University of Alberta

Apprehending Death: The Older Adult's Experience of Preparing an Advance Directive

by

Marion Dianne Godkin ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Faculty of Nursing

Edmonton, Alberta

Fall 2002

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Degree: Doctor of Philosophy

Year this Degree Granted: 2002

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August 29, 2002
Date of Submission

University of Alberta

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Abstract

In the context of new technologies, an ageing population, and healthcare constraints, many older adults will be faced with a decision to withhold life-sustaining treatment at some point in their lifetime. Through advance directives, individuals make choices about the treatment and care they want to receive in situations of future incapacity. In this interpretive inquiry, the older adult's experience of preparing an advance directive was explored. Data sources included audio-taped transcripts from conversations completed with 15 older adults, copies of participants' written directives, literature, and research reports. Data were analysed through immersion and engaging in processes of reflecting, questioning, clarifying, and writing.

A composite narrative with supporting descriptions from participants was developed to describe five primary themes: protecting self and others, facing one's mortality, talking about death, choosing an ally, and getting it done. Older adults sought to protect themselves from healthcare professionals' actions, technology, and suffering. They also sought to protect others from being burdened with making end-of-life decisions, shouldering unnecessary expenses, and feeling helpless. Facing one's mortality and talking about death were integral aspects and contributed to strengthening family relationships, sharing values and beliefs, and a renewed valuing of life. Choosing an ally, an individual(s) to be one's advocate, was a complex and important undertaking that required thoughtful consideration. Getting it done was a time-consuming endeavour that required awareness and information, as well as careful and reflective contemplation. Healthcare providers' involvement throughout the older adult's process of preparing an advance directive was minimal.

Some authors have suggested that advance directives have failed to live up to their expectations as a means of controlling the dying process and decreasing healthcare costs. The findings of this study, however, suggest that preparing a directive results in other important outcomes for older adults including self-reflection and discovery about their own life and death and fostering of relationships with children, other family members, and friends. For participants in this study, completing an advance directive was a way of apprehending or coming to know death. The findings have implications for healthcare practice, public and professional education, policy development, and future research.

Acknowledgements

A gift opens doors; it gives access to the great. (Proverbs 18:16)

When I began my doctoral studies several years ago, I did not know and could not have imagined all of the wonderful and challenging opportunities that lay before me. A number of individuals and organisations have contributed to the successful completion of my doctoral degree and I would like to acknowledge the many gifts I received from them.

Throughout my program I was blessed with a great supervisory committee that continues to nurture my development as a scholar through their supportive and encouraging actions and behaviours including Dr. Wendy Austin, Prof. Gerald Robertson, Dr. Marjorie Anderson, and Dr. Brenda Cameron. I was especially privileged to have as the chair of my supervisory committee, Dr. Vangie Bergum, a woman with extraordinary vision and wisdom who exhibits all of those qualities one looks for in a mentor. Her generosity in sharing her time, talents, and patience freely with me will always be warmly remembered.

Funding to support my doctoral education was gratefully received from the Canadian Institutes of Health Research (formerly the National Health and Research Development Program), the Alberta Heritage Foundation for Medical Research, the Canadian Nurses Foundation, the University of Alberta, the Faculty of Nursing (University of Alberta), and Mu Sigma Chapter of Sigma Theta Tau International Nursing Honor Society.

I would like to extend a heartfelt thank you to my fellow graduate students for many memorable hours spent engaging in lively philosophical debate, sharing one another's writing and ideas, or simply partaking together a nourishing meal. I look forward to continuing relationships with the friends and colleagues from many corners of the world that I met during my doctoral program. I hope our paths will cross frequently.

Throughout my extended stay in Alberta, thousands of kilometres from my home province of Ontario, my family members have remained my most steadfast and hearty supporters. The sadness I feel at leaving this great learning institution, the University of Alberta, is tempered by my anticipation to be in closer geographic proximity to my parents, siblings, and a multitude of nieces and nephews. A special thanks goes out to each of you for your continued support and encouragement.

Lastly, I would like to offer a sincere thank you to the older adults who participated in this study. Their willingness to share their time and their stories was essential to the completion of this research. Through their experiences, I was inspired to reflect more thoughtfully on my own life and death and that, I believe, is one of the greatest gifts of all.

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Chapter 1: Arriving at the Question

> To truly question something is to interrogate something from the heart of our existence, from the center of our being. (van Manen, 1997, p. 43)

In the Still of the Night

One of the defining moments of my nursing career transpired very early in the morning as I worked the night shift on a haematology and cardiology unit. Penetrating the quiet stillness on the floor, an urgent call for help was issued from the nurse responsible for patients on the west wing. I was first to arrive. What I saw when I entered the room was a frail, emaciated elderly woman--breathless and pulseless--lying prostrate on the bed, the hospital corners on the sheets undisturbed. In accordance with hospital policy, I began cardiopulmonary resuscitation efforts. As I attempted to breathe life back into her limp body, my lips came into contact with hers--blue, clammy, cool, and lifeless. The code team arrived shortly thereafter and sprang into action. Over the next 20 to 30 minutes as the elderly woman lay on the bed, nude and inert, she was stabbed with large bore needles, zapped with electricity, and physically battered with chest compressions by a roomful of strangers--quickly, skilfully, violently. After an 'acceptable' period of time, the resuscitation efforts ceased, and the elderly woman was pronounced 'dead.' My physical response was immediate and caught me off guard. I ran to the staff bathroom where I vomited until I had nothing more to give. I was left shaking, perspiring, not quite sure of what had just happened. I reached for the bottle of Cepacol mouthwash hoping to rinse the experience out of my mouth, my body, my mind.

It was only after the patient's family arrived at the hospital that I learned more details of her life. Her name was Edith. She was 84 years old. She was a mother, a sister, a grandmother, a friend. She was terminally ill, suffering from leukaemia. During the past few weeks of her hospitalisation, her condition had been spiralling downwards. She and her family members were aware of her poor prognosis and the primary goal of her care for the remainder of her days was to have been comfort-oriented. Unfortunately, a do not resuscitate (DNR) order was never written. My 'gut reaction' to this situation was unwanted, unexpected, and unbelievably intense. Upon reflection, I think it represented the sense of anger and despair that I felt. I believe that what we did to that elderly woman one early Wednesday morning just as the sun was rising was violently wrong. I feel that I personally contributed to a system that failed to provide the best care for a patient --the level of care that every patient deserves. But we had done even worse than that--we had done a patient, Edith, harm. Where had we gone wrong? Why did this happen? What could we do differently to prevent such a tragic and unnecessary situation from occurring again in the future? These are questions that have captured my attention and motivated my continued exploration of end-of-life decision-making during the past decade.

Martha's Legacy

During my clinical experiences I also witnessed peaceful, comfortable deaths, so I knew this vision that I held closely of a 'good' death was not some romanticised version of reality that I had only dreamed or read about. Martha had such a death. She was a 66 year-old grandmother, who also had leukaemia. Her husband and two daughters, along with their husbands and young children, visited often while she was in hospital. Martha was a woman on a mission. She wanted to leave a legacy for her grandchildren and was relentless in her determination to finish recording her family history complete with pictures, letters, and other memorabilia in a scrapbook. On videotape, she recorded messages of love and support for her family. She wanted her presence to remain alive with them forever. Martha also knew her limits. She had researched her disease thoroughly, asked lots of questions of her healthcare providers, and clearly articulated to her family and physicians the type of care she wanted to receive under various conditions. She did not want to be resuscitated or transferred to an intensive care unit, unless the precipitating event was clearly only a temporary setback from which she was likely to fully recover.

Alongside memories of Edith's failed resuscitation attempt, I also hold an equally vivid, but contrasting, image of Martha just a few hours before her death. She is lying comfortably in bed, propped up on either side by big fluffy pillows that her family brought in from home. A bright and colourful crocheted afghan is draped over the end of her bed. There is music softly playing in the background. One of her daughters is gently massaging her feet with lotion, its peppermint fragrance permeating the room and snuffing out the smell of hospital. Her husband sits quietly reading in a chair at her bedside. Martha's eyes are closed. Her skin is sallow and her face is gaunt, but her expression is calm with the faintest hint of a beautiful smile.

Although I met Martha before the concept of advance directives was widely known and prior to their legalisation in any Canadian province, in essence, Martha had done precisely what an advance directive is designed to do. She had communicated her treatment wishes about her own end of life to her family and healthcare providers. She had confronted her own mortality and, taking into consideration the limitations imposed on her by her disease, had mapped out her destiny. What was this experience of preparing for her end of life like? What meaning did it hold for her? How did she do it? Why did she do it? What contribution did outlining her end-of-life treatment wishes (i.e., preparing an advance directive) play in helping Martha to achieve the goal of dying well? I wish that I had asked her these questions, but I did not. It was only in retrospect that I came to understand their significance and that I had missed an incredible learning opportunity. Many individuals, even when death is imminent, do not make known their wishes regarding treatment and care at the end of life. Not every individual is able to confront, much less accept, his or her own mortality--healthcare providers included. And unfortunately, not everyone dies well.

Although Edith and Martha's stories represent real situations that I have encountered, names and other defining characteristics have been altered to protect the identity of the patients, their families, and my colleagues. Their stories are incomplete, in part, because of the constraints imposed by memory, language, and space and, in part, as a protective strategy to safeguard my own psyche. Sometimes the stories, wholly disclosed, are too difficult for me to revisit in their full measure. What makes them so hard to recount, this hesitation to apprehend death in its entirety, in its wholeness, is one of the threads that has become tightly woven into the fabric of this text.

Purpose

In this study, through an exploration of the older adult's experience of preparing an advance directive, I am seeking knowledge that will help me and others to understand the answers to some of the questions that arose through my interactions with people like Edith and Martha. The purpose of this study is to produce an evocative text--one that has the capacity to inform us and move us, as healthcare providers and healthcare recipients, to a fuller understanding of the older adult's experience of preparing an advance directive and to inspire ethical action at the end of life.

Research Questions

The overarching question addressed in this study is: What is the older adult's experience of preparing an advance directive? There are also a number of subsidiary questions explored. These include: What factors influence an older adult to choose to prepare an advance directive? What content do they include in their directive? Who do they consult during this process? How do they select a proxy? What impact does this experience have on them and their relationships with others? How does this process affect their views on death and dying? What does it mean to confront one's own mortality? How do advance directives contribute to the objective of dying well?

Definitions

Advance Directive. An advance directive is a document in which competent individuals record their future healthcare wishes and/or identify a proxy who will make decisions on their behalf. Advance directives come into effect only when their maker becomes incapacitated and is no longer able to take part in the decision-making process (de Raeve, 1993; Kelley, 1995; Leslie & Badzek, 1996; Yamani, Fleming, Brensilver, & Brandstetter, 1995). In Alberta, the legislation governing advance directives is referred to as the Personal Directives Act. It allows individuals to make decisions about all personal matters, not just health care, with the exception of those pertaining to finances for which a power of attorney is required (Province of Alberta, 1996).

Proxy. A proxy is a competent person appointed by an individual to make healthcare decisions should he/she become unable to do so (de Raeve, 1993; Kelley, 1995). In addition to the term proxy, one is likely to encounter terms such as durable power of attorney for health care, substitute decision-maker, or agent, the latter being the designation used in the Alberta legislation. An agent is defined in the Alberta legislation as "a person designated in a personal directive to make personal decisions on behalf of the maker" (Province of Alberta, 1996, p. 2).

Dying Well. The notion of what it means to die well is more difficult to concretely and succinctly describe. Some authors suggest that it may include elements such as "being pain-free, operating at the highest possible level of functioning, resolving long-standing conflicts, satisfying final wishes, [and] relinquishing control over care to significant others" (Fisher, Ross, & MacLean, 2000, p. 14). These criteria, however, fail to capture the significance and weightiness of death as a major event in one's life. Indeed dying well may be a term that can only be defined at the level of the individual person, as each takes into account his or her history and situatedness in the world and relationships with others.

Significance

There is one certainty in life and that is death. Most of those who die are over the age of 65 years, and most desire a good death, one that is as pain-free and comfortable as possible. The average 65 year-old in Canada has a life expectancy of an additional 18 years, the last few of which are often accompanied by chronic health illnesses and varying levels of disability (Fisher et al., 2000). Over 90 pecent of deaths in North America today take place in hospital or nursing home settings under the care of health professionals (Ross & West, 1995; Fisher et al., 2000). Approximately 70 percent of all Americans will be faced with a decision to withhold life-sustaining treatment at some point in their life (Kelley, 1995; Matzo, 1997). As Canadians exist in a comparable context in terms of access to healthcare technologies, healthcare cost restraints, and an ageing population, the percentage of individuals who will face end-of-life decisions in Canada is likely to be similar.

Since the mid-twentieth century, medical technology has rapidly evolved and the end of life is no longer clearly defined. Life can be artificially extended almost indefinitely. Two landmark court cases in the United States prompted the development of legislation regarding advance directives (Downie, 1992; Ross &

West, 1995). First, in 1975, national attention was focussed on the right-to-die issue in the case of Karen Ann Quinlan (Matzo, 1997). In 1983, the Nancy Cruzan case was the catalyst for the drafting of the Patient Self-Determination Act. This case focussed on the question of what could be considered clear and convincing evidence of an individual's prior wishes (Johns, 1996; Kelley, 1995). With the passing of legislation allowing Albertans to prepare advance directives, it is an opportune time to examine this experience more fully. Additionally, advance care planning for death and dying is an area in which many healthcare providers express discomfort and a need for further education (Goetschius, 1997; Kelley, 1995). A fuller understanding of the older adult's experience of preparing an advance directive and its connection to dying well may ultimately help healthcare professionals to better care for individuals who are making end-of-life decisions. It may also provide information that will be helpful to individuals, especially older adults, who are considering or in the process of completing their own advance directive.

Organisation of Thesis

In this chapter, I describe how I arrived at the question for this study: What is the older adult's experience of preparing an advance directive? A review of the literature and an identification of the gaps in knowledge around this topic are presented in Chapter 2. Chapter 3 contains both a description of the methodology chosen to address the research question and an account of how the study unfolded from start to finish. It is beginning with Chapter 4 that I veer somewhat from the more traditional format of a thesis where one would expect to find a chapter in which results are highlighted, followed by another in which the findings are discussed. Instead, you will find five chapters that integrate the analysis and interpretation of the study data. These chapters are organised around five general themes that emerged during the process of analysis: protecting self and others, facing one's mortality, talking about death, choosing an ally, and getting it done.

Also in Chapter 4 you are introduced to Alice Dawson. Alice represents an amalgam of the individuals that I interviewed in this study and that I have encountered during my own clinical practice. Much of what Alice says comes directly from the conversations I had with individuals who had completed their own advance directives. My goal in writing Alice's story is to blend the voices of many into one coherent and articulate voice that shows the experience of preparing an advance directive as fully as language allows. By creating Alice and giving a personal voice to the older adult's experience of preparing an advance directive, I hope that you will be able to come closer, nearer, to this experience, yourself. If you are an individual, particularly an older adult, who has already completed your own advance directive, what I have written should resonate with what you have yourself already experienced. Alice's story continues through to Chapter 8.

Concurrently, in Chapters 4 to 8, I respond to Alice's narrative by questioning, interpreting, and discussing what she has said. At times these reflections take me to other data sources both in and beyond my study. This includes citing additional quotations from the transcripts of participants, making reference to the scientific literature, exploring fictional accounts that illuminate some aspect of preparing an advance directive, and examining my, as yet, failed attempts to complete my own advance directive. When you encounter *italics* in the text, you will know that it is Alice who is speaking. When the text appears normal, you will know that the thoughts and words are mine. You may want to begin by reading Alice's story in its entirety first, omitting what I have written in between. But I trust you will eventually return to read the intervening sections so that together we can strive to uncover that which may have been taken for granted in the older adult's experience of completing an advance directive.

In the final chapter, Chapter 9, the implications of the study's findings for healthcare practice, education, policy, and research are discussed. As with most studies of a qualitative nature, there are few definitive conclusions and many questions remain unanswered. As I lived through the various phases of this study from conception to completion, my own attempts to apprehend death in a meaningful way continued alongside those of the participants. The contribution of the participants to this study is invaluable. If individuals had not volunteered their time and their selves, this thesis would not exist. In my writing, I have endeavoured to remain true to the spirit of their individual stories. If through reading this thesis, you gain a greater awareness, appreciation, and understanding of the older adult's experience of preparing an advance directive, I will have achieved my primary goal. If it inspires you to act ethically when you next encounter an older adult who has or is engaged in the process of end-of-life decision-making, it will have been doubly successful. And lastly, if the writing evokes a sense of wonder about your own end of life, if it causes you to silently ponder the way you live out each day, and if it stimulates new questions for you about life and death--thoughtful questions that you have never considered before--then the ultimate aspirations for my writing will have been realised.

