makes me think of how people are constantly creating meaning in their lives, meanings of their life and meanings of their dying and death. As though these stories are monuments that tell of the enduring significance of their life. Stories may be told to keep the person alive. Alive and active now as they become debilitated, and alive in the memory of others. If storytelling is a way of creating meaning in a person's life then what message do we convey when we fail to truly listen? Listening to stories often gives us a way of knowing the person but they may also be valuable tools to understand a person's particular experience of dying. This is not only background data or demographics (which nurses readily accumulate for the purpose of assessment) but information that conveys how a person's life has been lived. When we listen only for the purpose of 'information gathering' could it be possible that we are ignoring how history and the lived life of the person influences their interpretations of dying? Are we denying people of the ability to express their individual experience and meanings of living and dying? I had expected to hear about

dying, and about today. Yet history has an equal place in the story of what it means to be dying today.

“You kinda try to be prepared”

Years of nursing have taught me that people often go through a process of preparation. I used to believe this was a way of letting go where good-byes were said, financial matters and funeral plans were completed and the person was close to accepting the inevitability of their death. So when Hank and Christine commented on their readiness to die, I initially felt I understood what they were telling me. Their stories contained words that resonated with what I already understood. They were telling me words I had heard before. Was I listening? Our understandings of what it was like to prepare to die should only be starting points. Points where we understand what being prepared might mean. Points where we must travel forward beyond assumptions to clearly see everything preparation entails for these people. The narratives revealed more than my initial assumptions.

Hank started our conversation by telling me “I’m getting everything all set and ready in case I die” (Hank #1, p. 1). I did not doubt his story, rather I was captured by how he was telling me his story. He continued “In most cases when people sell their stuff they always need it back. So this is going to help me get the cure” (Hank#1, p. 1). I continued to find myself grappling with what seems a convoluted notion. It is as though Hank was planning or preparing in hopes of a day that would never come. As though his actions stalled death. Here, I found a tendency in myself to rely upon categories and frameworks to interpret his words. My ability to understand was momentarily stopped as I started to read Hank’s story with conclusions about facing reality, bargaining and denial.

For Hank, selling his car, musical equipment and treasured fiddles was one way he faced his death and hoped for a cure. Music and his fiddles in particular had always been important in Hank's life and he took great pleasure from playing for the enjoyment of others. He related how when he was receiving therapy in the hospital he played the fiddle for the other residents, "and we played for two and a half hours. There were people dancing in the lobby and in the rooms, and all over the place" (Hank #1, p.9). When Hank told me he had sold his two fiddles I remember feeling disbelief. At first all I could think of was how perhaps he would enjoy his days more if he kept his fiddles and played them. What a loss I thought this must have been for Hank, a loss that seemed self-imposed and preventable. Maybe I felt this way because I did not share his hopes and beliefs. These actions did not seem rationale but Hank's energy and passion made me see that these actions made sense and were very rational for him. It was as though preparing for death he challenged death. As though he might have some control over mortality.

This idea is less convoluted as I consider how we attempt to avoid bad, painful, or messy things in our life. We try to prepare for what is beyond our control. We purchase insurance hoping fires will not burn our homes, thieves will not steal our possessions, injuries will not happen at work, and our cars will not be in traffic accidents. Is it a leap to then believe that 'paying the price' and giving away things of personal value will prevent death from coming? Preparing for death is as much about control as it is about dying. It is human nature to shy from uncertainty and as a result, many of our actions attempt to control variables in our lives. We choose careers, arrange our days and plan for the future. Why not try to control dying? Could being prepared offer control to worlds that are uncontrollable?

In our second conversation Hank's words remind me that I am sharing a person's story only at particular moments. Being prepared to die occurs moment by moment. Arriving at a place of preparedness is a process that never stops but constantly changes in personal meaning. In our second conversation Hank talked less of his hopes and the sale of his belongings. Instead he related with a sense of pride that his financial and funeral arrangements were recently completed. "If you didn't have things ready for your wife, for your kids, for your family, it would be quite a load on your mind. You know, there would be something you wish you could have done" (Hank #2, p. 11). Readiness for death had taken on a different meaning in Hank's life than the first time we spoke. It was more about preparing for others, for the reality of his death, than before. Preparing to die escapes definition. It changes and transforms itself according to circumstance. What it means to prepare today is different than it is tomorrow. Like the flux it may move and change in an instant.

People may redefine what preparing to die means but for Hank and Christine its presence remained a constant in their lives. Christine lived with this perpetual state of readiness "You know it's coming you just don't know when. You kinda try to be prepared" (Christine #1, p.5). One of Christine's passions was her interest in history and genealogy. Years had been consumed with updating family histories, tracking distant relatives and chronicling the lives and impact of her ancestors. Christine prepared for dying by keeping scrapbooks and family photos updated for her children and grandchildren. I had the sense that if a picture of a relative were found today, it would be pasted into the album before tomorrow. To be prepared at all times makes me wonder how dying might always be in a person's thoughts. Dying is something of which they are always conscious.

For Hank this consciousness alleviated anxiety and lessened his fear of death. Being prepared made him wonder how others can be fearful of dying. "They are not ready to die yet, they really want to live till they are one hundred and we don't always get that chance you know. So I would suggest to anybody that you try to be prepared at all times" (Hank #2, p. 11). Christine did not mind this constant reminder that she was nearing the end of her life. It motivated her. It compelled her to continue to live and be active. These tasks of preparation kept Christine active and heighten her sense of purpose. For Christine being prepared to die was not simply slowing down at the end of her life but keeping up, and says not only something about how we chose to die, but how we chose to live.

For me, preparation involves action. Conversely, the dying process involves physical changes that limit and confine the body's ability and movements. I was reminded of this as I looked at Hank, no longer able to walk, and at Christine whose breathing became labored as she crossed the room. Preparation is driven by actions – things that need to be done, controlled, defined, and completed. Our culture values the ability 'to do' and getting ready to die allows people to claim to undertake or even accomplish specific tasks that are not just beneficial for themselves but also for others. It keeps them with the 'rest' of society, the living the busy, the active. Preparation gives people direction and purpose.

Following this line of thought, preparing to die is expected of people who are dying. There is a generalized notion that this is a needed and necessary step, with the flip side being denial. If a person is not actively preparing to leave this world they must be denying the inevitable. Interestingly, 'healthy' individuals duck and weave issues of death, yet we expect those who are dying to face what we cannot – our own mortality. Although this assumption is unspoken, it exists, and I believe it accounts for how quickly Hank explained

he was 'getting ready' It was as though he was telling me what I wanted to hear, or knew what tasks a dying person should do. There is also an assumption that preparing for death signals acceptance of death. As bystanders do we expect people to be prepared and accept death to quell our comfort? If readiness has allusions of control, activity, and decreasing anxiety about dying, does it hold the potential to make dying more comfortable for everybody?

This desire to be prepared to die was motivated not just for the individuals themselves but also for their families, friends and loved ones. I believe Hank arranged his will and money matters to relieve his family of this stress when he dies. In Hank's life his roles of husband and father included: teaching his children, directing the family's future, working and earning money to support the family. By prepaying funeral costs, setting up trust funds, and arranging his funeral Hank was continuing to maintain his caregiving role in the family. When he dies he would no longer be present to support, help and assist his family. It must be painful to know that you cannot help loved ones during difficult times, even if this painful time is because you have died. I wonder about the difficulty in knowing how your death will affect people you love. Could people who are dying feel guilt or a responsibility towards friends and relatives? Death is often anticipated and received with sadness, and upset. It seems naïve to not know how your death would impact those around you. Perhaps being prepared also is one way that people try to lessen this grief and assist their families after they are gone.

Hoping...