Chapter 2: Exploring the Literature

> First, how do you know if a problem--a research question--is really a good question, if you do not search to see if anyone already knows the answer, or has perhaps worked on some portion of the problem, and may be able to shed some light on the matter. (Morse, 1994, p. 3)

Overview

Since the notion of advance directives first emerged in the 1970s, a plethora of articles have been published and literally hundreds of studies conducted that examine various aspects related to their development and use. In this chapter, I summarise the literature that is most pertinent to a discussion of the older adult's experience of preparing an advance directive. I describe those areas where we already have considerable knowledge and identify other areas where significant gaps in our understanding still exist. To provide a context for this review and critique of the literature, I begin by providing an outline of the historical development of advance directives. This is followed by a discussion of the perceived benefits of completing an advance directive, as well as philosophical and pragmatic issues and concerns that have been raised about their use. The current state of knowledge around the older adult's knowledge, attitudes, and behaviours about advance directives is described. The role of nurses in the area of advance directives is also briefly discussed. Lastly, I indicate how this particular study addresses some of the knowledge gaps identified through reviewing the literature.

Historical Development of Advance Directives

In the 1970s, life-sustaining technologies had progressed to the point where individuals with life-threatening conditions, previously untreatable and fatal, could now be kept alive for indefinite periods of time. In 1975, national attention in the United States focussed on the right-to-die issue in the case of Karen Ann Quinlan (Arthur, 1988; Matzo, 1997). Karen Ann was a young woman who following a drug overdose was in a persistent vegetative state requiring respirator support. Strongly believing that their daughter would not have wished to continue living in this condition, her parents successfully petitioned the courts for her father to become her guardian and decision-maker. Fully expecting her death shortly thereafter, her father asked that the respirator be discontinued. Karen Ann, however, began to breathe on her own and lived for another 10 years in a persistent vegetative state. It was not considered morally justifiable at that time to withdraw food and nutrition (Beauchamp & Childress, 1994). A year after this court case, in 1976, the California Natural Death Act was enacted and it is regarded as the earliest law legislating the use of advance directives (Johns, 1996; Matzo, 1997). The American Medical Association initially opposed the legislation believing that it was contrary to the charge of the Hippocratic Oath "to do no harm" and that they, as physicians, were in the best position to determine what health care an individual should or should not receive (Matzo, 1997).

In 1983, the Nancy Cruzan case, again in the United States, was the stimulus for the drafting of the Patient Self-Determination Act (PSDA). Nancy was also in a persistent vegetative state and her parents petitioned to have her feeding tube removed. After the case moved through various levels of the court system, the Supreme Court finally ruled in 1989 that the tube could be removed (Kelley, 1995). This case focussed on the question of what could be considered clear and convincing evidence of an individual's wishes and determined that written documents outlining an individual's desires fulfilled the necessary requirements (Johns, 1996; Kelley, 1995). Further to this ruling, the PSDA was enacted as law in the United States in 1991. The legislation stipulates that all healthcare agencies must advise patients of their legal right to refuse or accept treatment, provide information to patients about advance directives as per state law, and provide education for staff, patients, and the public about advance directives (Ackerman, 1997; Berrio & Levesque, 1996; Gates, Schins, & Smith, 1996; Johns, 1996; Kelley, 1995; Leslie & Badzek, 1996; Neumark, 1994; Ross & West, 1995; Shore, Rubin, Haisfield, McGuire, Zabora, & Krumm, 1993). The impetus for legislation around end-of-life decision-making came from the public rather than healthcare providers or insurance companies (Ross & West, 1995).

In their earliest formulations, the term living will was utilised. A living will was typically a standardised document that included general statements that instructed that the individual "be allowed to die and not be kept alive by artificial means or 'heroic measures'" (International Self-Counsel Press) and was applicable only in cases of terminal illness. This term has fallen out of favour and been replaced by the more generic term advance directive. There are two major types of advance directives--treatment or instructional directives and proxy directives. A treatment or instructional directive is a written document that individuals execute while competent in which they state their wishes regarding health care should they become incompetent and unable to make decisions for themselves (Backlar & McFarland, 1996; Degrazia, 1999; de Raeve, 1993; Kelley, 1995;

Leslie & Badzek, 1996; Perrin, 1997; Yamani et al., 1995). In a proxy directive, competent individuals appoint a person or persons to make healthcare decisions for them should they become unable to do so (de Raeve, 1993; Kelley, 1995; Perrin, 1997). Depending on the jurisdiction, the appointed individual(s) may be referred to as a healthcare proxy, durable power of attorney for health care, substitute decision-maker, or agent. Although there is some legislative variation across jurisdictions, advance directives characteristically differ from living wills in that they are not limited to situations of terminal illness or treatment refusal. Through an advance directive, individuals may also indicate types of medical treatment that they do want to receive under various sets of conditions.

Court challenges focusing on the right for individuals to control what happens to their bodies, even in situations of incapacity, have had similar outcomes in Canada (e.g., Malette v. Shulman, 1990; Nancy B. v. Hôtel-Dieu de Québec, 1992). Following in the footsteps of their American counterparts, a number of provinces have passed legislation that addresses the issue of advance directives. Alberta's legislation (Province of Alberta, 1996), entitled the Personal Directives Act, which came into effect in 1997, is among the most flexible and comprehensive. One of its most unique aspects is that it covers decisions related to all personal matters not just those related to health care (e.g., accommodation; with whom the person may live and associate; participation in social, educational and employment activities; legal matters), excluding only financial matters (Dossetor, 1997). Most other legislation about advance directives is restricted to healthcare decisions. This piece of legislation also allows for the preparation of both instructional and proxy directives. Compared to pre-formulated, standardised documents that are required in some jurisdictions, the structure and content of this instructional directive is open and flexible. Individuals can include information and instructions about any personal matter that is of concern to them. The legislation does place several limitations on agents, in that they cannot provide consent for the maker to undergo psychosurgery, organ or tissue donation, participation in research that offers little or no potential benefit, or sterilization that is not medically necessary unless these provisions are clearly specified in the written portion of the directive (Province of Alberta, 1996).

The factors that have stimulated the development of advance directives include the development of new life-sustaining technologies, rising healthcare costs, an ageing population, raised consumer awareness about health matters, and increased healthcare litigation (de Raeve, 1993; Johns, 1996; Kelley, 1995; Matzo, 1997; Ross & West, 1995). This set of conditions is most evident in a Western, and particularly North American, context and thus advance directives are primarily a Western phenomenon. The vast majority of philosophical and empirical publications around the subject matter of advance directives originate in North America. The approach to the development of advance directives in North America has been predominantly legalistic and largely premised on the notion of personal autonomy. As the impact of globalisation continues to be felt world-wide and conditions change, the development and implementation of advance directives may (or may not) occur in other areas of the world. It will be important for those of us with a Western perspective to observe how approaches to end-of-life decision-making unfold in other areas of the world, particularly in those areas where the notion of personal autonomy is less predominant. What we learn may assist us in enhancing our own approaches to end-of-life decision-making.

Perceived Benefits of Completing Directives

The primary purpose of an advance directive, as reported in the literature, is to allow individuals during conditions of incompetence or incapacitation to maintain control over decisions affecting their health care thus respecting the principle of autonomy; the desired outcome is humane, dignified, and appropriate care reflecting the principle of beneficence (Colvin, Myhre, Welch, & Hammes, 1993; Hayley, Cassel, Snyder, & Rudberg, 1996; Leslie & Badzek, 1996; Mendelssohn & Singer, 1994; Perrin, 1997; Ross & West 1995; Singer 1995a). The principle of autonomy or self-determination is one that is highly valued within North American society (Beauchamp & Childress, 1994; Hayley et al., 1996). A secondary purpose is to reduce burden and guilt. Family members, healthcare providers, and indeed society as a whole, generally find it difficult to make decisions about life-sustaining treatment on behalf of others. A completed advance directive provides guidance in the decision-making process and is often thought to result in a reduced feeling of burden for family members and healthcare providers (Backlar & McFarland, 1996; Colvin et al., 1993; Downie, 1992; Kuhse, 1999; Mendelssohn & Singer, 1994; Sawchuck & Ross Kerr, 2000). The feeling of burden for the maker of the directive may also be reduced. Individuals who have completed an advance directive often report that it gives them 'peace of mind' to know that they have done what they can to ensure that their end of life will proceed as they have directed (Colvin et al., 1993; Dooley & Marsden, 1994; Leslie & Badzek, 1996; Mendelssohn & Singer, 1994; Singer 1995a). As a result of discussing issues related to death and dying through the process of completing their own advance directive, some individuals may feel better informed and prepared to face their death (Downie, 1992). Another perceived benefit is that when individuals engage in a dialogue about their advance directives with their family members, friends, and healthcare providers, they often report that these relationships are improved (Backlar & McFarland, 1996; Johns, 1996).

Opposition to Advance Directives

Philosophical Issues. Historically, the most persistent argument against the use of advance directives has been a philosophical one, centred on the notion of personhood (Degrazia, 1999; de Raeve, 1993; Downie, 1992; Kuhse, 1999; May, 1997; Mendelssohn & Singer, 1994; Tonelli, 1996). This line of reasoning plays out in two contrasting ways. One line of reasoning concludes that an individual who is now incompetent, is no longer the same person, and hence, any directive prepared while competent ought not to have moral authority in the current situation (Degrazia, 1999; de Raeve, 1993; Mendelssohn & Singer, 1994). While this may in some ways be true, I would argue that there is still some ongoing connection to the previous person and that what has been written in an advance directive may be the closest representation of their wishes that we are currently able to access. The second argument goes even further and concludes that an incompetent individual no longer meets the criteria of personhood and is thus a non-person (Kuhse, 1999). As a non-person, any connection to the person who wrote the advance directive is thus severed, and the document's contents are declared illegitimate. As a non-person, the incompetent individual is deemed to have no right to receive life-sustaining treatment (Kuhse, 1999). Although these arguments around the notion of personhood may be philosophically sound, they seem to be of limited value at the bedside when an end-of-life decision must be made for a specific individual. They seem to rely upon a conception of person and body as distinct entities (Emanuel, 1995). As a nurse who has cared for individuals both before and after an incapacitating event (such as a stroke), I do not find that this argument fits well with the realities of nursing. I find it difficult to accept that the individual I cared for yesterday is a person, and today, because of a catastrophic event that happened overnight, is no longer a person and only a body. If it were only a body lying in the bed and not a person worthy of care and attention, I would not be called or required to act. Yet, in my experience in such situations, I am called to act in an ethical manner that strives to do exactly the opposite of separating person and body. In my nursing care, I am seeking to preserve the personhood and dignity of the individual to the greatest extent possible.

Uncertainty, described as the inability to predict or imagine the future and one's response to unforeseen situations, is proposed as another reason why some individuals philosophically oppose the concept of advance directives (Colvin et al., 1991; de Raeve, 1993; Kuhse, 1999; Sam & Singer, 1993; Tonelli, 1996; Winland-Brown, 1998). In this argument, it is suggested that individuals are not capable of making future-oriented decisions about unknown circumstances and thus any written directions provided in anticipation of a certain event are essentially meaningless. A second issue of uncertainty revolves around the element of doubt that is present in any diagnosis or prognosis (Dooley & Marsden, 1994; Downie, 1992). Both the details and nature of the diagnosis and prognosis and how they are communicated to individuals may influence the decisions that individuals make. For example, individuals might make different decisions if they were told they had one year to live versus one month to live. A third related concern is the notion that individuals might change their minds when actually confronted with a particular situation (Downie, 1992; Shore et al., 1993; Singer, 1995a). These are valid concerns and need to be considered when one is preparing an advance directive. Uncertainty, however, is a part of every aspect of living, not just dying, and it does not appear to represent a sufficient reason to wholeheartedly dismiss the concept of advance directives and the prospective discussion of end-of-life care options. Given that we have, at this time, limited ways of knowing an individual's wishes once they have become incapacitated, previously stated wishes may be the closest facsimile available to us.

Pragmatic Issues. Instructional or treatment advance directives are subject to the limitations of language. A lack of clarity, insufficient specificity, and ambiguity in the wording of life-sustaining treatment preferences are frequently cited as problems associated with instructional or treatment directives (Dooley & Marsden, 1994; Downie, 1992; Institute of Medical Ethics, 1993; Johns, 1996; Kelner, Bourgeault, Hebert, & Dunn, 1993; Kuhse, 1999; Perrin, 1997; Ross &

West, 1995; Shore et al., 1993; Teno, Licks et al., 1997). Proxy directives have limitations as well. Not everyone has a suitable surrogate decision-maker within their network of family and friends (Backlar & McFarland, 1996; Sam & Singer, 1993). To be effective a proxy must be knowledgeable about the values and goals of the maker, must be acting in good faith, and must agree to act as a proxy (AGS Ethics Committee, 1996; Hayley et al., 1996; Sansone & Phillips, 1995; Thomasma, 1993; Zucker, 1991). If meaningful and comprehensive discussions between the makers of directives and their surrogates have not transpired, it is unlikely that they will be able to accurately represent the other's healthcare preferences (Doukas & McCullough, 1991). In a number of instances, there is evidence that these requirements are not always adequately fulfilled (Hayley et al., 1996; Hardingham, 1997; Kelley, 1995; Perrin, 1997; Levenson & Pettrey, 1994; Sansone & Phillips, 1995; Yamani et al., 1995).

Barriers to Completing an Advance Directive

There are a number of factors, beyond those of a philosophical nature, that have been proposed as barriers to completing advance directives. These fall into three general categories: healthcare consumer issues, healthcare provider issues, and healthcare system barriers.

Healthcare Consumer Issues. One of the most frequently reported barriers is a lack of knowledge on the part of the public about the purpose of and process involved in completing an advance directive (Ackerman, 1997; Backlar & McFarland, 1996; Berrio & Levesque, 1996; Dooley & Marsden, 1994; Gates et al., 1996; High, 1993a; High, 1993b; Johns, 1996; Pearlman, 1996; Sam &

Singer, 1993; Shore et al., 1993; Singer, 1995b; Winland-Brown, 1998; Wood & DelPapa, 1996). Some individuals believe that an advance directive is an unnecessary document because they incorrectly assume that family members automatically have the legal authority to make decisions for their incapacitated loved ones (Berrio & Levesque, 1996; Shore et al., 1993). In many jurisdictions, such as Alberta, this is not the case. Others prefer to leave decisions about life-sustaining treatments to their doctors, who, similarly, do not have the legal or moral authority to make such decisions (Berrio & Levesque, 1996; Dooley & Marsden, 1994; High, 1993b; Sam & Singer, 1993; Winland-Brown, 1998). Most individuals falsely believe that family members and healthcare providers intuitively know what end-of-life care they would want to receive (Ditto et al., 2001; Meyer, 1993; Perrin, 1997; Sansone & Phillips, 1994; Sonnenblick, Friedlander, & Steinberg, 1993). For some, an additional barrier to completing an advance directive is the fear of abandonment. These individuals are worried that signing an advance directive will result in their receiving inadequate treatment and limited care at the end of life (Berrio & Levesque, 1996; Gates et al., 1996; High, 1993b; Neumark, 1994; Pearlman, 1996; Singer, 1995b; Wood & DelPapa, 1996).