Hope is a common theme within literature on dying. It has been objectified, romanticized, theorized and even quantified. (Dufault & Martocchio, 1985; Jevne, 1994;

Lamm, 1995; Neckolichuk, Jevne & Maguire, 1988; Stoner, 1988). As I listened to the narratives of dying I also heard stories of hope. Again I effortlessly slipped into an understanding based primarily upon my beliefs, and assumptions. Although difficult to admit, I have assumptions about how the process of dying and the idea of hope influence one another. Prognosis, age, spiritual beliefs, diagnosis influence my thoughts and have tones of judgement. The question should not be, but often becomes, whether hopes are present, possible or even realistic. It is here that the notion of hope enters into an arena of doubt and debate, where the persons meanings are questioned. This results in dichotomous camps of acceptance or rejection.

As I think about hope it seems that whether it is generalized or particular, it is frequently interpreted as opposing or denying death. When I was a nursing student, I remember learning ideas similar to these: "despair only retards healing, hope only enhances it. Anxiety and despair can be lethal, confidence and hope are life-giving... No matter the prognosis, no matter the realities always encourage a person's hope" (Lamm, 1995, p.129). We accept that when death is imminent hopes change. People hope for a good death, hope to live long enough to see distant children, or hope for time-limited desires. Is it rational for these hopes to change because after all, isn't their battle against death hopeless? "There is no hope for this. There are no treatments here, no. I have to get this constipation cleared up it's the only treatment I am getting here, and some painkiller and things to keep me comfortable. That's all they are able to do here. Keep me comfortable" (William #2, p.5). William's comments lead me to thinking about being hope-less. People are often seen as being hope-less when they seem to give in, give up, or give way to their fate. Yet William had not given in, up, or way to dying. He was not hopeless and ready to die. Rather, hope

for a cure did not become part of how he understood the experience. So the presence and the lack of hope generates multiple meanings of dying. William did not quickly relinquish life because he did not hope for a cure. Neither does he 'go quickly unto that dark night'. He chose to live with his inevitable destiny something that was not necessarily accepted but neither was it feared.

Hank's hope was very obvious in our first conversation. Hank felt that prayer, use of herbal therapies and selling his possessions were actions that would cure him. Hope directs a person to improve their present condition (Dufault & Martocchio, 1985). Hank did not passively hope to be better, rather he directs his money time and energy towards his ultimate goal of improved health. A tension surfaces though between his hopes to change his fate and his belief that he was dying. Hank told me he considered himself dying. He also said he was hoping for a cure. The medical world had spoken words that painted a hopeless picture. It was at this time that Hank looked away from medicine towards alternative therapies for the hope he was losing. There are many people who may look for hope in treatments and beliefs that are not found within the walls of hospitals or the world of empirical reason.

I found myself assuming that a person's hopes were either more 'life encompassing' or more futile. As though hopes at some definitive point in illness were drastically different than when we are not conscious of mortality. It is as though hope when we are dying is different than hope when we are living. Each person's meaning of hope serves different purposes as people choose various ways to live with terminal illnesses. Hank's hopes for a cure energized him to be active in his illness, to assume responsibility for his health. "And maybe there is a chance you see. So if there's any possible chance it'll help I'm going to

take it and that's all there is to it" (Hank #1, p. 14). His hopes did not placidly sit at the doorstep of medicine waiting to be addressed. Instead he claimed an authority over his health, and his hope.

When I met Hank for our second conversation I couldn't help but notice the differences in his physical condition, the setting and in his hope. Our second conversation took place in a hospital room. Hank was now paralyzed and doctors had told him he had a month to live. He still told stories of hope but they were different. No longer were his hopes 'full' rather the stories were like repeated words that had lost some relevance and meaning for him. The stories were concluded with "In my situation I think it's so far gone that it's too much.... I hope I'm wrong" (Hank #2, p.5). It seemed that perhaps hope still lived within him, but served a different purpose. I got a sense that for Hank to deny there was some hope how ever small would be conceding the battle of life. Perhaps he 'hopes' for the benefit of his family and friends who are not at the same place in the process of dying. Maybe he is saying what others expect him to say, that there is still a desire to live.

"My body"

When I listened to the language of those who were dying, I was reminded of how often I am ignorant of my body, how it carries me, and is part of who I am. The stories told seemed to tell some common tales about our bodies. "People telling illness stories do not simply describe their sick bodies; their bodies give their stories their particular shape and direction" (Frank, 1995, p.27). I had the sense that their bodies were like working machinery that wears after time with disease, and can alter how we function in life. Hank said, "It feels like I am running out of breath" (Hank #2, p. 16). Christine said often she feels like she was "just running out of power" (Christine #1, p. 1). She continued "Some

days I am so tired I can hardly get around. My body is just bone tired... When my heart is not working like it should, it's not getting the blood flow" (Christine #1, p. 16). When I hear these narratives I wonder about how difficult daily tasks must be. I think about how sensitive a person must be to every heartbeat, and new ache or pain. I think about how running out of power or breath might be frustrating, limiting and even scary. Is it possible that people resent these limitations, or is it possible that life like the physical changes has also slowly changed. If a person is so tired, as to be bone tired how is life curbed? James relates that perhaps he was more than tired "Well you don't have the strength and the stamina to keep going" (James, #1, p. 16). Our bodies contain us, move us and are necessary for physical actions. This may seem a simplistic notion but what might James be feeling when he doesn't have the 'stamina' to keep going? How might he feel about this body? No longer does Frances plan a day of shopping and visiting with any certainty that she will be up to the task. As though she lived with her disease and the uncertainty that follows as well. Life probably changes in many ways.

The stories of dying can be told through the particular experiences of the body (Benner & Wrubel, 1989; Frank, 1995). The participants gave me the sense that our physical body can serve to prepare us to die. I do not suggest that it is obvious but the body plays so many different roles in the continuum of illness (Benner & Wrubel, 1989). It is as though we are ignorant of it. Unconsciously demanding it to walk, sit, eat and sleep. Illness changes this relationship when a physical symptom alerts us that it no longer can be unconscious in our lives. The participants describe these life-changing moments. Christine talks about times when her failing heart dramatically affected her routine.

I went through a spell where, well, I just passed out. I had no warning what so ever, I just flop. And I'd be all right, I didn't feel so good afterward but...And this happened wherever I happened to be which was upsetting. I didn't want to go anyplace. because I didn't want to fall on the floor in somebody's house, or in the store, or wherever (Christine #1, p.3).

She did not question the reality of a stammering body. It was a fact of her life. The challenge for Christine comes when she must refrain from activities. She explained the frustrations of not being able to perform simple tasks, and how shortness of breath woke her at night. The tension comes when her reaction to these physical limitations was unexpected. She said, "I didn't get upset". I questioned "I think of things like fear. I think I might be a little scared about doing that again, or what was going on. You didn't feel those thoughts?" Christine replied "No. I don't think I did" (Christine #1, p.3). I found it difficult to believe what she was telling me. During the course of our two conversations I came to believe that Christine moved step by step, gradually to the place where her relationship with her body changed. There were contradictions in her story. At one point she said it was upsetting, and in another she said she was not upset. Perhaps they are about being upset at different things. Perhaps it is upsetting to think you may collapse anywhere yet not upsetting when she thinks about the end of her life. Perhaps daily life and living with a dying body is as important as the future and the moment of death.

Influence of medical landscapes

All of the participants were Home Care clients, in close contact with their physicians and a part of the medical system. As a result of this it was impossible to ignore the influence of health care systems in their stories. These contexts influenced the people's

interpretations and seemed to uncover assumptions, both from the storytellers and the medical systems of which they are a part.

The relationships established between the storytellers and health care professionals undoubtedly influence these expressions of dying. At times the people accepted the roles medical professionals played in their lives. They had been taught ways to understand their illnesses based on knowledge that was shared with them by these professionals. Medical terminology was now a part of their stories. They used jargon like, biopsy, morphine pumps, t2, progesterone, and cystoscopy, to develop and express their situation. At times these types of words were included in their interpretation of their dying. How do these influences change the stories? I am alerted to this medical jargon because implicit in them is a particular way to find meaning in an experience. Medical words do not belong only to professionals. Television and media have brought this influence and these words into our day-to-day worlds. They become our words and new ways to use language to understand what happens in and to our bodies.

Doctors are often shouldered with the task of delivering news when cures are no longer possible and dying is inevitable. James describes how doctors “pass the death sentence” (James #1, p. 18) as though he like a judge or executioner had the power to decide who lives and who dies. Where would we get the impression that physicians have this power? Could this be a backlash from current ideologies where physicians and health care systems are thought to have the ability to heal all, and cure all (Kastenbaum, 2001)? It is my impression from these conversations that the relationships with physicians changed once a palliative diagnosis was made. James and Hank in particular were hesitant and wary. No longer did they look to medicine for answers and it was as though the influence of

medicine somehow shifted. Dying became their realm and more influenced by their interpretations. James narrated one instance where he challenged his physician's perspective and actions. "I go to see the doctor and I'm in there and he's got wrote in my chart 'do not resuscitate', I look at him, and well I don't intend to die yet!" (James #2, p.7). For James the reality of a terminal illness does not mean life is unimportant even if a doctor may assume this.

When I heard Frances' story I thought about how her body became a battleground with cancer staking a claim, physicians countering with surgical defense and bystanders watching the action. The relationship between patient and doctor seems different than the other stories.

I don't know, it spread, they took the lump out. And they didn't take the whole thing at first. The doctor did ask me before the operation... Do I want a lumpectomy or a mastectomy or a complete one? And I said well really I don't know. I have never thought about it. I said you're the doctor it's up to you I guess. But anyhow after I came to I had this lumpectomy. Course my sister was horrified. Take them off you don't need either one of them. But anyhow she was right (Frances #1, p.8).

I am in awe with the way the physician and sister seemed to claim her body as territory. While involving Frances in the decision making, ultimately it was the surgeon who entered her body and plucked the diseased portions. Perhaps Frances did not feel this way, but for me her words captured this idea of an invasion of her body. At moments I wonder if Frances cared as she gave power and control to the physician, to use his skills to remove disease from her body and cure her. I wonder what she would say to the physician when she learned that the cancer had returned. What did she feel when she looks at the scars, the war wounds, and knew she was losing the fight? Even her sister joined in this, now public, debate. I think how difficult it might be to accept that there was different

decision or another way to compete with cancer. There seems to be little regard for any of the other possible ways Frances feels about this cancer, this surgery, and this body as she was dying. For Frances maybe this is not an example of passivity or relinquishing control but speaks to the differing priorities in her life. In order to remove the cancer perhaps she needed to allow the physician to make decisions and assume responsibility for her health. The issue of power and control over your body may not seem important when the same body needs the skills of a surgeon to possibly postpone dying. I also think about the energy and control that is needed when we place our fate in the hands of another person. Assuming Frances was complacent shuts out seeing other possible interpretations.

When Hank mentioned the role that physicians and the health care system played in his life and dying, he seemed to point to his need to control and take charge of his life. As though he felt it was his responsibility, and no health care provider would assume this role. As I listened to Hank I had the impression that there was a line that separated the health professionals from the consumers, or patients. I also had the impression that Hank did not believe that the two groups shared the same concern for the health of the patients. He told how a therapist had encouraged physical therapy for him three times a day but nursing staff was so busy that his wife stayed all day to perform the tasks. Frustrations and a bit of anger surfaced as he told me that he believed he could have been cured if only the physicians had checked out his entire body for a recurrence and not only the old cancer site. I began to wonder how it must feel to be so helpless in a system that has the power and often the responsibility to diagnose and help people. How would it feel to hear a doctor say "We can't afford it, we haven't got the time? If we went and checked everybody that's got cancer for their next bout we won't be able to keep up. We can't do it" (Hank #2, p.5)? He

seemed mildly mistrusting. I say mildly because he was not aggressive in his criticism of the health care system, but it seemed to me that he wanted the health care system to acknowledge that they were not always right or infallible. Hank listened and continued to hope in the stories of others who were misdiagnosed or who outlived predictions. He sounded more like a person who must live and was dependent on a system he did not completely trust. He also seemed indifferent to the traditional medical establishment, judging and taking what resources and information he needed. Hank started using herbal treatments when he had decided it was time to 'work on this' illness. Non-traditional therapies offer a guise of control for Hank. He was not as restricted by medical opinions, rather he claimed the freedom to make his own choices about dosages, types of treatments, and decided what was best for himself. Has traditional medicine become so rigid that the patient has less influence about how to live and how to die?

Illness made Hank alert and focused upon how his body functions. He was aware of the fragile nature of his body. Hank's story reminded me how simple actions can mean something very different for each person. The nursing staff's directives and focus seemed different from Hank's. He talked about the nurse that was caring for him that day. "This lady was coughing right over me, working and coughing and I said I hope you haven't got the flu. Ah, she said, just a little cough" (Hank #2, p. 6). A little cough has a different meaning when you are in bed and can't move or are physically compromised.

Frances' self-knowledge informs how she understands the experience of dying. Yet I still found myself questioning this self-awareness. I questioned her palliative diagnosis: Was she dying? Could she be in my study? As though without a medical diagnosis or label a person could not relate their story of dying. As we travel forward in our lives don't we all

have stories about living and dying? Blood tests, diagnostics, CAT scans and biopsies somehow add to the credibility of our illness stories. Medical measurements are definitive and absolute compared to a person's self-knowledge, which is abstract and subjective. There is favoritism for these objective ways of knowing, and when we deem them to be more credible than personal accounts we are also saying something about who holds the power and authority. But Frances re-captured this authority. She made comments that suggested there was a myth of control for professionals. She asserted her opinions and did not heed or care what others said. She determined she was dying. She knew she had cancer of the breast before the doctor found the lump. She also knew she had an irregular lump on her scalp. She had authority of her body. She understood what was happening in it, and to it.

"I'm still living"

It is hard to pinpoint a moment in time where a person is dying. It is naive to think that dying occurs at specific times, with specific symptoms. Frances believed she was dying yet no one had told her this, and Christine commented that we are all dying. Are we talking about the same thing? Dying is one portion of living and no one will travel this road in the same way. It is here in the present that the dance with living and dying appears most intricate. It is as though the dance of living attempts to understand how to act and react with the idea of our approaching death. Each person integrates dying into their living, how they choose to do this is as individual as they are. If you are dying, there are many ways to live with it, and there are many aspects of this process that also must find space in a person's life. Dying, illness, and the symptoms these bring forth may not be welcome, and they may

not be conscious thoughts, but somehow these aspects change a person's life and are part of the experience.

James told me how his illness and dying had become a reality of life, something he tried to live with. He did not emphasize his illness. He believed there was little he could do to control his fate. He made comments like "Crying about it doesn't make life any easier" (James #1, p.1). "That's the way it is" (James #1, p.1). "Well everything changes your life. Just it don't make it any better. To me it don't make it any worse" (James #1, p.1) "I'm still living" (James #2, p.16). I found myself questioning attitudes that seem so accepting. But what choice did James have? What would it say if he did not accept this illness? Interestingly, James chooses to live with this reality. For James to continue with living, dying needed to be acknowledged, but not overemphasized. There seemed a tension between what he was saying and what he didn't say. As though maybe life was worse because of his illness. Perhaps the tension was not in James' words but within James himself. Maybe life was only worse if he allowed it to be? As though James has chosen to live with his illness in this way.