Cultural, religious, and demographic characteristics, as well as personal beliefs about death and dying, have been identified as other factors that may affect an individual's knowledge, attitudes, and behaviours around advance directives and the end-of-life decision-making process (Bedolla, 1995; Dooley & Marsden, 1994; Eleazer et al., 1996; Hepburn & Reed, 1995; Hoffmann, Zimmerman, &

Tompkins, 1997; Johns, 1996; Leslie & Badzek, 1996; Pearlman, 1996). A belief in fate or in the will of God prevents some individuals from completing an advance directive (Berrio & Levesque, 1996; Sam & Singer, 1993; Winland-Brown, 1998). Alternatively, there are people who have a difficult time assimilating the concept of mortality into their belief system, so preparing a document about life-sustaining treatment is not perceived as relevant (Dooley & Marsden, 1994; Winland-Brown, 1998). Some individuals find discussing their own death and incapacity uncomfortable (Hoffmann et al., 1997). An individual's current state of health has also been shown to influence preferences (Singer et al., 1995). An association between knowledge of life-sustaining treatments and intensive care and the desire to complete an advance directive has also been noted (Sam & Singer, 1993). With respect to gender, women have been found to prefer proxy directives, while men are more likely to complete instructional directives (Leslie & Badzek, 1996). The finding that African-Americans view life-sustaining treatment more favourably compared to Caucasians has also been validated (Hoffmann et al., 1997). These differences are often not acknowledged or addressed in discussions about advance directives. Procrastination, a characteristic that seems to be universally human, is another healthcare consumer issue that is believed to contribute to the low rate of advance directives (Berrio & Levesque, 1996; Hoffmann et al., 1997).

Healthcare Provider Issues. A reluctance on the part of healthcare providers to initiate conversations about advance directives, in part, because they have not received training on how or when to conduct such discussions has been reported in a number of studies (Berrio & Levesque, 1996; Colvin & Hammes, 1991; Forrow, Arnold, & Parker, 1993; Heffner, Fahy, & Barbieri, 1996; Johns, 1996; Kelley, 1995; Pearlman, 1996; Perrin, 1997; Shook, 1992; Singer, 1995b). Another factor limiting discussions is the paternalistic view of health care that is held by some providers (Howe, 1993; Johns, 1996; Perrin, 1997; Ross & West, 1995). There is also an indication that some healthcare providers are not well informed about advance directives and are unfamiliar with the laws in their jurisdiction (Idemoto et al., 1993; Wood & DelPapa, 1996). There is some evidence to suggest that advance directives are at times ignored by healthcare professionals, that care provided is inconsistent with that requested in a directive, and that their existence is often not acknowledged in the patients' medical records (Anderson, Walker, Pierce, & Mills, 1986; Lynn & Teno, 1993; Perrin, 1997; Prendergast, 2001; Shore et al., 1993; Teno, Licks et al., 1997). Additionally, it was noted in several studies that physicians and nurses were not active participants in the development or implementation of advance directive policies in either the hospitals or nursing homes where they were employed (Ackerman, 1997; Mezey, Mitty, Rappaport, & Ramsey, 1997). Concern has also been raised that healthcare providers may be inadequately prepared to determine if an individual has capacity and is sufficiently informed at the time the directive is written and prior to its implementation (Meyer, 1993; Mezey, Mitty, Rappaport et al., 1997; Yamani et al., 1995).

Healthcare System Barriers. A variety of organisational and structural barriers to the implementation of advance directives within the healthcare system have been identified. Discussions about advance directives require time and planning. There is limited opportunity for in-depth discussions to take place within healthcare settings and time spent in such discussions is not recognised as a priority, nor is it generally financially reimbursable (Hoffmann et al., 1997; Pearlman, 1996). In the United States, the PSDA has forced healthcare facilities to address the issue of advance directives with all individuals who are admitted for care. However, admission into a healthcare facility is usually a stressful event and probably does not represent the best time to engage in discussions about future healthcare planning (Haynor, 1998; Shook, 1992; Shore et al., 1993). Procedural problems include a lack of clear and consistent policies about: 1) the processes for making and communicating end-of-life decisions; 2) the portability of advance directives from one institution to another and from home to hospital; 3) the criteria to be used for determining decision-making capacity; 4) the educational process for patients, staff, and the community; 5) the review procedure for advance directive documents; 6) the mechanisms for handling conflicts including the role of ethics committees; and 7) the physical storage of the advance directive itself (Ackerman, 1997; Idemoto et al., 1993; Johns, 1996; Meyer, 1993; Mezey, Mitty, Rappaport et al., 1997; Shook, 1992; Winters, Glass, & Sakurai, 1993).

Utilisation and Effectiveness of Advance Directives

The number of individuals in the general public reported to have completed their own advance directive ranges from two to 25 percent (Dooley & Marsden, 1994; Emanuel & Emanuel, 1989; Heffner et al., 1996; High, 1993a;

High, 1993b; Johns, 1996; Leslie & Badzek, 1996; Ott, 1999; Perrin, 1997; Ross & West, 1995). This statistic stands in juxtaposition to the finding that between 60 and 90 percent of the population consider them to be a useful and relevant document and would be interested in completing one (Anderson et al., 1986; Johns, 1996; Mendelssohn & Singer, 1994; Molloy, Guyatt, Alemayehu, & McIlroy, 1991; Sam & Singer, 1993). Of physicians and nurses surveyed in several studies, 80 to 98 percent indicated a positive or strongly positive attitude toward advance directives (Davidson, Hackler, Caradine, & McCord, 1989; Hughes & Singer, 1992; Wood & DelPapa, 1996), but only 7 to 16 percent had completed their own directive (Anderson et al., 1986; Blondeau, Lavoie, Valois, Keyserlingk, Hébert, & Martineau, 2000; Hughes & Singer, 1992; Wood & DelPapa, 1996). The barriers discussed previously do not seem to fully account for this large discrepancy between attitudes and behaviours.

Several studies, the largest and most comprehensive of which was the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) in the United States from 1989 to 1994, have tested interventions designed to increase the rate of completion of advance directives (Teno, Lynn et al., 1997). The underlying assumption in these studies was that increasing rates of completion would result in individuals receiving end-of-life care that more often reflected their previously stated wishes. Researchers also assumed that lack of knowledge was a major contributing factor to low rates of completion. Despite a reported increase in the level of understanding of participants, most studies of this type have shown only modest increases in advance directive completion rates before and after intervention (Berrio & Levesque, 1996; High, 1993a). In the SUPPORT study, a group of nurses were specially trained to discuss end-of-life preferences with seriously ill patients. The rate of documentation of advance directives in patients' charts rose, however, the impact of this change on the actual provision of end-of-life care and overall costs of providing care was described as negligible (Fins, 1997; Lynn et al., 2000; Perrin, 1997; Teno, Lynn et al., 1997). There have been valid and unsatisfactorily answered concerns raised about the appropriateness of this intervention and the chosen outcome measures (Fins, 1997). However, because it was a large randomised control study with prestigious national funding, its findings, which were published widely, seem to have been adopted as unequivocal and have influenced many to suggest abandoning the concept of advance directives entirely. Something this study does confirm is that simply counting the rate of completion of advance directives, as others have suggested before, is an inadequate measure of their effectiveness (Singer et al., 1995). At least one study has shown that a scenario-based advance directive, if attended to, can improve the accuracy of decision-making by hospital-based physicians (Coppola, Ditto, Danks, & Smucker, 2001). If end-of-life care was being managed well, the low rate of completion of advance directives would not be particularly important or troubling. However, there are reports that many individuals continue to die in pain, that as few as 41 percent of seriously ill patients have been involved in discussions with their physician about their prognosis or cardiopulmonary resuscitation (CPR), and that patient refusals of interventions such as CPR are being routinely ignored by physicians (Freeborne, Lynn, & Desbiens, 2000; Lo, 1995).

Authors of the SUPPORT study concede that they did not measure outcomes such as the impact on family burden, the patients' state of comfort, or their peace of mind (Teno, Licks et al., 1997). Few studies that systematically examined these outcomes were found in the literature. However, in a Canadian study involving 1,292 residents in six nursing homes (three of whom participated in the systematic implementation of an advance directive program and three of whom acted as control sites), researchers measured several outcomes including number of directives completed, satisfaction with care and involvement in decision-making, and costs (Molloy et al., 2000). The rate of completion of directives was significantly higher in the intervention group, but there were no significant differences in satisfaction with health care and involvement in decision-making between the intervention and control groups. The total healthcare costs per resident were found to be significantly lower for those in the intervention group (Molloy et al., 2000). In a study by Ditto and colleagues (2001), discussions between surrogate/patient pairs around end-of-life issues "were found to produce a sense of mutual understanding and comfort with end-of-life decision making" (p. 428) even though the discussions did not significantly impact the accuracy of surrogate decisions. In this study, responses of surrogates and patients to hypothetical scenarios were compared. Perhaps the outcome of promoting comfort is of more significance and relevance to individuals and their surrogates than a guarantee of absolute accuracy.

Proxy directives are considered problematic because the abilities of surrogate decision makers to accurately represent the wishes of incompetent individuals have been empirically challenged (Ditto et al, 2001; Levenson & Pettrey, 1994; Meyer, 1993; Sansone & Phillips, 1994; Sonnenblick et al., 1993; Thomasma, 1993; Tonelli, 1996). Even when surrogate decision-makers in the context of a randomised study were involved in a discussion with patients as they prepared their advance directives, Ditto and colleagues (2001) did not find any increase in the accuracy of surrogate decisions. Although questions can be raised about the adequacy of the advance directive forms utilised in this study, the tools (e.g., hypothetical scenarios) used to measure concordance rates, and the sufficiency of a brief, single-session discussion, it raises concerns about whether or not those who have been named as proxy decision-makers are knowledgeable about the wishes of the individual. As suggested previously, it may be that accuracy is less important to the makers of directives than achieving some level of comfort and trust between individuals and their surrogate decision-makers. In a study by Coppola and colleagues (2001), the predictions of family proxies were more accurate than those of physicians. Sonnenblick and colleagues (1993) found an interesting proxy bias in that life-sustaining treatment was requested more often for elderly parents by children who lived close-by and visited more frequently compared to those who were in less contact with their parents.

Content of Advance Directives

Very few studies that systematically examined the actual content of advance directives prepared by individuals were found. In the SUPPORT study, advance directives from the medical records of 4,804 seriously ill patients were examined (Teno, Licks et al., 1997). A total of 688 documents were found, of these 598 named a proxy or stated a preference noted in a standard living will. According to the analysis of the authors, 90 documents included additional instructions: 36 included instructions to forgo life-sustaining treatment; 11 provided decision-making advice to surrogates; 24 included instructions for organ donation, cremation/burial, or autopsy; 6 included information about where they would like to live; 11 included vague and confusing instructions; 3 included technically inaccurate statements; and 2 included instructions to extend life requesting that all available medical technology to sustain life be utilised (Teno, Licks et al., 1997).

The Role of Nurses

There is general agreement that nurses, because of their intimate and frequent contact with patients, their families, and friends, are well-suited and favourably situated to participate in discussions with patients about advance directives (Idemoto et al., 1993; Johns, 1996; Meyer, 1993; Mezey, Mitty, & Ramsey, 1997; Neumark, 1994). One of the roles for nurses that is frequently raised is as an educator. This includes education of nurses, themselves, as well as patients, families, staff, and the public about advance directives (AGS Ethics Committee, 1997; Dooley & Marsden, 1994; Goetschius, 1997; Howe, 1993; Leslie & Badzek, 1996; Matzo, 1997; Perrin, 1997; Sanderson, 1995; Shook, 1992; Storch & Dossetor, 1998). In order to assume these roles, nurses need to be informed and knowledgeable about the legislation in their own province and their agency's policy about advance directives. A second role identified for nurses is that of patient advocate. This includes facilitating discussions between patients, families, and health providers so that all parties are well informed and ensuring that the wishes of the individual are respected (Goetschius, 1997; Johns, 1996; Mezey, Mitty, & Ramsey, 1997; Perrin, 1997; Storch & Dossetor, 1998). An assessment role for nurses is also identified. This includes assessment of patients' values, preferences for health care, and responses to discussions about advance directives (Dooley & Marsden, 1994; Forrow et al., 1993; Leslie & Badzek, 1996; Meyer, 1993; Mezey, Mitty, & Ramsey, 1997). In an attitudinal survey of 306 nurses in Quebec, researchers found "that nurses have a strong intention of complying with advance directives written by patients" (Blondeau et al., 2000, p. 399). Nurses need to be aware of and sensitive to potential ethnic, cultural, and religious differences in the attitudes of individuals toward advance directives. Nurses are also identified as key players in the assessment of decisional capacity which must be specific to each patient and to each healthcare decision (AGS Ethics Committee, 1996; Kipnis & Gerhard, 1995; Mezey, Mitty, & Ramsey, 1997; Mezey, Mitty, Rappaport et al., 1997; Pearlman, 1996; Yamani et al., 1995). A role for nurses in terms of policy development and research into the area of advance directives is also considered important (Shook, 1992). Perhaps most importantly, nurses who are often at the bedside of dying patients have a role to play in assisting patients to achieve the goal of dying well, in the manner of their choosing, within the confines of professional codes of ethics and the law.

Older Adults and Advance Directives

Attitudes. In a recent study of older adults in Alberta, "a majority of participants supported the idea of completing a personal directive and could not identify a reason for not completing the document" (Sawchuck & Ross Kerr, 2000, p. 18). Most elderly individuals do not wish to have their lives artificially prolonged in the context of a serious life-threatening illness where there is little hope of recovery (AGS Ethics Committee, 1996; Ott, 1999). Particularly in the context of terminal or irreversible illness, many elderly people do not want to receive aggressive medical treatment (Freeborne et al., 2000; Gamble, McDonald, & Lichstein, 1991; Perrin, 1997). Quality of life is generally seen as a more relevant factor than quantity of life when it comes to end-of-life decision-making (AGS Ethics Committee, 1996; Ross, MacLean, Cain, Sellick, & Fisher, 2002). The wishes of older adults have been found to be moderately stable over time (Gready et al., 2000; Ott, 1999; Perrin, 1997). Some variation in life-sustaining treatment preferences was noted across illness scenarios with most stability noted for the least and most serious health conditions (Gready et al., 2000). Preferences to refuse treatment were more stable than preferences to accept treatment (Gready et al., 2000). Many elderly persons would prefer that a spouse or family member make decisions for them if they are unable to make decisions for themselves (Gamble et al., 1991; High, 1993a; High, 1993b). Most seniors report wanting their families to be involved in the decision-making process and trust them to act according to their wishes (Sawchuck & Ross Kerr, 2000).

The vast majority of seniors are willing and welcome the opportunity to discuss with their physician the types of medical care they wish to receive at the end of life (Gamble et al., 1991; Ott, 1999; Perrin, 1997; Sawchuck & Ross Kerr, 2000). Older adults have indicated that they want to be involved in making choices about their health care (Ross et al., 2002; Sawchuck & Ross Kerr, 2000). Although many have talked with family members about end-of-life decision-making, at least informally, few have ever participated in such a discussion with their physician (Gamble et al., 1991; High, 1993a; High, 1993b). There is some reluctance amongst seniors, however, to initiate these discussions with their physicians (Perrin, 1997).

Eleazer and colleagues (1996) in a retrospective chart review of 1,193 elderly persons enrolled in the Program for All-Inclusive Care of the Elderly in the U.S. found significant differences in the type of advance directive and code status preferred between White, Black, Hispanic, and Asian frail elderly persons, with Black elderly persons more likely to select aggressive interventions. They conclude that ethnicity "may be more important than other socio-demographic factors including gender, age, educational attainment, marital status, and the presence of children" (Eleazer et al., 1996, p. 943). In the approach to end-of-life decision-making, itself, there are also cultural variations. Mexican-American elders, for instance, generally place less emphasis on personal autonomy and rely more heavily on care providers to act upon the principle of beneficence (Bedolla, 1995). In contrast, most Native American groups hold strongly the notion of self-determination and, for many, death is considered a natural part of the life cycle (Hepburn & Reed, 1995).

Knowledge. Sufficient knowledge to complete an advance directive has been identified as a primary barrier to completion, but the extent to which this has impacted the low completion rates of advance directives is suspect (High, 1993a; High, 1993b). In the elderly population, it is reported that between 52 and 83 percent are familiar with the concept of advance directives, but actual completion rates are much lower (High, 1993a; High, 1993b). A study of a sample of 60 Alberta seniors indicated that "most of the older adults...had a general awareness of the purpose of personal directives, although they tended to define them solely in terms of refusal of medical treatments" (Sawchuck & Ross Kerr, 2000, p. 18). Some older adults have been shown to have knowledge deficits related to the nature and efficacy of particular life-sustaining treatments such as cardiopulmonary resuscitation (Ackerman, 1997; Godkin & Toth, 1994).