Some people may read James' responses and wonder if he was denying the severity of his illness, or ignoring a harsh reality. That is only one possibility of how James was finding meaning in dying. Perhaps James did not give his prognosis such influence. Perhaps he made sense of dying differently. Somehow, this made sense for him now. Who are we to assume we completely understand his perspective? As health care has attempted to recapture humanistic elements, we have broadened our perspective to attempt to incorporate more holistic approaches to client care (Phillips, 1997; Mayer, 1989; Mitchell, 1997). With this wave has emerged a re-focussing upon healthcare relationships and

communication about dying (Kastenbaum, 2001; Mayer, 1989). My conversation with James made me question if this approach was appropriate for everyone. James' life seemed a delicate dance of living and dying where James determined their roles. When medical settings, treatments, procedures and professionals become a part of a person's life, does mortality become emphasized? He had not emphasized it.

Living with dying was expressed by other people in this research. Christine and I discussed dying and I questioned how or if dying was a part of her life, something that lived with her. She told how she did not let it overshadow her existence. It did not have a pivotal role. Christine pointed out that the idea of dying was not something that she seems conscious of. It was though our conversation raised this notion to a place where she was conscious of it, and able to talk about it. As I think about how people do not think of themselves as dying, I consider that rarely do I think of myself as 'living'. This research study has raised the experience of dying to a place where it can be examined and observed, but perhaps this is artificial.

Christine: I don't think about it, and I don't dwell on it, and I don't worry about it. It's just something, well I know it's there and I know it's coming but so what.

Gail: Okay. This helps me because not everybody shares your opinion and I think it's interesting the way you live your life knowing this.

Christine: Well, I don't know any other way to live. I'm not going to sit down and cry, and moan and groan and complain and, it only makes it worse. I have too much to live for yet (Christine #1, p.5).

When I first heard this comment I questioned how crying could possibly make things worse? I came to see that for Christine this was her reality, her way of understanding and living with it. For Christine crying did make it worse. This perspective then allowed me to see that perhaps dying and what will happen tomorrow are not worth worrying about today.

Why would I assume they were? Why would I assume that crying and overwhelming grief were appropriate and expected responses to such news? Often as health care professionals, we encourage conversations about dying and death. Palliative care literature tells us that mourning, bereavement and anticipatory grieving are 'normal', and 'expected' (Kubler-Ross, 1969; Victoria Hospice Society, 1998). This may be the case for some people. Yet I need to remember that this, like all broad theories, is not true for everybody. I came to this understanding as I continued to hear how a palliative diagnosis and a person's illness did not change people's lives as dramatically as I assumed.

"You've got to live with a little bit of pain"

James' experience of dying included living with the pain that accompanied his cancer. For James pain seemed to be a constant reminder of his physical condition. "As long as the pain medication is in balance I live from day to day" (James #1, p.2). James tries to place dying in the background, but daily, pain held the threat of moving it to the foreground. So there seemed to be a tension. A tension between how James coped with dying and a disease that constantly reminded him of its presence in his life. Pain was something he could not ignore yet he was not prepared to give in easily to its demands. "I thought to myself, mister you're not going to last very long. You've got to live with a little bit of pain...you have to fight" (James #2, p. 13). He developed the idea that if he were to give into the pain he would be drugged and sleeping in a chair. This was not how James wanted to live. This could be one reason why James felt that he needed to 'fight' the pain, and yet 'live with it'. James was striking a balance between living with pain and his illness, and pushing it to the background. The use of pain medications in palliative care has been

emphasized (Librach, 1991; Victoria Hospice Society, 1998). Controlling and limiting a person's pain reflects a commitment by care givers to providing comfort, and directing care which is thought to improve the quality of a person's life. Yet if a person believes that pain is something to be battled or conquered wouldn't this affect their compliance and their use of medications? Taking this a step farther, there needs to be an examination of how this discomfort has meaning for each person. From James' perspective the meaning of pain could include this battle against the disease, not only a fight for life but also a fight for how he chose to live his life.

James was very emotional during our conversations. While talking with him I had the impression that what he said did not always reflect what he felt. As though his words only momentarily captured ideas, and there were many different ideas to come. He seemed to be new to these ways of thinking and making sense of his illness. As though dying were a process and how he understood his story changed frequently. As though he was forced to be conscious of this flux, his understanding of his life, his illness, and his reality.

Aging and dying

Sally Gadow has spent much of her nursing career looking at the philosophy and delivery of care in aging populations. Her work is thought provoking, and she frequently questions society's views on nursing relationships, aging and death. In her article, Aging as Death Rehearsal: The Oppressiveness of Reason (1996), she says ageism affects our perceptions of dying. She discusses how age holds negative connotations because age is an unwelcome reminder of our mortality. With age comes death. The older the person, the more natural and acceptable dying is thought to be. "Aging becomes synonymous with dying. The connection is concealed by normalizing the unthinkable, closeting death within

the meaning of aging” (Gadow, 1980, p.38). I felt the restraints of this prejudice while doing this research and in my day to day nursing practice. When people question me about this research they invariably take solemn tones. When I counter that the people have told me stories that were quite positive, the response always questioned the age of the participants. I found these conversations maddening. Both bystander’s commentaries and my emotional responses tell me something important about how ageism and dying are perceived.

The age of the people in this study was not solicited. This was done with hopes of limiting how the stories might be interpreted based upon their ages. Although I do not know the ages of the people with life threatening disease, I do know that each had gray hair and wrinkles. Although my desire was not to discuss how age affects the experience of dying, I cannot ignore it. Their comments made this worthy of discussion.

Christine commented “I know how old I am and I (laughing) know it’s coming” (Christine #2, p.2). Her comments struck me as pragmatic and rational, and I wondered how she came to the view that dying was acceptable at a certain age. Where would a person get such an idea? How would it feel to believe that after a certain age, dying would be okay? I wonder if Christine’s belief that dying was acceptable ‘at her age’ could be influenced by a society that values youth. As though with age, death becomes more acceptable, less of a loss. How does age affect our interpretations of what dying means? At what age is there a shift from what was not acceptable to the acceptable? So is dying about age? Some people may quickly draw this conclusion and determine that people are more accepting of death as they become older. It is difficult for me to admit that this statement does reflect the participant’s beliefs. For Frances, age limits her options for treatment and

cure. She is interested in media coverage of new treatments and therapies for curing cancer. This interest and hope dampened when she remembered her age. "Then I think what do you care at your age. I can't" (Frances, #1, p.10). The older a person is, the less valuable, dynamic, productive, and necessary they are thought to be (Gadow, 1990, 1996). Although not blatantly stated, these values continue in a society that strives to fend off signs of sagging, wrinkling, slowing, and aging. Although dominant, this is only one perspective. For Christine and Frances the experience of dying was also part of what aging and growing old meant to them. It affected their perception and affects the experience.

Living on

It appears sentimental to say that people who have died live beyond death. And this may be the case. But I feel there are a multitude of examples of how people impact our society on an emotional level even after they have died. We do not have to journey far to see that people who have died continue to find a type of existence here among the living (Leon, 1999). Statues of past heroes, gravesites, memorials, the names of our roads, the names of our buildings often honor people who have lived: Lest we forget. They show us the past; they show us their achievements, their mistakes, their lives humble, glorious, or common. They leave us parts of themselves. The people in this study may never find their likeness engraved in stone but they still leave monuments: These monuments are varied but they exist and re-enforce how we are all inter-connected in this world.

The idea of 'living on' is my interpretation of the people's words and narratives. For me, it captures many ideas that may seem diverse, but converge on what happens after the moment of physical death. How we understand existence after death has, like the experience of dying, multiple layers. There seemed to develop from the conversations two

ideas of 'living on'. Firstly that faith and spiritual beliefs generate meanings of living that are not bound by this earthly world. Christine in particular talked about God, heaven and dying as a transition to another place. 'Living on' in a life after dying on this earth. Another interpretation of 'living on' has to do with the notion of how we leave monuments "Something set up to keep alive the memory of a person" (Webster, 1979, p.1166) for other generations. Aspects of people who have died are preserved in the minds of the living by these monuments (Leon, 1999).