Behaviour. Despite holding attitudes that are congruent with the notion of advance directives, that is, wanting to have a say in their care, being willing to participate in discussions about end of life, wishing to limit treatment in some circumstances, and having some knowledge about advance directives, relatively few older adults have actually completed an advance directive. Depending on the older adult group that was studied, completion rates ranged from zero to 26 percent (Gamble et al., 1991; Havens, 2000; High, 1993a; High, 1993b; Sansone & Phillips, 1995), essentially the same rate as that found in the general population. In long-term care settings, the rates of completion are somewhat higher ranging from 20 to 70 percent (Mezey, Mitty, Rappaport et al., 1997; Molloy et al., 2000). Those with higher levels of education are somewhat more likely to have completed an advance directive (High, 1993a; High, 1993b).

For older adults who designated a surrogate decision-maker, it was most often an adult child, followed by a spouse (spouses would likely come first except that a large number of seniors are widowers), sibling, niece, or nephew (High, 1993a; High, 1993b; Sansone & Phillips, 1995). When asked if they have discussed their wishes about life-sustaining treatment with their preferred surrogate decision-maker(s), less than half indicated that they have done so and the specificity of those discussions was variable (Diamond, Jernigan, Moseley, Messina, & McKeown, 1989; Sansone & Phillips, 1995). In a study that examined the concordance rates between individuals and their surrogates regarding end-of-life wishes, the only factor that was statistically significant was a previous discussion about life-sustaining treatments with the surrogate (Sansone & Phillips, 1995). Factors that were not found to be significantly related to concordance rates included religion, ethnicity, age, education, setting, or having known someone who received life-sustaining treatment (Sansone & Phillips, 1995).

<u>Reasons for Completing a Directive</u>. As part of a larger intervention study to increase rates of completion of advance directives, older adults who had completed an advance directive were asked to identify their primary reason for doing so. In order of importance, the reasons for completing an advance directive were reported as not wanting to burden family (41%), not wanting to be kept alive on artificial support (33%), not wanting to suffer (11%), and not wanting to incur

the high cost of life support (5%) (High, 1993a). Another more recent study conducted in Alberta confirmed the finding that reducing the stress and guilt of family members is one of the most common reasons that elder's give for considering completing an advance directive (Sawchuck & Ross Kerr, 2000).

Barriers to Completing a Directive. Several of the barriers to completion identified in the general population also surfaced in studies with older adults such as a belief in fate, relying on children to make decisions, procrastination, and discomfort in discussing death (Sawchuck & Ross Kerr, 2000; Winland-Brown, 1998). High (1993a) found that half of the older adults in his study reported putting it off and/or deferring to others as the most common reason for not executing an advance directive. Several authors have proposed that older adults may be hesitant to sign any sort of legal document for fear that it may limit their freedom in some way (Gamble et al., 1991; High, 1993a), but to my knowledge this theory has not been tested empirically. In the only phenomenological study related to advance directives that I came across in my search of the literature, Winland-Brown (1998) interviewed 17 older persons about their reasons for not preparing an advance directive. She found that "older persons vacillate between (a) fear and acceptance of death, (b) trust and mistrust that others would or would not act according to their wishes, (c) the assumption of immortality or the inevitability of death, and (d) the denial or lack of knowledge of the necessity for legalizing their wishes" (Winland-Brown, 1998, p. 38). Although many of the individuals who were recruited to participate in this study through chance encounters at locations such as bus stops, seniors centres, and medical office buildings expressed concerns about their own death, no one refused to participate in the study, suggesting once again a willingness of older adults to engage in discussions around end of life.

Interventions to Increase Completion Rates. Interventions, primarily focussing on education as a means to increase completion rates in the older adult population, have been only modestly successful (High, 1993a). Of six intervention strategies utilised in one randomised control study, the only one that resulted in a significant increase in the completion rate was a combination of a moderate level of educational material and a face-to-face meeting to assist the individual in completing the document (High, 1993a). As reported earlier, Molloy and colleagues (2000) conclude that "systematic implementation of a program to increase use of advance directives reduces health care services utilization without affecting satisfaction or mortality" (p. 1437). In their study of six nursing homes, the rates of completion of advance directives compared to other studies were quite high with 70 percent of residents in the intervention sites and 57 percent of residents in the control sites having completed an advance directive. In this study, the implementation of a specific advance directive form, entitled Let Me Decide, was used. The directive includes both instructional and proxy components and the implementation process involves the use of specially-trained nurses to educate "hospital staff, nursing home staff, residents, and families about directives and measuring a person's capacity to complete directives" (Molloy et al., 2000, p. 1438).

Gaps in Knowledge

A number of articles that discuss philosophical, ethical, and pragmatic issues related to advance directives are published in the literature, but none were located that explored the personal experience of preparing an advance directive from a phenomenological or experiential perspective. The published articles focus primarily on issues such as philosophical opposition to the concept of advance directives, decisions that should be covered in an advance directive, knowledge and attitudes of healthcare providers and consumers toward advance directives, barriers to completion, policy considerations, and how to determine decision-making capacity. As one would expect, intervention studies to increase completion rates focussed on those who did not already have directives in place. Relatively little attention has been paid to those who have already prepared a directive. It would seem that talking with individuals who have completed an advance directive might provide some important insights. They may be able to shed some light as to how they overcame the barriers to completion reported in the literature and encountered in practice.

Many authors treat the completion of an advance directive as a straightforward procedure suggesting that if you follow the established guidelines an advance directive can be completed quickly and efficiently. Indeed in a single session, in one study, this is exactly what participants were expected to do. Depending upon which arm of the study they were enrolled in, participants were asked to fill out one of two types of directives, scenario-based or value-based, with or without any discussion with the researcher (Ditto et al., 2001). If completing an advance directive was truly this simple, it remains to be explained why there is such a discrepancy between the high number of individuals who support the concept of advance directives and the low number who actually complete one. Again, it would seem that engaging in conversations with individuals who have completed an advance directive would provide information that would help us to understand this discrepancy. Perhaps there are deeper and more personal reasons for completing an advance directive that have not yet been fully uncovered or explicated. In my own experience of attempting to prepare an advance directive, I encountered a number of roadblocks, some of which I stumbled over, others I found to be impassable at the time. During the process, I wrestled with my innermost feelings about myself as a human being. Was I living the life I ought to be living? Was I worthy of the gift of dying well?

North American society has labelled death as the ultimate evil, a scandal that cannot be eliminated by reason (Becker, 1973; Gadow, 1996). "Death is the nemesis of rationalism. Within human existence, it represents the last wildness to be tamed" (Gadow, 1996, p. 36). We have done our best to separate life from death, but the two have always been and remain "intimately related" (Krishnamurti, 1992, p. 7). "Even though death is a defining event in later life, there is a lack of knowledge about the meaning of death for seniors" (Fisher et al., 2000, p.14). The notion of dying well which was my own rationale for wanting to complete an advance directive surfaces in several articles, but rarely is it explicitly connected to preparing an advance directive. In a recent publication, A Guide to End-of-Life Care for Seniors, there is a chapter entitled "Living and

Dying Well in Later Life" which begins to make linkages between advance care planning and dying well (Fisher et al., 2000). The authors are quick to point out, however, that most of the research in this area has focussed on death in younger populations. Ross and colleagues (2002) suggest that there is a "paucity of research to guide decision-making" (p. 144) at the end of life for seniors. We know little about how individuals, particularly older adults, come to face their own mortality, how they decide on the content for their directives, how they choose a proxy, whom they consult with in the process, or what impact this experience has on them and their relationships with others. We do not know if or how preparing an advance directive reflects an individual's views on death and dying. This interpretive inquiry, in which the older adult's experience of preparing an advance directive is addressed, will begin to fill in some of these gaps in the literature.

Chapter 3: Describing the Methodology

> The phenomenological method attempts to push off method for method sake, to push off sureness and become unsure, to resist conceptual analysis with the view to explain. (Bergum, 1991, p. 61)

Interpretive Inquiry

The methodology chosen for this study is interpretive inquiry. I begin this chapter with a general description of interpretive inquiry and its philosophical assumptions and then move to a discussion of its appropriateness as an approach for addressing this study's overarching question: What is the older adult's experience of preparing an advance directive? Finally, I describe how the study unfolded--the methods used to collect data, the individuals who participated, and the process of data analysis and interpretation. Limitations of the methodology and this study are also discussed.

Historical Evolution of Interpretive Inquiry. Husserl was one of the first philosophers to focus on the subjective experience of human beings as a legitimate object of inquiry. He was interested in discovering the essences underlying human experience, the absolute truths of human experience (Cohen & Omery, 1994; Hallett, 1995). To accomplish this end, he used the processes of description, eidetic intuiting (searching for essences or basic structures), and phenomenological reduction (bracketing one's own presuppositions) (Cohen & Omery, 1994; Hallett, 1995; Kvale, 1983). Although he was interested in describing the life-world of human beings, because of his concentration on finding value-free objective truth in the form of essences, his approach is considered positivistic rather than interpretive (Hallett, 1995; Omery, Kasper, &

Page, 1995). It was his successors, such as Heidegger, Gadamer, and Ricoeur, who introduced interpretive inquiry as a philosophical approach for understanding human experience in the form of what has been labelled modern hermeneutics (Allen & Jensen, 1990). These approaches include hermeneutics as a phenomenology of existential understanding and hermeneutics as a system of interpretation (Allen & Jensen, 1990; Kvale, 1983). In contrast to Husserl, who was interested in phenomenology's epistemology or the nature of knowledge, Heidegger was attracted to its ontology or nature of beings, and he sought to understand the meaning of 'Being' as presence in the world (Cohen & Omery, 1994). Gadamer, Ricoeur, Merleau-Ponty, and others further developed Heidegger's ideas by expanding upon notions of temporality, historicity, and semiotics (the study of language) (Cohen & Omery, 1994).

Hermeneutics, itself, is an ancient Greek discipline that centres on the study of the interpretation of text (Kvale, 1983; Leonard, 1994; Potter, 1995). The etymological source for hermeneutics is the Greek verb *hermeneueuen*, meaning to interpret and the noun *hermenia*, meaning interpretation (Pascoe, 1996). These terms, in turn, originate from the Greek god, Hermes, a messenger with extraordinary communication skills who is credited with the development of language and writing (Jardine, 1992; Pascoe, 1996; Smith, 1994). The terms interpretive and hermeneutic are often used interchangeably in the literature (Cushing, 1994).

Definition of Interpretive Inquiry. Interpretive inquiry can perhaps best be described by examining its goal, which is an understanding of the meanings of lived experience (Benner, 1994; Bergum, 1991; Burch, 1989; Leonard, 1994; van Manen, 1997). It is a novel, deeper, richer, and embodied understanding of the meanings embedded in taken-for-granted, everyday practices and experiences that is sought in interpretive inquiry (Allen & Jensen, 1990; Benner, 1994; Cohen & Omery, 1994; Jardine, 1992; Leonard, 1994; Meleis, 1997; Merleau-Ponty, 1962; Pascoe, 1996; Ricoeur, 1981; van Manen, 1997). Through interpretive inquiry, one may gain an understanding of self, other, and the world (Benner, 1994). Both the philosophical approaches of phenomenology as the description of lived experience and hermeneutics as the interpretation of text contribute to this understanding of lived experience (Bergum, 1991).

Philosophical Assumptions. There are several philosophical assumptions that underlie interpretive inquiry. These include:

1. Every interpretation is value-laden (Benner, 1994; Leonard, 1994; Smith, 1994).
2. There is no absolute truth and one can never understand the other completely (Benner, 1994; Leonard, 1994; Pascoe, 1996; Smith, 1994; van Manen, 1997).
3. Persons are beings situated in the world with a culture and a history (Benner, 1994; Bergum, 1991; Leonard, 1994; Pascoe, 1996).
4. There is no mind/body or subject/object split as reality cannot be comprehended separately from an individual's experience (Omery et al., 1995; Pascoe, 1996).

Framing of the Research Question. The research question is of paramount importance in interpretive inquiry and may reflect upon the researcher's own background, interests, and moral character (Bergum, 1991). It is in part the researcher's curiosity or fascination with a certain phenomenon that leads him or her to pursue further study of the phenomenon through interpretive inquiry (van Manen, 1997). As new understandings may be revealed through interpretive inquiry, a research question should be sufficiently broad and open to allow for modification as the analysis unfolds (Benner, 1994; van Manen, 1997).

Methods of Interpretive Inquiry. As interpretive researchers are interested in the lived experience of human beings, one of the common methods of data collection is personal interviews in which both the interviewer and interviewee are active, engaged, and embodied participants (Benner, 1994; Kvale, 1983; van Manen, 1997). Of utmost importance to the successful interview in interpretive inquiry is the interviewer's openness and ability to listen and sensitively reflect upon the participant's story (Bergum, 1991; Kvale, 1983; Taylor, 1995), "to hear and understand the voice of the participants" (Benner, 1994, p. 100). The interview, although focused on a particular lived experience, unfolds more like a conversation or dialogue than a one-sided question and answer period with a predetermined agenda (Bergum, 1991; Benner, 1994; Kvale, 1983). The goal of the interview is to capture stories or narratives that are concrete and descriptive and as close to the actual lived experience as possible (Benner, 1994; Kvale, 1983; van Manen, 1997). Multiple interviews may be conducted to provide opportunities for clarification and deeper understanding (Benner, 1994). Rather than taking the account of the lived experience as unchanging truth or knowledge, one may need to carefully consider how individuals are historically situated in the world and how the language used to tell their own experience, and indeed the experience itself, is socially constructed (Scott, 1992). In addition to the text that is generated from transcripts of the taped interviews, other data that may be used in interpretive inquiry include observed behaviours, interviewer's journals, diaries, videotapes, focus group transcripts, audio-tapes, photographs, films, novels, biographies, art, documents, and newspapers (Allen & Jensen, 1990; Benner, 1994; Hallett, 1995; Kvale, 1983; Leonard, 1994; van Manen, 1997).

Analysis of Data. As may be surmised from its name, data analysis in interpretive inquiry can be described as a process of interpretation. Through the process of interpretation one seeks to uncover new, richer, and deeper meanings about a specific phenomenon (Jardine, 1992; Kvale, 1983; Potter, 1995; van Manen, 1997). Jardine (1992) describes the task of interpretation as bringing out the "living interweavings [of texts and textures of human life] in their full, ambiguous, multi-vocal character" (p. 51). As there is no one set of procedural guidelines to follow for interpretive inquiry or analysis, it is by its nature an inherently creative process (Kvale, 1983; Ray, 1994; Smith, 1994). It is also dependent upon, limited by, and assisted through language (Smith, 1994; van Manen, 1997). A variety of approaches to interpretation have been developed and one or more may be used in any particular interpretive study. Interpretation is ongoing throughout the entire research process (Benner, 1994). It is manifested by the researcher's attentiveness and engagement with the phenomenon through reading and reflecting on the text, over and over again (Allen & Jensen, 1990; Benner, 1994). "Through engaged reasoning and imaginative dwelling in the immediacy of the participant's world" (Benner, 1994, p. 99), the researcher seeks more in-depth levels of meaning by repeatedly asking the question "What do I now know or see that I did not expect or understand before I began reading the text?" (Benner, 1994, p. 101).

As the interpretive process continues, there is an ongoing dialectic that takes place between the text as a whole and its constituent parts, with the researcher continuously shifting attention from the foreground to the background, from the global to the individual, from the shared to the unique (Allen & Jensen, 1990; Benner, 1994; Cohen, Kahn, & Steeves, 2000; Kvale, 1983; Leonard, 1994; Meleis, 1997; Pascoe, 1996; Smith, 1994). This circular process of heightening understanding is known as the hermeneutic circle (Leonard, 1994; Pascoe, 1996; Smith, 1994; Taylor, 1995). A theoretical analysis is also possible, as text can be analysed within the parameters of a particular framework or conceptual model (Benner, 1994; Cohen & Omery, 1994; Kvale, 1983). Analysis should not, however, be limited to or driven by theory as this precludes new and varied understandings (Benner, 1994; Cohen & Omery, 1994). Thematic analysis is frequently carried out in an effort to discern commonalties and differences pertaining to the phenomenon and to identify themes (general categories), paradigm cases (strong instances of a particular phenomenon), and exemplars (vignettes that demonstrate aspects of the phenomenon) (Benner, 1994; Bergum, 1991; Leonard, 1994; van Manen, 1997). An examination of the four lived existential themes of temporality, spatiality, relationality, and corporeality provides another avenue for interpretation (Benner, 1994; Bergum, 1991; van Manen, 1997).