The five people spoke objectively about their belief that death happened when the body ceased to function. Somewhere in their words and in what they didn't say told me that death and dying might not be as finite as I had always thought. It is as though our physical body may be an insignificant piece of who we are, as humans. We often define death as the moment our heart stops beating and our lungs no longer propel our breath. Interestingly, they talked about death and dying in this clinical way, yet their words also challenged and seemed to move beyond this absolute.

Gail: When do you think a person is dying?

Christine: When the heart stops beating.

Gail: So at that moment, there's...that would be a relatively short time period.

Christine: In the twinkling of an eye.

Gail: Is when you die.

Christine: Yup (Christine #2, p.24).

Christine's comments opened up my understandings of dying. I assumed that dying was a process of months or weeks or days. Christine imagined that dying occurred in one brief moment. Is it possible that if dying is perceived to be one moment in time, it loses significance in the greater scheme of a life of months, decades and years? If dying occurs in a blinking of an eye, it re-focuses upon the living up to this moment. Dying becomes not

only a physical event but an existential event as well. 'The twinkling of an eye,' these words add the dimensions of the magical, and the mysterious.

It is possible that living can extend beyond the death of the body, just not in familiar ways (Leon, 1999; Lizza, 1999). Christine spent time considering her mortality and integrating these ideas with her spiritual beliefs. Christian faith for this woman stressed the ideas of soul, rebirth, heaven and afterlife. "I'm the only one that has a religion background or, all the rest of my family they don't go to church. They don't belong to a church. What have they got to look forward to when they die" (Christine, #1, p.9)? This faith made dying for her an event that was anticipated with hope. Something to look forward to. She believed she would 'go over there' when she died as though it was a threshold to pass, or maybe just a place different from where she was that day. "There are evenings when it seems like he's sitting there. I can almost feel him there. And I wonder if his spirit comes back" (Christine, #1, p.17). She had little uncertainty about the dying process. She did have uncertainties about this afterlife.

Gail: You think about him a lot?

Christine: Oh, all the time. I always want to tell him something, ask him something, talk to him, touch him.

Gail: Do you still talk to him?

Christine: Yes, Nobody knows about it though I don't tell anybody... That's my secret (Christine #1, p.17).

She recognized that others may not share her views. Not everyone's views about dying will mesh with what I have written. Society influences, either consciously or unconsciously, how we live. What would the conversation have been if others knew she talked to her dead husband? Why should this comforting idea be oppressed and remain unspoken? Perhaps this directs us to the influences of society and the dominant narratives

about living and dying. A faith in a life after death is not a belief shared by all circles of people. For Christine it was a secret. It was also something that impacted the way she interprets living with a terminal illness. This secret (like many others I think exist) told me about her experience of dying only when it was shared.

William brought up for me this notion of monuments when he talked about a project he was planning in the community. He was aware that he would not see its completion but wanted to be involved in the planning. I asked him if he thought this may be a way of leaving a legacy. He commented, "Well, could be... Some man a lot more famous than I'll ever be, he said, 'My work is done my testimony stands' That's something to think about... I've done more good than harm" (William#1, p.9). For William leading a good life seems to be a worthwhile monument. As though with dying he can reflect on life and believe that others may remember him in a positive way. This idea of doing good in his life was interesting because William had made numerous contributions to his community and a building was named in his honor. Perhaps it is modesty but it is also likely that how we are remembered, our connections and relationships with people are the greatest monuments. "I always figured that, that's my greatest achievement, was that I lived right here for seventy-six years and I was welcomed in every house" (William#1, p.28). The photographs, albums and poems Christine shared with me continued my thinking about how people can live beyond death. Our memories are not erased when breath is gone. Christine's interest in genealogy will serve as her legacy. "I keep scrapbooks and genealogy and photograph albums and all that clippings... I made some books for my grand-kids, and my two children" (Christine #1, p.5). Hank will continue to live in the memories of the wife he has left, and the children he has raised. He talked about how he taught his children values and

responsibility, qualities that are part of them now. "The importance of lineage, the biological continuation in subsequent generations, ensures a sense of ongoing existence and being beyond one's death" (Leon, 1999, p.388). Somehow Hank and the others knew this although they never explicitly stated such a belief in our conversation. It is shown in the actions that have lasting value and whose products will remain after they have gone.

The other vistas

In most instances the themes I expressed about the experience of dying are not new. Health literature has discussed notions of history, preparing for death, hope, and living with dying. What is important for nurses and in some ways unique to this research is how the interpretations are examined in different ways. These interpretations do not lend themselves to conclusions. Instead this way of understanding becomes important when the individual's personal experience, and meanings, are seen to challenge the taken for granted ideas we have about the experience of dying. The particular meanings forced me to shift my gaze. Their perceptions of dying encourage not just revisiting common themes, but viewing them from alternate angles and vantages. Although the images on the horizon may be the same, shifting my position shows me other vistas.

Chapter Six: The Views Beyond

Just as there is no true beginning there is no true ending to the journey of understanding the world in which we live. Although this particular research reaches its end, like beginnings, the points in time are imposed in some ways. Imposed because the task becomes one where some order must be restored, perhaps artificially, to this continuous process of understanding. This chapter looks to the horizons, the places where these new understandings fuse with the horizons found within nursing education, research and practice.

Everyday, we look at our familiar surroundings. We focus on our daily tasks as we prepare meals, care for our bodies, and look forward to where we travel. The horizons that meet our eyes and the focus of our gaze changes frequently. Sometimes these activities have an unconscious quality and we do not always appreciate what we see, or question what is before us. Unconsciously, we position ourselves in the world, in a doorway, in a kitchen, in a bedroom of our house, on a road in a northern Canadian town, in relation to other people or other places. Likewise these particular stories of dying have a position within what is known about dying. Included in these layers of understanding are part of the horizons of understanding in nursing education, research and practice. The stories of Hank, James, William, Christine, and Frances provide ways to understand the experiences of dying. These stories push the boundaries and change, even if slightly, what was known before these conversations. These changes subtly redirect our gaze where we can see the view beyond preconceptions of death.

Nursing education

Nursing researchers and theorists are presenting new ideas that reach toward new horizons for nursing knowledge. They challenge not only our perceptions of illness, health, and the person, but also critically question how these phenomena exist in the contexts of the world in which we live (Liaschenko, 1997; McCormick & Roussy, 1997; Meleis, 1987; Miller, 1997; Parse, 1995). This research has implications for nursing education because it probes the idea of dying from the person's perspective and examined assumptions which shape how an experience is understood. "Scholarship stands for change and possibilities that widen the intellectual horizon as well as the space of experience. That makes its importance decidedly human" (Kleinman, 1995, p.3). There is much to be learned from the human stories of these five people. They discuss dying in words not always attributed to dying, like 'inevitable destiny', and 'running out of power'. The way each person lives with dying and makes sense of their experience cannot be found in any book.

Giving away and selling valuable possessions might challenge death and prolong life. Initially I found this idea confusing to understand. Yet when Hank passionately and earnestly told me he rid himself of his violins for this reason, I came to understand how this idea made sense for him. I had never thought about preparing to die in this way. This meaning of dying like others in this research tell us more about dying than definitions, theories or generalizations. New knowledge and understandings are generated as we hear stories like Hank's, stories we had not heard before. The knowledge comes from the storytellers themselves. As the example of Hank's belief suggests, hearing these narratives has potential to build upon what we already know about dying, and can inform nursing

practice. By exposing nurses and students to research studies that place the person central to the phenomenon, new doors are opened to the experiences of dying.

This research has me discovering and questioning my assumptions about dying. Prior to this research I had assumed that dying happened over hours, days, weeks and months as the physical body started to shut down and deteriorate. I assumed dying was something that happened in these time periods and particularly that dying happens when we are alive. Christine refocused this element of time and believes it happens in the twinkling of an eye. If dying is believed to be a momentary event perhaps the meanings change. Included in this text are some examples of my questioning and thinking: How is dying understood? Are we talking about the same thing? How do people's histories and lives relate to dying? Are living and dying separable? As bystanders do we expect people to be prepared to accept death? Why would I think talking about dying is uncomfortable? These questions could not always be answered. Yet they were purposeful because they pointed to how my assumptions are influenced by society and can obstruct how I think about the topic and relate to the storytellers. It is hoped that by reading this research others may also question how they understand dying.

Watson (1997) encourages questioning the taken-for-granted to uncover the depth of human experience. "My plea is for informed passion, passion that is informing by thought, reflection, and contemplation, giving rise to moral landscapes and contexts of human nature and relational concerns" (p.211). This research responds to aspects of Watson's (1997) plea. William, James, Christine, Frances and Hank's narratives generate awareness of how a person might think and feel about the experience of dying. Understanding another's situation enlarges not only our knowledge but also this passion for substance. Examining

my assumptions became a way to recognize that my notions about dying can originate in the communities of which I am a part. Why would talking about dying be uncomfortable? With Watson (1997) and Caputo's (1987) urging I try not to conclude, to remain in the play and learn through thought, reflection and contemplation. What does this discomfort tell me about dying? How does comfort relate to dying? Does it? I am left wondering. Hermeneutic research like this, invites nurses to wonder about what is left unsaid and taken-for-granted. We are challenged to see uncommon elements in seemingly common human experience.

Nursing research

How this study 'fits' or applies to nursing research at first seems deceptively easy. There have not been hermeneutic studies that address this particular phenomenon, or capture what this research captures. The challenge becomes whether or not we can remain in the mystery and play of understanding. The impetus for this study was the need to understand personal experiences of dying. The implications for further nursing research remain the same. This is not the end of the journey. Others may travel this same road of hermeneutics to understand the phenomenon of dying. Their journey will stop at different places, will ponder different ideas, and may veer from my path. There will always be varying vantages and interpretations. If this research were to be repeated the narratives and the stories would again change. So to would our understanding. This re-circling keeps into play the multiple possibilities about what dying includes and excludes.

Methods of nursing research that advance our discipline flow from conversations about nursing education and knowledge (Bunkers, Petardi, Pilkington & Walls, 1996; Engebretson, 1997). Just as there is a need for a broad knowledge base, there needs to be different and diverse methods of nursing research. Qualitative methodologies cannot

portray all types of knowledge a nurse uses. But these types of research can help us understand the nebulous areas of human phenomena and experience. Qualitative studies help us to momentarily pin down ideas that are abstract and cannot be proven. This is not an exercise in futility, rather it helps us understand the world in which we nurse, and ultimately the same world that surrounds us.

For me, the relevant question is how this research relates to praxis: the appreciation and integration of the theories, themes and narratives in the context of day to day nursing (McCormick & Roussy, 1997). At one time I interpreted praxis as being one directional. Praxis refers to the utilization of theories in practice (McCormick & Roussy, 1997). But this is not necessarily a movement in one direction. Relevant and purposeful research will be utilized if it reflects the nursing practice from which it emanates. There should not only be implications for further research but implications for how this research relates to bedside nursing, the concerns of nurses and the people who face dying. This study arose from my desire to answer questions. These questions came from my work with people who were dying. It should return to the bedside.

Rarely are nurses immune to the impact of the people we care for. Although nursing work can be hectic, we still listen to the stories of people's lives. Conversations with other nurses almost always highlight this humanistic element. Rarely do we recall stories about techniques, equipment or procedures. Frequently we talk about a particular patient, interaction or relationships that have developed. There is a reason for this. I believe within many nurses is a desire to understand people and experiences. The nurses and health care professional that surround me have been supportive and want to hear the stories of these five people. This reflects their eagerness to understand what people have to say. It does not

seem presumptuous to believe that these stories may find a place in the perceptions of dying when there is such an interest at this 'grassroots' level. As ideas sprung from the five narratives and as I developed my thinking about these stories, I reviewed these notions with other nurses. It was my attempt to pull this research down from philosophical questioning and surmising, to the reality of nursing practice, and care of people whose death is imminent. How does this stimulate new thoughts about dying? How does this influence our care of people?

Caring for people who are dying

Dying is a pragmatic issue which presents itself in the here and now, in clinical practice and importantly at the bedside when we listen. "Those of us who have spent time in the company of people with mortal illness have learned from them that we are always challenged to know more and to help more effectively, but above all to listen" (Kearney, 1996, p.13). When we listen as Kearney (1996) encourages, we are often presented with people's expressions of life, death and the interweaving topics. Thoughts about dying can easily slip into the realm of the philosophical or abstract. This research did not, just as interpretations do not, occur in a vacuum. They are stories, ideas, and interpretations that reflect real life and real lives. What are we hearing? How do we make sense of these narratives? What do they tell us? How do they affect nursing care?

It is perhaps constructive to explain how this research is significant for nurses, practice and most importantly for people who are dying. There have been many lessons learned in undertaking this research. In this research there are implications that relate to our relationships with the people we care for, the importance of uncovering meanings of dying, and how making sense of illness, death and dying moves our thinking, and changes the

experience. For me, perhaps the greatest significance for nursing practice is the seemingly simple admission that we don't yet understand.

Attempting to understand human experience is significant for nursing practice because of our necessarily close contact with people. Nurses are frequently in positions to potentially understand people beyond casual pleasantries or brief conversations. We have privileged positions where the richness of a person's history and life are often revealed. Within these relationships is the potential to teach us. We should not assume we know, about them, their situation, or their dying. These lessons need not be time consuming or viewed as one more task of many. Nurses do a multitude of tasks: they start intravenous lines, administer medications, chart client conditions, and change beds. Rarely is this all that we do. I have known caring, skilled and thoughtful nurses who, while doing even the most menial of jobs, are able to use these opportunities to better understand the person they are helping.

Understanding particular experiences of dying and co-creating meanings is not a simple or unnecessary task. Understanding dying becomes a requisite activity and one that I believe many nurses do, albeit often unconsciously. This obligation to understand the people we care for can happen within the framework of nursing process, and specifically in nursing assessments. Nursing assessment, as theory and practice show include the initial assessment, data collection and intake procedure, but also the on-going evaluation and reassessment to reflect changing patient needs and deliberate nursing interventions. This process, while being foundational to our practice and care, is one way the meanings of dying integrate into practice.

Exploring meanings can assist us to understand people's decisions and actions.

Initially a patient like James, who chooses to not take narcotics regularly to ease discomfort, may be misinterpreted. He may even be labeled 'non-compliant'. When we understand that James chooses to live with a little pain because taking medications in some ways is interpreted as ceding the battle against cancer, we may interpret his actions, or interpret his situation in a different light. These new interpretations may then result in the nurse acting differently or collaborating differently. What is important is to understand the meanings James creates in order to live with his illness.

This research shows that meanings of dying are personal, and change. As we saw in conversations with Hank, hope and preparation were not parts of dying that once understood stayed the same. Rather the meanings and relevance changes for Hank as his prognosis worsened and he came closer to death. Generating meanings is necessary not only because people's meanings change but also because meanings are different for each of us. Not continually seeking these meanings has us falling back into steadfast, unchanging assumptions such as what the ideas of hope or preparation should include. When we do this we miss something.