Writing is an integral and fundamental part of the interpretive process (Benner, 1994; Bergum, 1991; Cohen, et al., 2000; van Manen, 1997). The process of interpretation can never be fully complete, but may end when "one has reached a '*good Gestalt*'" (Kvale, 1993, p. 186), which implies that the written interpretation has an inner unity, coherence, or consistency (Kvale, 1983; Leonard, 1994). Sharing the written interpretation with others including study participants, colleagues, family, and friends to elicit their feedback will help the researcher determine if the interpretation is sufficiently adequate and complete (Benner, 1994; Hallett, 1996; Jardine, 1992). In practice, the end may be dictated by external time limitations or when the researcher reaches a point of exhaustion (Kvale, 1983).

Evaluation of Interpretive Studies. The application of the standard criteria of reliability and validity, as used in quantitative research, is not an appropriate way to determine rigour in interpretive inquiry (Hallett, 1995; Kvale, 1983). In evaluating an interpretive writing one should ask the questions: 1) Does the writing speak to you, inform you, move you?; and 2) Is the interpretation reasonable, credible, applicable, and recognisable? (Allen & Jensen, 1990; Hallett, 1995; Leonard, 1994; van Manen, 1997). If the response to both questions is yes, the interpretive process has been successfully accomplished. The reader should also be able to follow the researcher's line of reasoning through transparent documentation of the interpretive process as it unfolded (Hallett, 1995; Kvale, 1983; Leonard, 1994).

Interpretive Inquiry and the Development of Nursing Knowledge

Historically, knowledge and understanding have been dichotomised. In the dictionary, however, knowledge is defined as: 1) the fact or state of knowing; 2) having acquired through experience; 3) the total or range of what has been perceived or learned; and/or 4) erudition: learning (Webster, 1984). To know is defined as 1) to perceive directly with the mind or senses; 2) to believe to be true; 3) to have understanding or experience of; 4) to be subjected to; and/or 5) to recognise or be familiar with (Webster, 1984). When conducting an interpretive inquiry, the researcher may not necessarily indicate the attainment of knowledge *per se* as an objective of the study, yet the terms understanding, experience, and recognition are all aspects of knowing that resonate with the goals of interpretive inquiry. Habermas, a 20th century philosopher, describes three types of knowledge: understanding, technical, and emancipatory (Kvale, 1983). It is the knowledge of understanding that interpretive inquiry seeks and, when satisfactorily completed, attains.

For knowledge to be declared relevant to the discipline of nursing it must meet several criteria as outlined below.

1. Nursing knowledge must address the scope and subject of enquiry of the discipline. The phenomena of interest to nursing are generally considered to include the concepts of clients/patients/persons, nursing, environment, health and the interactions between and amongst these concepts (Algase & Whall,

1993; Allen & Jensen, 1996; Carper, 1975; Conway, 1985; Fawcett, 1984; Fawcett, 1996; Meleis, 1997). As the subject matter of interpretive inquiry is the contextually lived experiences of human beings, there appears to be a good fit between nursing's scope and subject of enquiry and that of interpretive inquiry (Allen & Jensen, 1990). Interpretive inquiry provides an opportunity to examine phenomena such as experiences of illness and health in an in-depth and meaningful way that is not always possible through quantitative approaches (Hallett, 1995).

2. Any approach to the development of nursing knowledge must be consistent with the values and the beliefs espoused by the discipline. Although not universally accepted by all nursing scholars, these values generally include holism, humanism, and contextualism (Algase & Whall, 1993; Annells, 1996; Coward, 1990; Fawcett, 1984; Gortner, 1993; Holmes, 1990). Interpretive inquiry is holistic in that it does not recognise a mind/body, subject/object split and seeks to holistically understand phenomena (Bergum, 1994; Leonard, 1994; Pascoe, 1996; Smith, 1991). By focusing on human beings and their lived experiences, interpretive inquiry is inherently humanistic (Pascoe, 1996; Smith, 1991). Interpretive inquiry is also contextualised as it obtains the personal and unique stories and narratives of individuals who are situated in the world with a culture and a history (Bergum, 1991; Bergum, 1994; Leonard, 1994; Pascoe, 1996). As Pascoe (1996) summarises, a hermeneutic or interpretive philosophy is a framework that allows "nurses to explore and

understand fundamental but often elusive phenomena in such a way that they are not stripped of their human relevance" (p. 1313).

3. The discipline of nursing is comprised of several types of knowledge including scientific, esthetic, personal, and ethical (Carper, 1975). The types of knowledge that interpretive inquiry may produce include esthetic, personal, and ethical knowledge (Allen, Ross Kerr, & Jensen, 1991; Benner, 1994; Bergum, 1991; Pascoe, 1996). Esthetic knowledge refers to the art of nursing and includes "know how" knowledge that is essential to solving problems in everyday nursing practice (Allen et al., 1991; Benner, 1994; Schultz & Meleis, 1988). Personal knowledge is related to knowing the self and the self in relation to the other (Allen et al., 1991; Carper, 1975; Pascoe, 1996; Schultz & Meleis, 1988). Ethical knowledge has to do with the notion of knowing what is the right thing to do in a given situation (Carper, 1975). Upon reading an interpretive writing and gaining an understanding of the meaningfulness of a lived experience, nurses may gain esthetic, personal, and ethical knowledge which can compel them to act in a morally and culturally-sensitive manner in their everyday practices. "Nursing knowledge gained through this process [of interpretive inquiry] is dynamic and evolutionary in nature, thus enabling nurses to explore nursing phenomena in a fresher and deeper way" (Pascoe, 1996, p. 1312).

In addition to making a contribution to nursing knowledge, interpretive inquiry has several other advantageous features. As researchers are not limited to one interpretive approach, they are free to be creative in their study design and analysis and to study a phenomenon in an innovative and meaningful way (Hallett, 1995; Kvale, 1983; Smith, 1994). If know-how knowledge is utilised in practice it will assist nurses in their care of patients (Meleis, 1997). Personal knowledge of the self and the other that is learned through the interpretive process may also evoke action in the form of additional research, political action, and improved relationships (Benner, 1994; Bergum, 1991; van Manen, 1997). This knowledge may serve as building blocks for subsequent empirical and interpretive inquiry studies, leading to further knowledge and theory development in the discipline (Benner, 1994; Leonard, 1994; Omery et al., 1995, Smith, 1991). Finally, the experience of being a participant in an interpretive project, itself, and having the opportunity to give voice to one's own story may be a positive and life-changing experience (Bergum, 1991; Kvale, 1983).

Limitations of Interpretive Inquiry for Nursing Knowledge. Interpretive inquiry produces necessary, but not sufficient knowledge, for the discipline of nursing. Interpretive inquiry does not produce scientific knowledge (i.e., empirical, objective, prescriptive, or causal knowledge) (van Manen, 1997) and is insufficient to answer all of nursing's questions or solve all of its problems. Because most interpretive inquiry depends on the active engagement of willing and articulate individuals to engage in a dialogue with the researcher, there are certain individuals and sub-groups of the population whose lived experiences are less accessible, such as those who are incapacitated, those whose communication skills are limited, and young children. Lastly, the lack of procedural guidelines and the inherent requirement of creativity in the interpretive process, which I described previously as an advantage of interpretive inquiry, may also be a limitation. For those researchers who have an objectified view of reality and are more comfortable with specific rules and procedures, interpretive inquiry may not be a good fit.

Appropriateness of Interpretive Inquiry for This Research Question

I am interested in exploring the older adult's experience of preparing an advance directive. In my work as a nurse with both older adults and persons with life-threatening or terminal illnesses, I was often in awe, and sometimes struck, by the decisions that were made around life-sustaining treatments. This interest has been sustained over many years and continues to capture my attention. The preparation of an advance directive is an experience that can be accessed through conversations with individuals who have lived it. Thus as is required for an interpretive inquiry to be conducted, I have a lived experience to investigate; I have a commitment to the phenomenon; and I have an open and inquiring mind.

Relevance to Nursing. It is a common experience for nurses to work with individuals who have or are in the process of making end-of-life decisions, and thus, the phenomenon of interest in this study is well within the scope and subject of enquiry of the discipline of nursing. It is an area in which many healthcare providers express discomfort and inadequate knowledge. It is possible that through attainment of a deeper level of understanding of the meanings associated with advance directives for older adults, that practical, personal, and ethical knowledge will be generated which would facilitate nurse-patient interactions around end-of-life decision-making (Berrio & Levesque, 1996; Ross & West, 1995). As death is a certainty for us all, personal knowledge about making end-of-life decisions holds additional relevance.

Data Sources. There is a small, but slowly growing pool of older adults in the community who have completed an advance directive from which I can draw study participants. In addition to conducting and transcribing interviews with willing volunteers about their own experience of completing an advance directive, their advance directive documents, themselves, may offer a rich source of data. As an advance directive is a reflection of an individual's intentions, values, and beliefs, the meaning of the statements contained within the written directives will need to be carefully uncovered (Potter, 1995). In addition, literature and movies that explore end-of-life decision-making will be examined.

Skills Required for Interpretive Inquiry. In considering whether or not to use interpretive inquiry as the methodology for this study, it was necessary for me to assess whether or not I had the skills and resources it requires. I am patient. I am attentive to detail. I have a desire to learn. I am a good listener. And perhaps most importantly, I have a group of individuals around me who are skilled in the process of interpretive inquiry who are able and willing to guide me. All of these attributes were necessary prerequisites to my undertaking of this interpretive inquiry and were essential in helping me produce an appropriate end product.

Pathway to Understanding

Although interpretive inquiry as a research methodology and philosophy is a relatively new discovery for me, I think it carries great potential to contribute to knowledge development in the discipline of nursing. An excellent interpretive writing is like the creation of an award-winning chef. With some basic ingredients and fundamental principles of food preparation, chefs use their energies and imagination to prepare a tantalising and satisfying feast. Similarly, the interpretive researcher guided only by the direction of certain philosophical assumptions and with inner perseverance creates an evocative text--one that has the capacity to inform us and move us continually forward on the pathway to understanding.

Subjects and Setting

The older adult population is the group of interest for this study for several reasons. First, older adults have been the primary focus of my nursing practice for a number of years. Second, this sub-group has a unique perspective to offer with respect to dying well and preparing advance directives as they, on average, are more likely to be nearer to their end of life by virtue of their age (Shook, 1992). Third, each year it is this age group that accounts for the large majority of deaths and subsequently most end-of-life decisions (Haynor, 1998).

Participants were recruited by word of mouth through colleagues (n=3) and study participants (n=1), through a presentation I made at a local senior's residence (n=2), through postings on bulletin boards at community locations including the Society for Retired and Semi-Retired and local senior's centres (n=4) (see Appendix A), and through an advertisement in the local senior's paper (n=4) (see Appendix B). During the course of the study, persons attending information seminars on advance directives offered by the Office of the Public Guardian were invited by the seminar leader to participate in the study and given a copy of the recruitment poster (see Appendix A). One participant was recruited through this strategy.

In each case, the participant was asked to contact me by telephone. During the initial telephone conversation, I described the study, ensured that the individual met the inclusion criteria, and arranged a time and place to meet. Participants were selected if they: 1) were 65 years of age or older; 2) indicated they had completed an advance directive; 3) were able to speak and understand English; and 4) were willing to talk about their experience of preparing an advance directive. All those who telephoned me and met the criteria agreed to participate in the study. At the request of participants, they were all interviewed in their own homes. After 15 participants were interviewed, sufficient information for an in-depth analysis of the older adult's experience of preparing an advance directive had been gathered and recruitment strategies were discontinued. Interviews were conducted over a three to four month period.

Description of Participants. In interpretive inquiry one is seeking a description and understanding of an experience, rather than aiming for generalisation of findings to a specific population and thus a detailed accounting of the demographic characteristics of individual participants is not relevant. I am instead providing a general description of the participants to provide some context for the analysis and discussion that will follow and to show the diversity (or in some instances, lack thereof) that was represented in the group. Participants ranged in age from 67 to 84 years with an average age of 72 years. Four in the group were men; eleven were women. The sample was well educated (12 had at least some college/university education), predominantly white (14), and middle to upper class. They represented a variety of marital states as four were widowed, four were married, three were divorced, and four were single. All but those who were single had children; those who had children had an average of three. Most had at least one child who lived near-by and all had at least one child to whom they described their relationship as close. All were retired; most at some point in their lives had worked in professional, technical, or clerical positions. Most described their ethnicity/cultural background as British or European. The majority completed their advance directive after the legislation was passed in Alberta in 1997 and all had completed an estate will.

Procedure

Prior to beginning the interview, I reviewed information about the study and provided individuals with an opportunity to discuss their participation. Each was asked to sign a consent form. Participants were also asked during the consent process for permission to contact them about participation in further aspects of this study and in a possible future follow-up study. Participants were informed that responding no to these additional requests would not affect their participation in the initial interview. Participants were given a copy of the information sheet and consent form (see Appendices C & D). Participants took part in an audiotaped personal interview with me that lasted between one to three hours. Although the interviews were conversational and unstructured in nature, I was cognisant of a number of guiding questions (see Appendix E). Participants were asked for permission to make a copy of their advance directive. Ten completed directives were obtained. Reasons for not providing a directive included: two individuals who indicated that they wanted to make some additions to their directives and that the document was not yet complete; two individuals who preferred not to provide a copy for reasons related to privacy; and one individual who had used a template that he had purchased and thus he did not feel it provided any additional information that would be helpful to the researcher. In instances when a copy of the directive was not provided, the content of the directive was discussed in some detail during the audiotaped conversation.

The primary source of data was the transcripts of audiotaped personal interviews with participants. The advance directive documents prepared by the participants were also used as a source of data. Some basic demographic information was collected for the purpose of describing the participants (see Appendix F). Literature and films exploring the theme of preparing for end of life were also used as sources of data. Literature and films were obtained in a variety of ways, through word of mouth, keyword searches of public and university library databases, and serendipity. The initial conversations were sufficiently rich in texture and content for an in-depth analysis of the experience of preparing an advance directive, so I did not employ either of the strategies of repeat interviews or focus groups. There is considerable debate in the literature about the advantages and disadvantages of sharing both transcripts and analysis with participants (e.g., Angen, 2000; Morse, 1998; Sandelowski, 1993). As a result, I chose not to provide participants with sections of the analysis and interpretation.

Data Analysis

Data analysis in interpretive inquiry is a continual process of interpretation. As it was collected and transcribed, textual data was analysed by immersing myself in the data and engaging in processes of reflection, questioning, clarifying, and writing. Along the way, I jotted down ideas, images, and thoughts that came to mind about the interviews and the interpretive process in a journal. The interpretive process began with my reading and re-reading of the transcripts, as well as the advance directive documents, and by listening to the audiotaped conversations. I then wrote and re-wrote many of the participant's stories until I was satisfied that I had captured essential elements of their experience and reflected what I perceived as significant highlights of our conversation. Across these stories, I looked for commonalties, for points of divergence and confluence. Five themes that describe the older adult's experience of preparing an advance directive emerged. These included protecting self and others, facing one's mortality, talking about death, choosing an ally, and getting it done. Concurrently, I gathered, read or viewed, literature and films that explored the experience of preparing for the end of life and kept notes that documented what I heard and read that related to that experience.

As I struggled with finding a way to authentically and articulately present the older adult's experience of preparing an advance directive, I experimented with various ways of writing. At first I used quotations from the transcripts and excerpts from the stories of individual participants to weave together descriptions of the various themes, such as talking about death. This approach, however, seemed cumbersome and disjointed. Then I began to write a composite story that represented both the words and experiences of all of the participants and at the same time no particular person in this study. The name of the individual whose story is told is Alice Dawson. The story also draws on experiences I have had both as a nurse and as an individual who has experienced the deaths of family members and friends. In telling this story, I hope to accomplish what one Cree woman describes as follows. "If a person with a story can go deep, where people are angry, sad, where they're hiding thoughts and emotions, raise the past they've maybe forgotten and can't really recognize any more, push them to spirit-walk into themselves--to do that with a story is a gift" (Wiebe & Johnson, 1998, p. 12). In between sections of Alice's story, I reflect upon what Alice says and incorporate quotations from the transcripts of participants, make reference to the scientific literature, explore literary accounts that illuminate some aspect of preparing an advance directive, and examine my own failed attempts to complete my own advance directive.

As I stated in Chapter 1, my goal in writing Alice's story is to blend the voices of many into one coherent and articulate voice that shows the experience of preparing an advance directive as fully as language allows. In writing her story, some of my own biases and personal experiences have on occasion found their way into the text. I hope that these departures will add another dimension, an additional layer, to her story rather than detract from it. As this composite story developed, Alice's character developed and flourished. It is through Alice's voice that I have attempted to make the older adult's experience of preparing an advance directive come to life. Much of what Alice says comes directly from the transcripts. You will be introduced to Alice in the next chapter.

The interpretive process was not an independent or solitary one. Throughout the process, I regularly shared my writing with my supervisor, other committee members, and a small group of students who were using similar methodologies in their doctoral studies. Their contributions to shaping the story and its interpretation are meaningful and indelible. It is hard for me at this point to even recognise what thoughts and ideas are my own and which have developed through discussions with others. I do know that working collaboratively significantly enhanced the end product and confirmed for me the importance, indeed necessity, of having colleagues participate throughout the interpretive process.

Ethical Considerations

The study was reviewed by and received ethical approval from the Health Research Ethics Board in the Capital Health Region. As described earlier, an information sheet explaining the study was discussed with potential participants and an opportunity for them to ask questions provided. Participants who agreed to participate signed and were given a copy of the consent form and information sheet (see Appendices C & D). Participants were informed verbally and in writing of their right to withdraw from the study at any point in time. Confidentiality of participants will be maintained by securing records in locked filing cabinets in a locked room for a designated period of time before they are destroyed. Contact information for participants is kept separately from tapes and transcripts. Access to records (tapes, transcripts, and demographic information forms) is limited to my supervisory committee members, my transcriber, and myself. Due to the nature of interpretive inquiry, anonymity through compilation of data is not always possible (i.e., participants may recognise themselves in the writing). The risks to participation in the study were limited to the potential psychological discomfort that may arise from discussing the experience of preparing an advance directive. In the conduct of the study, although there were instances in which difficult issues were discussed (e.g., the death of a spouse) and emotions expressed (e.g., crying, anger), none of the participants indicated that they found the experience psychologically disturbing, and indeed, a number expressed gratitude at having the opportunity to share their story and described their involvement in the study as an interesting and educational experience.

Limitations

As discussed earlier, interpretive inquiry has several limitations in terms of the development of nursing knowledge. Because participants have not been randomly selected from the population of interest, the findings of this interpretive inquiry are not generalisable to all older adults (or persons of other age groups) who have completed an advance directive. It was incumbent upon individuals to telephone me to inquire about participation in the study. Thus the stories of older adults who have completed an advance directive, but were uncomfortable in seeking out participation in the study or did not meet the other study criteria, have not been told and their experience may be different. In the conduct of the study, study participants were recruited and interviewed during a relatively narrow window of time. In retrospect, a more in-depth analysis of transcripts between interviews might have resulted in further development of some of the themes as they were emerging.

The final interpretation presented is mine, and it is possible that it fails to capture some important elements of the experience of completing an advance directive. Because of my own biases, I may have placed too much or not enough importance on particular aspects of the experience. I may have read too much or too little into something that was said in one of our conversations. To minimise these problems, I involved others in the interpretive process, I examined my own biases, I kept an audit trail of the process, and I returned often to the original transcripts. One bias of which I am aware is a belief that there is some benefit to be gained from considering and preparing for one's own end of life and involving others in that preparation. Hence, in reading the transcripts, I tried to set aside that assuredness and instead problematise those instances where I thought this was what was being said. Ultimately, it will be the readers of this dissertation, such as yourself, who will judge whether or not I have accomplished the goal of producing a text that offers a fuller and more comprehensive understanding of the older adult's experience of preparing an advance directive.

Chapter 4: Protecting Self and Others

> Maman had an old relative who had been kept alive in a coma for the last six months. 'I hope you wouldn't let them keep me going like that,' she had said to us. 'It's horrible!' If Dr N took it into his head to beat a record he would be a dangerous opponent. (de Beauvoir, 1965, p. 53)

Noticing Advance Directives

Every year about this time, I spend an evening sorting through my personal documents, looking to see if there is anything I need to change or update. And tonight's the lucky night. As I'm leafing through one of several file folders that I have tucked away in a fireproof security box, an old church bulletin falls to the floor. The notice printed boldly, succinctly, in black and white on the back page jumps out at me:

Information Session on Advance Directives
"Choosing Now for the Future"
by Jack Brown (Lawyer)
Tuesday, February 26 at 7:00 p.m.
Everyone welcome to attend.

It's been a couple of years now since I first completed my own advance directive. Believe it or not, it was at this information session that I made the decision to do so. I'm not sure why I've held on to this slip of paper for so long, but it brings back a flood of memories. When I first saw this notice, I didn't know much about advance directives, but I had remembered hearing a report on the radio that there was a new law here in Alberta that had something to do with them. From what I gathered, they had to do with me having a say in the kind of care and treatment I wanted to receive. And that sounded like a good thing. At least it was enough of an enticement at the time to secure my attendance at that information session (and for me to forgo my line-dancing class that week).

Perhaps, before I go any further, I should introduce myself. My name is Alice Dawson. I am a 74 year-old woman--although most say I don't look a day over 69! My husband of more than 40 years, Stuart, died just a bit over three years ago now. (Has it really been that long? In so many ways it seems like yesterday. There are still days when a waft of his cologne will catch me by surprise, when I turn to look at him and he isn't there.) His death was long and drawn out--cancer--multiple myeloma they called it. If you must know, the whole situation was hideous, horrible, but I'm not ready to talk about that with you just yet.

Together, we had three children--two girls and a boy. Funny, how I still think of them that way, as my girls and boy, but they are grown women and men with children of their own--my grandchildren, six in total. Now my grandchildren are entering adulthood. It's hard to believe so much time has passed. And how so many things have changed. But some things have stayed the same. Take my home for instance. Can you believe that I still live in the same house that Stuart and I raised our family in, here in the city? It's starting to be a bit much for me to look after with all the cleaning and the yard work, but it's so nice to have the extra space when my family comes to visit and there's something to be said about being in familiar surroundings. It makes you feel good. I have a lot of friends who live close-by, too. Almost everything I need is within walking distance--the grocery store, restaurants, the church, the community centre. If I need to drive somewhere I can--my car has a few miles under its belt, but it's in good shape and *dependable and I'm proud to say my driving record is accident-free. I'm not ready to move just yet. For now, I'm pretty happy right where I am.*

Let me think, what else is important for you to know about me? I suppose I should tell you that I was educated as an elementary school teacher. I received my training in normal school (I'd love to talk to the individual who came up with that name and ask what he or she was thinking). I worked in a rural one-room school teaching Grades 1 to 8, until my oldest daughter, Susan, was born, and we moved into the city. Then, I became, what do they call it now, oh yes, a stay-at-home mom. A few years later David arrived, and then the youngest, my baby, Christine. It was only when Christine started high school that I re-entered the work world and spent another 20 years or so standing at the front of a classroom. I've been retired now for about 10 years, but it seems like I'm busier than ever. Mondays--volunteering with the hospital auxiliary; Tuesdays--line-dancing class; Wednesdays--lunch with several of my long-time friends; Thursdays--choir practice; and on it goes. And then there's all of my family activities--watching my grandsons and granddaughters play hockey (I told you times had changed), birthday parties, school concerts, graduations, and the like.

Unlike going to school, getting married, or having a child, preparing an advance directive is not an experience that most are likely to encounter in the context of carrying out their routine activities of daily living. Gaining awareness about advance directives requires a different kind of exposure. In this chapter, the ways in which older adults come to be aware of advance directives and factors that influence their completion are described under the theme of protecting self and others. The older adults who participated in this study learned about advance directives in a variety of ways. For many, like Alice, their knowledge about the existence of advance directives was first raised through media exposure. One of the study participants followed the Karen Ann Quinlan case for a number of years, and it was through such news coverage that she learned about living wills and later advance directives. She said, "I certainly don't want to be hooked up to a machine. [After] hearing stories on TV about people in that situation and what a difficult position it was for doctors, and for family too, when they didn't know what you wanted done. So I decided that I didn't want to be in that situation." For this participant, the media was not only a source of information about advance directives, it also triggered her desire to complete her own directive. Although the role of the media in changing attitudes and behaviours has been explored in relationship to many issues, its role in providing information about advance directives has not been fully explored. In a study of community dwelling adults, Havens (2000) reported that most participants found out about advance directives through the media. After news stories around the deaths of Richard Nixon and Jacqueline Kennedy Onassis in 1994 that described how their living wills had affected the care they received were aired, Choice in Dying, Inc. was inundated with requests from the public for information about living wills (Havens, 2000). Havens refers to this reaction as a step in the change process labelled dramatic relief. "The process operates on the premise that strong emotional reactions to events occurring in the environment can move an individual to change" (Havens, 2000, p. 322). One wonders, however, how many of the individuals who requested information actually went on to complete a directive. Would there be a greater awareness about and propensity for individuals to complete directives if such stories were aired more frequently? Should we be taking advantage of the role of emotion in stimulating action?

On occasion, it was family members who introduced the older adults to the notion of advance directives. It is likely that family members found out about advance directives through the media as well, but this was not directly explored in this study. Others found out about advance directives from their lawyers during an appointment for other business, most often completion of an estate will. Questions have been raised about the appropriateness of the involvement of lawyers and the legal profession in the process of advance directive preparation (Singer, 1995b). There are concerns that the spirit of an advance directive will become entangled in legalistic and technical language and bureaucracy (Gamble et al., 1991). Others are worried that lawyers may not be able to adequately inform their clients about the healthcare decisions they wish to include in their written directives (Singer, 1995b). What expertise do lawyers have in death and dying? Will the resulting document be meaningful, relevant, or useful in a healthcare context? Why has this document about life and death, natural occurrences, become infused with legalese? Several participants in this study had prepared their directives in consultation with a lawyer. It seemed important for them to have had a sustained and positive relationship with their lawyer (or to have been referred to them by someone they trusted who indicated that the lawyer had a good reputation) prior to including them in the process. For some it was the last step in the process. After preparing their directives, these participants wanted someone to confirm that their document was written in accordance with the law. They wanted someone to give their document an official stamp of approval. They did not want a technicality to interfere with the enactment of their directive. One participant had a history of broken promises within her family. She believed that it was important to have her decisions written down and legally approved so that history would not repeat itself. As she said, "there were a lot of problems with myself growing up. I came from a broken family and then came from a blended family, which didn't blend too well. It was like oil and water....Nothing [major decisions such as division of the estate] was done on paper....If it's not on paper, I mean, you may be brothers and sister but you don't always think alike."

For some, the exposure to information about advance directives came about serendipitously. One participant regularly attended support group meetings for family members of residents in the nursing home where his elderly 97 year-old mother resided. At each meeting, there was usually an educational component. His introduction to advance directives came about this way. "I think we were kind of running thin on subject material but one day one of the nurses mentioned personal directives and asked us if we would be interested. We didn't want to say no because we didn't know anything about it and didn't want to make her feel bad so we said yes and that triggered the first meeting....and what a wonderful meeting it was." This was one of two participants who identified a health professional, a nurse, as the person who first introduced the notion of advance directives to them. The other participant was part of a walking group that included a nurse. As this participant said, "I have a walking group on Wednesdays and one of the gals is a nurse. She works at the University Hospital and she brought it up a couple of times that they were, you know, expected to ask this [ask if patients have an advance directive] all the time of people. And she was kind of gently nudging us that maybe we should be doing this. And again, as I said, because I'm a widow, you know, there isn't somebody right here who would make these decisions so it seemed a good idea." A few were not sure where or when they had first become aware. As one participant who lived in a senior's apartment building stated, "I don't really know first off where I heard about it. I know we had some meetings downstairs. You know, people have come and spoken on it."

I pause to consider my own introduction to advance directives. They have been a part of my consciousness now for so many years that I cannot recall an exact moment, yet I suspect it was during my undergraduate nursing education in the early 1980s. I can imagine it happening in the context of a clinical discussion about continuing life-sustaining treatment for a seriously ill individual whose prognosis is grim. I can visualise a group of nursing students around a conference table nodding their heads in agreement--the treatment should be stopped, the individual should be allowed to die. At that time, however, neither living wills nor advance directives were legally binding documents in the province where I was studying. A more personal introduction came later after I had been in nursing practice for several years.

After being prompted by the media, a lawyer, a family member, or another person, the older adults often sought out further information by attending presentations or workshops in locations like Senior's Centres or church basements. Participants frequently identified the church as a location for information sessions. Churches have been identified as a gathering place for healthcare consumers (Sanderson, 1995). The role of the church may be more significant than the paucity of literature in this area would suggest. Indeed the involvement of religious organisations or leaders in the process of preparing directives is rarely mentioned. One wonders if those who attend such seminars interpret the church's provision of a venue for information sessions and discussions as an endorsement of advance directives. Are those who participate in information sessions held in religious facilities more likely to complete a directive than those who receive information in a different, less orthodox, venue? If individuals do not have a religious affiliation is their access to information about advance directives more limited? These are questions for further consideration. Religious leaders are on some occasions suggested as a person to talk to about completing an advance directive, particularly in the absence of family members (Heydemann, 1997). The extent of knowledge that religious leaders have about advance directives has not been reported in the literature, but one might speculate that their educational background would prepare them well to engage in discussions around the concept of mortality and facing one's own death.

What was surprising to me in the participants' stories was the relative invisibility of healthcare providers in the process of raising awareness about advance directives. A few individuals reported talking informally to family members or friends who were in health professions, nurses in particular. One participant was considering seeking specific information from her family doctor. Before making a decision about whether or not she wanted to be resuscitated, she wanted a medical opinion regarding her chances of surviving cardiopulmonary resuscitation, given her current health status. Another had asked her physician about her cancer prognosis. After formulating their directives, several participants provided their physicians with a copy and briefly discussed its contents with them. Why is it that healthcare professionals--a group whom one would assume might be of assistance and could provide relevant information to individuals who are making decisions about their future health care--are not initiating discussions about advance directives? A partial answer to that question is foreshadowed in the quote that opens this chapter, "Dr. N...would be a dangerous opponent," and will become clearer as Alice continues her story.

Focusing on the Future

Rewind now to Tuesday, 6:45 p.m. The church basement is starting to fill; there must be at least 30 to 40 members of the congregation here. People of all ages are in attendance, but most I would say are sporting white or grey hair. My daughter Susan has accompanied me, for moral support, I suppose. Not that I am really concerned that I'll need it, but you never know. I've been known in the past to get a bit emotional, so it's nice to have someone familiar around. Let's face it, I am getting older (you don't know how hard that is for me to admit; to see it permanently inked on this paper is even more inconceivable). Tonight the discussion is going to focus on the future, and for me, death is a real part of that future. I don't really like to think about my own death. Actually, let me take that *back. It's not really my death that worries me. It's dying. I think death is just the beginning of another great adventure, a time where I will be reunited with my beloved Stuart, my parents, his parents, and others who have passed before, maybe even the puppy I had when I was just a kid, Speckles! Who knows? But dying, if I had a choice, I'd rather skip that part of the process. You see, as I told you earlier, I watched my husband die, little by little, and I wish that experience on no one. I don't know if it was harder on him or me and the rest of the family. We all felt so helpless.*

An advance directive is a future-oriented concept. It requires individuals to extrapolate their current thoughts and beliefs into some imagined future time and place. I wonder if an individual whose approach to life is to fully attend to the present--the here and the now--would be able to prepare an advance directive. Or would they say as so many people do that they will complete a directive when they are sicker or older (High, 1993b; Perrin, 1997; Winland-Brown, 1998)? When I met with two of the study participants, they were struggling with making the final edits to their advance directives. As one participant said, "I'm not sure what the procrastination is all about--I think my good health. If I were still sick, it would be finished." Many months later, I am still waiting to receive a copy of their finished products.

Alice describes death as a great adventure. I wonder how one's conceptualisation of death affects one's ability to complete a directive. If one does not conceptualise death as a great adventure is it more difficult to complete an advance directive? Is it important, necessary, to have supportive family members or friends with whom a vision of the future can be shared? These are questions that will resurface again later as Alice's story is revealed in greater detail.