This research may confirm what many nurses already intuitively and instinctively do. We recognize the experience of dying as being more than biological processes and often enter into relationships with patients where we gain knowledge about their particular experience. Although there may be affirmation that we do this in practice, nurses should be ever vigilant by continually questioning and being conscious of how these meanings relate to the experience. This understanding involves being conscious and thoughtful (vanManen, 1997), where the details and expressions of everyday life are recognized, examined and

questioned. Hermeneutics “encourages a certain attentive awareness to the details and seemingly trivial dimensions of our everyday educational lives. It makes us thoughtfully aware of the consequential in the inconsequential, the significant in the taken-for-granted” (vanManen, 1997, p.8). The experience of dying becomes taken for granted when we theorize, generalize or assume without question.

Each of the conversations with Hank, James, Frances, William and Christine captured thoughts and words that somehow surprised me. The fact that as caregivers we can be surprised when we hear about people’s lives makes questioning meanings important for clinical practice. Hermeneutic inquiry seeks to understand human experience and becomes a way to uncover taken-for-granted aspects of dying. Being surprised by what another person tells us often suggests we may have assumptions about the subject. “I hadn’t thought about that” or “I hadn’t thought about dying in that way”, are examples of when we become more conscious of the limitations of our thinking.

For a number of years I have worked with people who are terminally ill. This, and the specialized clinical knowledge I have developed, had me assuming I could talk about dying with a certain degree of skill and capability. Hermeneutics has challenged me to look and think about the way I and others express thoughts on the subject. Reading and re-reading transcripts of these conversations was an activity that alerted me to the language and words of dying. The language people use to tell their stories is embedded with meaning. When Christine describes herself as ‘running out of power’ it speaks to a meaning of illness that makes sense for her. It tells me something about how she may think about her body and the illness that is draining her energy. When James tells me that cancer is like ‘facing a smoking gun’ I interpret these words in a particular way. This sensitivity was not

only directed to the language of the participants. Having recorded these conversations in transcripts I was able to reflexively look also at the way I communicate. Why, in conversations, did I not always use the words dying or cancer? Why did I express a thought using those words?

Even my avoidance to stereotype, or theorize the experience failed me. For example I resisted the notion that aging and dying are inextricably linked. Christine's words open again the possibility. For some people aging is part of the experience of dying. My tentativeness and desire not to generalize had me circumventing particular questions and actually excluding this possibility. As Gadamer (1997) warns "One can say something tactfully; but that will always mean that one passes over something tactfully and leaves it unsaid" (p. 16). Recognizing now how this assumption about aging limited my understanding has me now wondering: For this person how do dying and aging influence how they interpret their lives? Do they influence it?

In this research these five people not only tell us what dying is like for them, but also offer interpretations of how others may understand their dying. So when we listen, or enter into processes such as this where the meanings of dying are heard, we expand the possibilities for understanding other people: people who share this world and may experience dying in similar ways. We can now say they offer possibilities: maybe like William dying is not feared but is seen as inevitable; maybe dying includes living with pain; maybe like Christine living extends beyond the death of the body. Maybe dying is about action as well as passivity; maybe dying is interpreted in relation to a deteriorating body; maybe dying is not what I assumed. What is important here is not the expanding list

of 'options' but thinking about what '*may-be*'. What may be the possible ways people interpret their lives and their dying?

The meanings of dying uncovered in conversations with James, Christine, Hank, William and Frances relate to the totality of the experience. As Gadamer (1997) reminds we must "recall the hermeneutical rule that we must understand the whole in terms of the detail and the detail in terms of the whole" (p.291). By reading about dying from different perspectives we may come to see that there are many ways of approaching death – all are included in the phenomenon – all acceptable. Thinking about dying in a global way is purposeful. Without attempts to be conscious of how expansive and dynamic the experience is, we could inadvertently limit the potential of individual perceptions. Personal narratives then risk being thought of as merely stories, with less emphasis upon how they can teach others.

The point has been made that people interpret dying for themselves based upon their history, their culture, and their particular situation (vanManen, 1997). These experiences while being particular for each individual may also be shared by others. For Frances part of dying was accepting medical procedures to postpone her eventual death. Likewise, other patients we encounter in practice may see medical interventions as influencing their interpretations of dying. So giving voice to Frances' narrative of dying opens up possibilities for others who may share her perspective. The experience of dying may be similar but will never be the same. Sometimes it is in the particulars that the invisible becomes visible. For we see that a particular view does not exist on the margins, exceptional in its difference, but may be a reality for others. When we understand

that we may share viewpoints the taken-for-granted has a way of becoming less influencing. For example the patient who does not fear death may interpret dying in ways similar to Christine, who sees dying as a transition to a place beyond this world. The assumption that life ends with our last breath is challenged as being not a truth, but another possibility. We are left questioning.

“The point is to make life difficult, not impossible – to face up to the difference and difficulty which enter into what we think and do and hope for, not to grind them to a halt” (Caputo, 1987, p.7). Difficulty encountered when we talk about dying says something about dying. It does not mean we should abandon attempts to understand or talk about dying, but as Caputo (1987) urges to recognize this difficulty. Nurses in practice engage in conversations where both patient and nurse use language in attempts to express and understand the experience. Like these conversations there may be difficulty because of assumptions and beliefs about dying that are unrecognized and below our surface. We should stay with this challenge, keep listening, thinking and questioning. This research highlights individual experiences and the universal experience of dying, to a level where we can think, muse, reflect, wonder and importantly where we can question the experience. Questions keep the wondering alive. Questions that assume we still don’t know. Questions that ask: Why would I think that? Why is it that way? How could this be? Is there more?

My vista

I can describe my vista. I can illustrate what I see before me, the trees, the water, and distant shoreline. Sharing my thoughts and feelings is also possible. In this research I have tried to detail for the reader how the experiences of dying might be interpreted. Interpretation is fundamental to this research, it is how I make sense of the five stories.

Exploring my interpretations helped me to understand how I travel to these places of new understandings. I have tried to place my assumptions and feelings in the forefront to account for why I came to a particular understanding. Yet the process and time spent thinking and reflecting upon these assumptions and my reality is hard to communicate.

The conversational quality of hermeneutic truth points to the requirement that any study carried on in the name of hermeneutics should provide a report of the researcher's own transformation undergone in the process of inquiry, a showing of the dialogical journey, we might call it (Smith, 1991, p.198).

I have tried to take the reader on this journey, to account for my changes in thinking. Yet I do not always realize where a particular thought has originated or where it takes me. Why I think what I do, is a hard question to answer. I tried to be conscious of my assumptions and to contemplate them through writing.

At the onset my assumptions were put forward. I return to them as I wondered how I have changed as a result of this hermeneutic research process. Many of these assumptions still prove to be accurate, perhaps what has changed is my conviction as to the importance of these ideas.

- * Living with a terminal illness is different than when an individual has not been given a terminal diagnosis.
- * The experience of dying will never be fully realized because of the infinite amount of individual interpretations and the dynamic nature of the phenomenon itself.
- * Individual experiences and particular meanings of dying need to be recognized as portions of how we understand the universal experience of dying.
- * People want to talk about the experience and portions of the experience can be communicated. In these conversations particular meanings can be generated and co-created.

- * I could write about this phenomenon in a way that is evocative and thought provoking for others. By writing about people's particular experiences and meanings of dying there could be change in the way we practice and work with clients.
- * Society has assumptions and beliefs about dying that serve to create a distance from individuals living with a terminal illness. This distancing is negligent and can be harmful to people who are dying.
- * Knowledge is dynamic and ever changing. New knowledge can be found and generated between individuals in conversations.
- * Dying individuals change how they perceive themselves, their bodies, their relationships and their lives.
- * Health care professionals are not meeting many patient needs because individual subjectivity is silenced in favor of generalized societal beliefs and assumptions.
- * I have a responsibility to challenge the status quo by examining how society influences our ability to understand the experience of dying.