Listening Attentively

There is the buzz of conversation emanating throughout the room--the ever-present gossip about one or another of the members of the congregation and the usual chit-chat about the cold turn the weather has taken and the many inches of snow that have fallen in the past 24 hours. One of this evening's organisers raps loudly on the table to get our attention. The presenter, Jack Brown, is introduced. He proceeds to tell us what he knows about advance directives and of his experience in assisting individuals in their preparation. I listen closely, attentively. He tells us:

> *An advance directive, or personal directive, as it is referred to in Alberta's legislation allows individuals to do one or both of the following:*
>
> 1) *you can provide written instructions about the type of care you want to receive should you become incapacitated and unable to make decisions for yourself; for instance, you might indicate whether or not you would want to be maintained on a respirator if you were terminally ill and/or*
> 2) *you can name an individual(s) to be responsible for making decisions on your behalf should you become incapable of doing so. This person is referred to as an agent.*

So far, so good. Out of the corner of my eye, I notice a man in the row ahead shifting uncomfortably in his seat. I turn my head to get a better look at his face.

It's Jim, a long time member of the congregation. A single tear is rolling down his cheek. His wife, Rose, died not long ago--I suppose it's been maybe a month or two. She'd suffered from Alzheimer's disease for years and at the end wasn't able to do anything for herself. Jim was so faithful to her, so good to her--he cared for her at home until almost the end. He fed her, bathed her, even changed her Depends--things I don't imagine he even did for his own children. I wonder what he's thinking right now, what he thinks about this whole advance directive idea. I wonder if Rose had an advance directive. I wonder if they had ever talked about the possibility of one of them becoming really sick. I wonder if he had ever imagined he would be the one doing the caregiving, that he would outlive Rose. So many unanswered questions. I need to talk about these things with my family. A poke in the ribs from my daughter brings me back to the room. I guess she'd noticed my attention drifting. I am back now, listening to the words of the speaker. Mr. Brown goes on to say that an individual can include instructions not only about healthcare issues, but also about accommodation, who the person may live and associate with, participation in social, educational, and employment activities, and legal matters. Everything except money--you need another type of document, a power of attorney, to deal with financial matters.

No matter how interested we are in the information being shared by a speaker, it is the human or relational side of a story that seems most likely to capture our attention. Alice is listening carefully to the lawyer, trying to take in what he has to say about advance directives, yet a subtle movement and single tear has taken her to an entirely different place--one where relationships are of utmost importance. From imagining the relationship between Jim and Rose, she moves to contemplating her own relationships with her family and expresses her motivation to act--to talk to them. This notion of talking about death will be expanded upon in Chapter 6.

In describing one aspect of the Alberta legislation, the lawyer talks about the notion of an agent. I wonder why the word agent was chosen to signify the individual who would represent the wishes of the incapacitated individual. For me the word agent conjures up images of James Bond, Agent 007 and Agent 99, the sexy sidekick on Get Smart. Both always had some gadget or gizmo that they managed to pull out just in time to save the day. Is this the kind of agent I would want making decisions about what happens to me? I shudder at the thought. How does the way we label things influence the way we think and act? What if this substitute decision-maker had been named a partner, a collaborator, or an ally instead of an agent in the legislation. Would that make any difference? The word, agent, has a legalistic or business connotation. Indeed an agent is defined as a person who provides a specific service or a person who acts for another in business, politics, and so forth. (Barber, 2001). For me, the term agent also holds a notion of concealment as in undercover agent or secret agent. What is absent from the definition is any ethical or relational component. There is the sense that the persons named have the right to speak and act on the individual's behalf. The notion, however, that the agent is connected to the individual in a more meaningful way is not evident. The moral obligation of the agent to carry out the individual's wishes seems less explicit. Alternatively, words like ally or partner emphasise an association or connection, a relationship, between two or more individuals working together toward some common end. An ally is defined as a person or organisation that co-operates with or helps another; similarly, a partner is defined as a person who shares or takes part with another or others in some activity (Barber, 2001). In Chapter 7, the experience of choosing an agent, the individual responsible for making decisions for the older adult should he/she become incapacitated, will be explored more fully.

Desiring Comfort and Peace

After outlining for us what an advance directive is, the lawyer went on to tell us some of the reasons for completing a directive that we might want to consider. First he said, it is a way of guaranteeing, at least to a certain extent, that life after we become incapacitated, including our dying, unfolds in the way we want it to. My desire is that it will be as comfortable and peaceful as possible --if that means giving me pain medication to knock me out, do it; if it means that I'll die a bit sooner, that's okay; I do not want to linger. I want to leave this world with my strong sense of pride and dignity intact. And by the way, I want to know what's going on--if I've got cancer and only a few months to live, you better tell me. I want to know. I need to know. Second, he suggested that preparing a directive might reduce the burden on family members and the healthcare system so that difficult decisions don't have to be made by family members or doctors and nurses in times of crisis at the bedside.

To illustrate his points, the lawyer tells us about a situation he encountered in which an advance directive had not been prepared and how it *might have been helpful in resolving the conflict that ensued. Mr. S., as he called him, had a terminal illness. It was anticipated that he would die within the next few months. During his hospitalisation, he developed life-threatening pneumonia. The healthcare team suggested to the family that the pneumonia not be treated and that he be allowed to die without any interventions to treat the pneumonia. His son, who lived close by and had been with his father throughout many of his earlier cancer treatments, agreed. His daughter, who had flown in from the United States to be with her father, thought that everything to save her father must be done. (Save him from what, I silently wondered.) Unfortunately, Mr. S. was by this time so sick that he was unable to be involved in the decision-making process. No discussions about this sort of scenario had taken place, although his son recalled that Mr. S. had told him early on in the course of his illness that he didn't want any "heroics." The healthcare providers were unsure how to proceed. If Mr. S. had documented his wishes in a directive or named someone to be his decision-maker, a more expedient and timely resolution to this dilemma might have been achieved. The lawyer's arguments are persuasive and my resolve to take on the task of completing my own advance directive is cemented that evening. Susan agrees that this is a good idea, a worthwhile pursuit.*

Protecting themselves from pain was one of the underlying motivations that many older adults verbalised as a reason for completing a directive. The goal of having a pain-free or as pain-free as possible dying process seems fairly straightforward. Our bodies/minds have been designed and conditioned to avoid pain. When we accidentally touch the hot burner on the stove, our hand withdraws automatically before we can even mentally register what has happened. It seems understandable that we would want to continue this pattern of avoidance of pain as we approach death. There are those who have a redemptive view of pain, an extrapolation of the 'no pain, no gain' adage, but most participants in this study were not strong proponents of that belief. Some of the older adults in this study were even willing to trade days of life for assurances of pain relief. Quoting directly from his directive, one participant stated, "I wish to be kept comfortable and free from pain and this means that I may be given pain medication even though it may dull consciousness and directly shorten my life." Similar phrasing appeared in several participants' directives. Another said, "But I certainly don't like pain, so if I couldn't manage the pain myself I would want painkillers, without some staff member worrying about whether I was going to get addicted because that is ludicrous to worry about addiction when somebody is dying."

Participants told distressing stories about family and friends who had suffered in tremendous pain at the end of life. One participant stated, "I really feel that people should be allowed to die when they are in agony. I cannot bear the thought of that happening to me, and I can't bear the thought of any other loved one going through what my friend did just in February. I just think that that is absolutely barbaric!" Another recounted, "He was right there, right in front of the nurses' station. And when I went in there he was throwing up and he was having a bowel movement and he was in tremendous pain and he said, 'Hi, I'm sorry....I'm sorry.' And I knew he wanted me to leave. And I went out and asked for help and just then his wife came along the corridor and a nurse came, but he was in agony. And he was a man with a tremendously high pain tolerance."

Given the discouraging reports on control of pain at the end of life reported in the literature (e.g., Freeborne et al., 2000; Lo, 1995) and confirmed in the stories of participants, two questions come immediately to mind. First, why do we as health professionals do such a poor job of controlling pain at the end of life? Second, will stating in writing one's wishes for pain control have any impact on practice? An additional question of a different nature is also triggered. As pain is a part of natural childbirth, is it possible that pain is a part of the natural dying process? In childbirth, the pain results in the birth of a child, which is typically a joyful occasion. In death, might there be some similarly positive outcome to pain --one that would make enduring or witnessing the pain more tolerable, even a worthwhile endeavour? Florence Scott Maxwell (1968) reflecting on her life suggests a further linkage between death and birth. She says, "I remember that in the last months of my pregnancies the child seemed to claim almost all my body, my strength, my breath, and I held on wondering if my burden was my enemy, uncertain as to whether my life was at all mine. Is life a pregnancy? That would make death a birth" (p. 76). Another author in describing the experience of her mother's death also uses the analogy of birth. Of her mother's death she says it "was like birth--the fear, the pain, the loss of control, the immense vulnerability, Mom's awareness that she was moving into the realm of spirit, the rhythmic breathing, the deliverance. We sisters were midwives. We knew that as her breath deepened, grew rhythmic, Mom gave birth to her own beautiful soul" (Shaw-

MacKinnon, 2001, p. 228). There is something comforting to me about this analogy--I find the image quite beautiful. I wonder if sharing this description of death would be helpful to those who are suffering at the end of life.

The notion of dignity was one that surfaced again and again in the conversations with older adults in this study. When asked to describe what they meant when they used this term they talked about concepts such as being independent, being respected, being listened to, and being heard. For instance, one participant said, "my husband lost his dignity, his independence and his pride, because he was totally dependent on them and they made the decisions." Participants told disturbing stories of older people who had been treated poorly, in part, because of their age and inability to speak or defend themselves. One participant recalled seeing a man publicly chastise his frail and elderly wife who was in a wheel-chair for asking for assistance to be taken to the bathroom during a hair appointment. The participant said, "you see treatment like this of old people, it's disgraceful." They talked about a society where the elderly are devalued and their life experiences and accumulated wisdom dismissed because of ageist attitudes. What they spoke of is well recorded in the literature (e.g., Kilner, 1990; Fisher et al., 2000), but to hear its confirmation in their personal stories was disheartening. It raises many more questions outside the scope of this study. How can a transformation in society's negative ageing stereotypes be accomplished? What role have healthcare providers played in perpetuating these negative stereotypes? What role can they play in eliminating them?

Experiencing the Death and Dying of a Loved One

Remember, when I said earlier, that it was the dying process, not death that frightens me the most. I think now might be the right time to tell you where some of my fears about dying stem from. The first person I ever saw die was my mother. I was ten or eleven at the time. I never really found out what was wrong with her--it just seemed to me like her parts wore out. What I do remember is her face contorted in pain, her body curled up in a foetal position on the bed that had been moved into the front room on the main floor of our house, and the perpetual moaning that seemed to emanate from some deep dark foreign place. It was often the last sound I heard as I drifted off to sleep. When my mother died, we were all there--my dad, my grandmother, the doctor, my brothers, my sister, and finally there was a sense of peace, a sigh of relief. Her body relaxed and the look of anguish on her face miraculously vanished. Although I knew my mother was dead and that I should be sad, what I felt inside was a sort of happiness. Without understanding how or why, I intuitively felt that she was now in a better place.

The only other person I have watched die is my husband, Stuart. After being diagnosed with multiple myeloma, my stalwart husband, my Rock of Gibraltar, slowly and unbelievably crumbled before my very eyes. It began as a rather benign (did that ever turn out to be the wrong descriptor) pain in his hip. Before we knew it, he was receiving chemotherapy and his body was fighting for its life. I didn't know a person could throw up that much, that diarrhoea could last forever, that the skin's surface could break down so quickly and expansively. The chemotherapy gave him a short reprieve from the aggressive disease, but it was *not long before his cancer returned. As if he hadn't suffered enough already, the next phase of the disease caused enduring, intractable pain. Near the end, even with the gentlest of hands, it was impossible to turn him or even touch him without hurting him. No amount of pain medication seemed to work. The doctors seemed eager to keep trying new combinations of drugs to try and stop the disease. Nobody talked about his death. Not the doctors. Not the nurses. Not my husband. Not me. And then one day as I sat knitting at his bedside, he made a horrible gasping sound and suddenly stopped breathing. I was alone in the hospital room with him. I didn't know what to do. I pressed the call bell and yelled for someone to come, to help. They came. En masse. They put a tube down his throat. They pumped on his chest. They attached wires to his body. They poked him with needles. I was standing huddled in the corner, my back against the wall, feeling small, forgotten, invisible. I was unable to speak, but inside I was screaming-- "Stop, don't hurt him anymore." Tears were streaming down my cheeks; I couldn't breathe. Time passed, and finally someone said, "It's time to call it." And as quickly as it had begun, it was over. He was dead. One by one, the crowd retreated from the room. The images, as swirling and chaotic as they were, are etched in my memory. They don't appear to me as often now, but as I begin to contemplate my own end (you see, yet again I have found a way to avoid the word death) and take on the challenge of preparing my advance directive, they have resurfaced. And I am once more frightened--for me, for my children, for my grandchildren. I don't want any of them to feel guilty about letting me go. I want them to know it's okay. I think it's my responsibility not to leave them with a lot of* *unanswered questions and a lot of decisions that might be upsetting. I want to make life easier for everyone at a time when there will be enough stress as it is.*

Many of the individuals in this study have been involved in situations in which they had to make a difficult decision about whether or not life-sustaining treatment should be initiated, continued, or discontinued for a family member, most often a parent or spouse. In those situations where there had been no previous discussions about end of life, several indicated that they still today feel guilty about the decisions that they made. One participant recalled how she and her brother consented to brain surgery for their frail 94 year-old mother, even though at the time the participant had doubts about whether this was the right course of action. Many years later she still harbours feelings of guilt.

Another participant, whose husband died of cancer, had a very different experience. She and her husband had prepared directives and when he was no longer able to make decisions for himself, she and her family members found it reassuring to return to the directive for guidance whenever a treatment decision was being made. If the treatment was compatible with the goals he had outlined and the family had discussed, it was initiated. If the treatment was not compatible, it was withheld. As her husband's condition continued to deteriorate, decisions about such treatments as tube feedings, blood transfusions, medications, and oxygen all had to be made. Making these sorts of decisions was still difficult and the ultimate outcome of death was sad, but feelings of guilt seemed much less evident. Indeed, this participant indicated that the family was very comfortable with the decision-making process and the outcomes. Why then is the decision to withhold treatment for a loved one, especially a treatment that is not likely to be beneficial and is potentially harmful, so difficult for many? Given that everyone dies, why are we so often ill equipped to deal with it when it happens to someone we know and love? Simone de Beauvoir's thoughts about her mother's death reflect how much easier it is to consider a stranger's ageing and death than that of a loved one. She says "'He is certainly of an age to die'....I too made use of this cliché....I did not understand that one might sincerely weep for a relative, a grandfather aged seventy and more. If I met a woman of fifty overcome with sadness because she had just lost her mother, I thought her neurotic: we are all mortal; at eighty you are quite old enough to be one of the dead" (de Beauvoir, 1965, p. 105).

Alice describes feeling helpless as she stood trapped in the corner of the hospital room and watched her husband die. To be helpless is to be unable to function independently or act without help, unable to aid, assist, or provide a person with what is needed or sought (Barber, 2001). Earlier she recounted her experience as a young child seeing her mother's pain, but being unable to provide comfort or relief. These experiences left their mark on Alice emotionally and physically. She does not want her children to have a similar experience with their own mother's death, her death. Protecting her children and grandchildren from the experience of helplessness is equally, if not even more, important to Alice than protecting her self from pain and suffering. This notion of protecting others, of keeping them safe from harm, was very strong in the participant's stories. One participant resolutely told me, "You know, they lost their father to cancer. And they watched him die by inches...and...(sighs) it took him a very long time to die and it was really so painful for my kids that it was just like they were being pulled through a keyhole. And when I first got my first cancer I was so angry I said, 'I am not going to put my children through that again.'"

This feeling of helplessness is also reflected in popular literature. Mitch Albom (1997) recounts his first encounter with death, that of a close family member, this way. He says, "My favorite uncle, my mother's brother, the man who had taught me music, taught me to drive, teased me about girls, thrown me a football--that one adult whom I targeted as a child and said, 'That's who I want to be when I grow up'--died of pancreatic cancer at the age of forty-four. He was a short, handsome man with a thick mustache, and I was with him for the last year of his life, living in an apartment just below his. I watched his strong body wither, then bloat, saw him suffer, night after night, doubled over at the dinner table, pressing on his stomach, his eyes shut, his mouth contorted in pain. 'Ahhhhh, God,' he would moan. 'Ahhhhh, Jesus!' The rest of us--my aunt, his two young sons, me--stood there, silently, cleaning the plates, averting our eyes. It was the most helpless I have ever felt in my life" (p. 14-15).