What was enlightening for me was realizing assumptions I did not know I held. When I engaged in conversations, journal writing, and thinking I became conscious of these beliefs. It was not until I talked with William and he expressed the ideas of inevitable destiny that I realized my perspective made assumptions about the significance of dying. I assumed it was a special time and an important life event. For William it held little importance. I assumed health care professionals determined who was palliative – until I listened to Frances. I assumed the hopes of people with terminal illness played a larger role than when these people were well – until I listened to Hank. It seemed my assumptions were never-ending. Questioning my assumptions proved to move my understandings and

once I was able to recognize them the placement of them as well as the new meanings changed in my mind. It facilitated openness to hearing what these meanings were saying to me. Tell me what it is like to know you are dying before the doctor does. Tell me what hope means for you. Tell me what you mean by inevitable destiny. I could not always ask these questions of the participants because it was after the conversations when I thought and wrote that they became salient for me.

Thinking and writing proved to be cathartic as fleeting thoughts were captured on paper long enough to be examined. There were attempts to anchor my consciousness upon the page, to show how I might understand my horizons, and the horizons of Hank, William, James, Christine and Frances. Much of my journal writing is woven into this text. It was hard, at times, to pinpoint the tensions I felt as I sorted thoughts, questioned my interpretations, and continued to think. The interpretations became more developed as I re-read the words that were spoken in the conversations. It was surprising for me when I thought about a particular theme then found in the text more of the people's comments supporting the ideas. There were also waves of ideas separate from the themes that seemed to continually emerge. These include: the importance of personal meaning, the caution against believing we have nothing to learn, and the importance of trying to understand another person's experience. Their re-occurrence in my thinking alerts me to their significance.

Doorways invite us to move forward, and once through the doorway perspective changes. As a nurse, before opening the door to a client's home for the first time, I often formed impressions of the client based upon assumptions generated from basic information such as name, age, and diagnosis. If a palliative diagnosis had been given by the physician I

made assumptions about what the person might be feeling, how they might be coping, what family stresses may be occurring, and how my relationship as a nurse may develop. These assumptions still come to the forefront of my thoughts as I meet individuals with life threatening illnesses. What has changed since this research, is now I use these assumptions as starting points or possibilities as to what a person may or may not be experiencing, not as rigid impressions that are either proved or disproved.

Looking beyond

This research has a place in the context and horizon of the world in which we find ourselves. Hopefully it will serve as a passageway for health professionals who read it, a catalyst to examine how we practice or how we think about not just dying but also how we interact with others. Even the process of understanding the importance of meaning for others is a beneficial outcome.

This research focused upon specific experiences – the experiences of dying. There were glances at the horizons beyond the chair or bed of the storyteller to places beyond the rooms of conversation. Indeed this interpretation now can find a place in other horizons: the horizons of the readers. By reading my interpretations the reader will somehow fit these ideas into their personal horizons. Perhaps the reader will feel differently about the experience of dying, perhaps they will not. There may be an embracing of these ideas, a rejection, or even an indifference to the ideas here. There also undoubtedly are subtle areas of grey, places in between where what has been read will affect each person in some way.

Opening doors suggests for me an acceptance and readiness to journey to the places where our movement may take us. Open doors do not block or impede us. They also do not obstruct the view beyond. In similar ways this research aims, and continues to strive to

keep open to the possibilities. To use Caputo's (1987) words, "and so it can claim here only to end, not to conclude. We do not aim at a conclusion but an opening. We do not seek a closure but an opening up" (p.294). Similarly this research has not implicitly detailed conclusions. It seems more appropriate to point in particular directions where the view may show us something new, remind us of the common, or continue the questioning.

I do not think I will forget William, Hank, Christine, James or Frances. These people have affected me. It is inevitable that some of the conversations and the thoughts that were stimulated will return to me. They are in some way a part of me. 'Living on', 'inevitable destiny', 'hoping', and 'aging'. these are in my thoughts differently now. Most likely they will re-emerge when dealing with other people who are dying. The challenge for me will be to use these as doorways, possibilities to understand what this new person has to tell me. Doorways that may help me understand this turmoil or thinking of another person. These new stories may be similar but will never be the same.

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APPENDIX A

Letter to Prospective Participants

My name is Gail Kulas, and I am a student of the University of Calgary in the Faculty of Nursing Masters Program. My background and interest is in palliative care nursing. For my thesis I will be exploring the meaning of dying as experienced by people with a terminal illness. I believe the stories of people living with a palliative diagnosis are often not emphasized. These stories can help other people who are living with a palliative diagnosis, and help the health care providers who work with them.

No one living will escape the process of dying. Yet what do we know about the dying process? There are many books, theories and models about death and dying, written by authors, theorists and health care professionals. This information helps our understanding of the dying process, but no human life is ever the same as another. We each have different experiences, feelings, emotions and reactions. I believe most theories can't capture everyone's story because we are all unique.

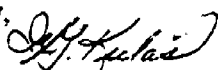
The purpose of this research is to better understand the experience of living with a terminal diagnosis. This meaning is to be determined not by observers, health care providers, or family members but by people living with the terminal illness. I hope this research study will enlarge the understanding of this stage in life.

All participants in this study have a terminal illness and are aware of their diagnosis. Participation in this study will involve two to three interviews. You can determine the length and location of our conversations.

Your confidentiality will be maintained and information obtained in this study will not be associated with your name in any way.

Participation is voluntary. You may opt out at any time. I understand that this is a sensitive issue and I will attempt to create a comfortable and safe atmosphere for all participants. I would appreciate your help with this study. I look forward to hearing from you.

Sincerely,



Gail Kulas

If you have any questions about the study you may contact me Gail Kulas at 532- 6607 or my supervisor Dr. Marjorie McIntyre at (403) 220-8847. Jane Manning as the V.P. of Continuing Care and Community Services in the Mistahia Health Region can also be contacted if there are concerns, at (403) 538-5387.

APPENDIX B



FACULTY OF NURSING

Research Project Title: The Meaning of Dying
Investigator: Gail Kulas
Masters Student, Faculty of Nursing

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

My name is Gail Kulas and this research study is for my thesis requirement at the University of Calgary Faculty of Nursing. This study will help people in both the present and the future to understand the experience dying. This information will help other people who are living with a palliative diagnosis, and the health care providers who work with them.

Your participation in this study is voluntarily. You will have the ability to determine where and when the interviews will occur, based upon your comfort and convenience. This study will provide you with an opportunity to express your perspective, thoughts, feelings and experiences in a conversation with the researcher. The conversations can often be 1 to 2 hours, but you can determine the length of my interview based upon your ability to participate and your comfort level.

The conversations may be audiotaped and the information in the conversations will be confidential. The information will be used in a research study that discusses the meaning of dying as expressed by persons living with a terminal illness. The audiotapes will be transcribed by the researcher and the data will be presented in the thesis format. False names will be determined by you and the researcher to protect your identity in the written product. The master list and all other interview tape recordings will be destroyed at the completion of the research. Some statements from our conversation will be used in the study and may appear in the published thesis, or related published articles. However, these statements would in no way identify participants in this study.

In having these conversations, we may talk about things you have not thought about before. This may result in a new way of thinking and generate ideas about new possibilities. However, sometimes conversations can trigger painful memories and this can be distressing. If this happens let me know. I will attempt to be sensitive to your needs and wishes, yet if at any time you feel uncomfortable during the research process or interviews you can withdraw from the study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial

consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact: Gail Kulas at (403) 532-6607 in Grande Prairie, or (403) 240-9887 in Calgary.

If you have any questions concerning your rights as a possible participant in this research, please contact the office of Dr. Marjorie McIntyre, at 220-8847, or Ms. Jane Manning V.P. of Continuing Care and Community Services in the Mistahia Health Region at (403) 538-5387.

Participant's Signature _____ Date _____

Interviewer's Signature _____ Date _____

Witness' Signature _____ Date _____

A copy of this consent form has been given to you to keep for your records and reference.