Burden is a notion that frequently enters into discussions around end-of-life decision-making. There is a general belief reflected in these stories and the literature that preparing an advance directive will ease the burden of end-of-life decision-making for family members and healthcare providers (Beauchamp & Childress, 1994; Backlar & McFarland, 1996; Colvin et al., 1993; Downie, 1992; Kelley, 1995; Kuhse, 1999; Mendelssohn & Singer, 1994; Singer, 1995b). But what is meant by this concept of burden? Why are end-of-life decisions considered burdensome? How does preparing a directive decrease the burden? In the dictionary, burden is defined as "something difficult to bear physically or emotionally" (Webster, 1984, p. 97). It seems to follow that making decisions about life-sustaining treatment are potentially difficult for several reasons. Perhaps the most compelling factor is their finality. If one makes the decision to shut off the ventilator which is keeping a loved one alive the outcome is likely to be death. There is no opportunity to go back and make a different decision, to have a second chance to get it right. End-of-life decisions are also difficult to make because they potentially sever long-standing, loving relationships. Deciding to stop feeding your mother, the one who nourished you, could be emotionally heart wrenching. That making end-of-life decisions is burdensome seems readily apparent. But the question remains--how does preparing a directive diminish the burden? Will having discussions about 'pulling the plug' with trusted family and friends make it easier to do so when the time comes? Will knowing that this is what their much-loved friend or relative wanted reduce the emotional pain of losing them, the guilt of making a decision in which the only predictable outcome is death? I think the answer is a cautious yes. If I was the appointed decision-maker for a family or friend, I think I would find it helpful to be able to say to myself, "I am doing what they wanted. I am fulfilling their last wishes." Although the burden may not be eliminated, I can imagine how this might be a healing thought to carry forward in my own life. The stories of participants reaffirmed this belief.

Most often burden is discussed in relation to the decision-making process itself, rather than in terms of witnessing another's suffering or feeling helpless. The notions of reducing feelings of helplessness and being witness to another's suffering are not as prominent in the advance directive literature. Is there a way that we, as healthcare providers, can do more to assist family members to feel helpful, needed? Can we provide them with the knowledge, resources, and space they need to help their loved ones? Can we do better at supporting and guiding them through the dying process? Are there times when our role might be to shield them from witnessing some of the most horrific situations? Perhaps someone should have removed Alice from her husband's room; at least someone could have stood with her, alongside her, and helped her make sense of what was happening. There are no right or wrong answers, no prescriptive care maps that tell us what to do next, in these sorts of end-of-life situations. However, if a satisfactory outcome is to be achieved, one must always be attentive and attuned to the other.

Controlling Technology

A week or so later, at one of our regular Wednesday lunches, I mention to my girlfriends that I am going to complete an advance directive. The first question one of them asks me is: "Why?" I start to rattle off some of the reasons that the lawyer had shared with us: "Well, first of all," I tell them, "I want to have some say in what happens to me. I don't want my life to continue if I am in severe pain or comatose with no reasonable hope of recovery. Second, I don't want my children to be forced to tell the doctors to 'pull the plug' on their mother. That would be an awful position to put them in. Once I've got it written down, they can *feel more comfortable that they are following their mother's wishes. They'll know it is acceptable. That it is truly what I want done." I pause for a moment and then add some of my own reasoning, some things that the lawyer hadn't talked about. "You see," I say, "I have a lot of reservations about the medical profession, I've seen first hand some of the things that they do, in the name of the Hippocratic Oath, or whatever. There are times when they don't know when to stop. They seem to have a hard time recognising when enough is enough. I know it's their training, to save lives, but I've lived a good life, it's okay for them to let me go." It is my hope and desire that by completing my own directive I will be allowed to die peacefully and comfortably.*

By preparing a directive, older adults are attempting to protect themselves from the actions of healthcare professionals, from technology, and from pain and suffering. They are also seeking to protect others (family, healthcare professionals, society) from being burdened with making difficult end-of-life decisions, from shouldering expenses related to unwanted life-sustaining treatments, and from the feelings of helplessness that may accompany witnessing an older adult in pain and suffering. One of the most enduring tenets of the Hippocratic Oath is to do no harm. Although the intentions of healthcare professionals may have been good, the older adults in this study had experiences in which they interpreted the actions of health professionals as detrimental or harmful. Alice's story was not unique. Without exception, everyone I talked with had seen others, most often close family members, suffer at the end of life at the hands of healthcare professionals. Some told stories of unnecessary invasive surgeries being performed, others talked about indignities family members experienced in their interactions with health professionals, and still others told anecdotes about family members whose lives were forever changed when resuscitative measures were used against their wishes and the individuals sustained significant brain injuries from which they never recovered. One participant in describing the care his elderly mother-in-law received said, "all she wanted to do was just go to sleep and die, but they [healthcare providers] wouldn't allow it--they forced that poor woman up every day and she was absolutely beside herself....I don't want that happening to me....maybe that's a selfish thing, but that helped me decide to go ahead with the directive."

In retrospect, researchers involved in the SUPPORT study recognised that in designing their study "a crucial fact was underappreciated: Advance directives rest on mistrust based on a history of overtreatment from physician paternalism" (Prendergast, 2001, p. 36). How did this history of overtreatment arise? When did this adversarial relationship between patients and healthcare professionals begin? What has happened to the image of the doctor or nurse at the bedside, holding the patient's hand, stroking her forehead, quietly supporting the individual through the dying process? Is there a way for healthcare professionals to value death in the same way we value life, rather than to view the two as mutually exclusive?

Life-sustaining treatments like ventilators, tube feedings, cardiopulmonary resuscitation, and organ transplantation are all costly procedures. Through their own experiences with family members, through television and news reports, and through the popular media, these older adults were aware of many of the technological advances that have been made in the medical field. They believed that life could be sustained almost indefinitely if the arsenal of weapons available to the healthcare team was fully deployed. The older adults were also adamant that they did not want to receive life-sustaining treatments if they were terminally ill or had little chance of recovering to their previous state of health. As one participant said, "I don't want to waste taxpayers' dollars by keeping me alive just for somebody's, doctor's, ego or something." By limiting treatments they perceived as unnecessary at the end of life, these individuals hoped that financial savings would be recognised by both their families and society at large.

It has been hypothesised that advance directives reduce costs at the end of life through the withholding of expensive life-sustaining treatments (Sansone & Phillips, 1995). Several studies that have examined cost implications associated with the implementation of advance directives have found negligible cost savings (Fins, 1997; Perrin, 1997). Others have found considerable cost savings (Molloy et al., 2000). Cost-benefit analyses of this type are very complex and the conflicting findings of these studies are difficult to interpret (Ott, 1999). Common sense, however, would suggest that withdrawal of life-sustaining treatment would be less costly than continued application of expensive technologies. Although cost factors should not be the driving force behind end-of-life decisions, given our current economic climate it is appropriate that they be given some consideration.

It seems ironic to consider that life-saving technologies developed to benefit humanity and to support life have become the enemy in situations were death is imminent. Once applied very narrowly to certain types of patient conditions, over the past few decades their use has become much more generalised. In their book entitled Final Passages, Ahronheim and Weber (1992) suggest that "we fear the unchecked growth of technology and the loss of a personal connection between ourselves and our caregivers....We no longer believe in the idea of a social safety net that will catch us or a morally responsible community watching over and protecting our interests. We feel somewhat abandoned" (p. 14). How has it come to be that technology has not only entered the room of the dying, it has taken over and invaded the space? Why has the social safety net disappeared? In preparing their directives, Alice and others like her are attempting to control the amount, timing, and types of technology that will be allowed to enter into their private sphere as they approach death. When used at the bedside, however, one wonders if advance directives might be looked upon as just another tool, an instrument that dictates care from afar and is disassociated from the individual lying in the bed. Anecdotally, I have heard about situations where the instructions in an advance directive were more highly valued and respected than those of the individual who wrote the directive who remains competent and fully able to be involved in his or her care. Is it possible that advance directives, themselves, have become just another piece of technology--another interference in the dying process, another tool that distances care providers from their patients and prevents engagement?

Fostering Family Relationships

I went on to tell my girlfriends the story of Mr. S. whose children were in conflict about whether or not his pneumonia should be treated. My children are *all very independent and they have divergent views on a lot of topics--Christine's into a lot of new age stuff--alternative medicine and the like, while Susan and David are more conservative. It's not that difficult for me to imagine a scene as they gather around my deathbed--Susan insisting that treatment be stopped, Christine saying there are alternative therapies that might help, and David, always the mediator, trying to help the two reach some compromise. And then there are the sons- and daughter-in-laws and my grandchildren, too. You know the phrase, too many cooks spoil the broth, well, I think the same thing could happen here if I don't do something to prevent it. Too many people, all with the best of intentions, trying to direct my care--a recipe for potential disaster! By writing out what I want and who I want to be making decisions, I hope I can prevent any disagreements and hard-feelings amongst my children. I don't want my death to be divisive. I want my children to remain close when I am gone. I want them to have good relationships with each other.*

Initially, I thought preparing an advance directive was a solitary activity undertaken to protect an individual's right to self-determination, done to ensure that what they wanted to happen to them actually occurred. As my conversations with older adults continued, particularly with those who had adult children, the importance of maintaining and fostering relationships into some projected time when they would no longer be able or present to do so in other ways, surfaced as a critical reason for completing a directive. As one participant said, "This way it's all there, there is no argument and, yeah, this is the way mom wants it and they go along, right there and then. Because I want them to continue to be friends. They can argue about the colour or something else, but the big things shouldn't have to be." Another said, "I have a responsibility to my loved ones not to leave them with a lot of unanswered questions and a lot of decisions that upset some and don't upset others and I believe that it is my job to make sure that they continue to be friends." Still another said it was her intent, "to try and alleviate the children not speaking to each other because each one wants something different." Preserving family connections was as important to these older adults as protecting themselves from pain and suffering. They viewed this as a lasting legacy in which they could play a pivotal role. Advance directives were perceived to be a vehicle that supported this goal.

Preserving One's Identity

Something I hadn't realised until I attended the information session was that you can include directions about more than just health care, like where I want to live and whom I want to associate with, in an advance directive. This forced me to consider some really deep questions like: Who am I? What are my defining features? What makes me, me? What do I really value in life? Hmm. A few ideas about the things that are important to me come immediately to mind. I want to stay living in my own home as long as possible. I wouldn't say I am a really materialistic person, but I am pretty attached to some of my things--my collection of Native artwork, my favourite stuffed reading chair, my photo albums, my curio cabinet bursting at the seams with mementoes from my travels. If I need to go to a nursing home, please don't let them play country music on the radio in my room. And I hate purple--so when I am old I ask that you not dress me in *purple or a red hat. (Sound familiar?) You may have guessed by now that I love to talk, and read, and talk, and listen, and talk. It is my life's passion. If I can't talk, if I can't engage in a conversation with those around me, I might as well be dead. And of course, there's my family, they're most important of all. No matter what, I want them to be close-by.*

Making an advance directive is perceived as a way of extending one's personhood into a future time of diminished capacity. Personhood is the quality or condition of being an individual person (Barber, 2001). Alice has described some of the things that make Alice, Alice. Some of what she identifies, like the music she abhors, may seem rather trivial in the context of a life and death discussion. Yet if you were subjected to listening to a style of music that you disliked, every day, all day, for weeks or months on end, it might be an unusually cruel type of torture and certainly would impact your overall quality of life. Although it has been argued that there is a discontinuity between who one is prior to and during incapacity, common sense would suggest that vestiges of the person are likely to continue to be present across time and incompetence (their dislike of country music for instance). I wonder if healthcare professionals have paid enough attention to the concept of personhood. We take complicated medical histories, we know everything about a patient's body parts, inside and out, but how often do we get to know the person as an individual? Entering into a dialogue with patients about their advance directives may be one way of gaining insight into who they are as a person. As Hatfield and McHutchion (1993) suggest, "the most useful part of a document like that [an advance directive] is to get the discussion started...For that's its greatest value. It is a voice for the silent and protection for the incompetent, but also a prompt for the competent" (p. 33).

In describing when they would no longer want to receive life-sustaining treatment, participants focussed on the notion of quality of life. Their discussions on quality of life primarily focussed on three areas: independence, being able to communicate, and familiar people and surroundings. One participant stated, "it's important to me that I'm able to feed myself, that I can still read, talk, watch television, or do just the things that I do today, maybe not quite as well as I do them now." Another expressed a similar sentiment when he said, "I don't want my family to have to sit me in a chair and have to feed me gruel all the rest of my life. I want a quality of life." For another individual, being ambulatory, able to get around independently was important, but she thought that "the most difficult to deal with [would be] if you couldn't communicate." Reinforcing this notion of the importance of communication, another participant said even more forcefully, "if they know that I can't speak, I don't want to wake up and find out I can't speak. If I can't speak, don't plug me in the channel." For this participant, life without the ability to speak was not perceived as worth living. Do we know what our patients consider as important to their quality of life? How would we, ourselves, define quality of life?

Two of the participants had lived through the experience of caring for their husbands at home during the dying process. They both spoke of the importance of familiar people and surroundings and how it had affected not only their husbands but also themselves and other family members. As one stated, "I was able to bring him home and I know he didn't want to go in a strange room with strangers, and I know that every day that he was alive and awake he was happy to be home." The other said, "there were people who thought we were a little crazy having him home, but for us it was the right thing to do....At the time three of the kids had young children. They could bring them here whereas you couldn't in the hospital....My youngest daughter had a baby amidst all of this who lived in the laundry basket at the foot of her grandpa's bed." These women also felt they were better able to control what was happening to their loved one than they would have been in the hospital. One talked specifically about being able to provide her husband with pain medication on a regular schedule and on time, something that had not happened when he was hospitalised because staff were busy and unpredictable events were always interrupting the delivery of care. How can we ensure that space, whether the patient is at home or in hospital, is made in the dying process for family members and familiar surroundings?

It is unfortunate that healthcare providers, as the opening quote from de Beauvoir so eloquently reminds us, have come to be seen as the opponent, as persons whom one must compete against. In many ways it is this perception of healthcare providers that has stimulated a number of individuals, including those older adults who participated in this study, to complete advance directives. Ultimately, if end-of-life care is to be improved, it would seem that this competitive stance must be replaced with one that values relationships instead. Developing relationships with our fellow human beings in a respectful, open, and responsive manner is of utmost importance throughout life, from birth to death, and a goal that is most worthy of pursuit. If we are to succeed in optimising the experience of death for every individual, we must work together to protect our self and others.

Chapter 5: Facing One's Mortality

> I would not admit that I was old. But one must face up to things: in a few days I shall be seventy-eight, and that is a great age. I must arrange my life accordingly. I am going to start a fresh chapter. (de Beauvoir, 1965, p. 17)

Seeing Death

I can clearly recall the first time I became aware, really conscious of the fact that one day I would die, that my own time here on earth was limited. When my own mother died, I was too young to really comprehend its full meaning and I don't remember making any connection between her death and my own mortality. It was a number of years later that death stared me squarely in the face--that I saw my self, dead. It was as I sat in the front pew of the funeral home chapel, awaiting the beginning of my grandmother's funeral service. I was 22 years old, newly married and expecting my first child. I remember tightly squeezing my husband's hand, so firmly that at one point he turned to me and tersely whispered, "Alice, loosen the grip, I can't feel my fingers." The whole experience was surreal. More than 50 years later the layout of the room at the funeral home is easy to describe. In front of me--a little to the left--is a lectern, standing at attention, awaiting words of adoration that are surely soon to follow. There are comfortable stuffed dark green velvet chairs with walnut-stained curved wooden arms in small conversation groupings along one edge of the room. In my mind's eye there are flowers everywhere--vibrant colours with shiny ribbons boldly proclaiming the relationship of the giver to the deceased--mother, grandmother, sister, friend. There is a certain smell, too, somewhat sweet but not quite floral, gentle and calming--difficult to precisely identify.

As I sat there quietly on the hard wooden bench the baby still growing inside me kicked--a hard kick high up in my belly--and kicked again. The contrast between my baby's vigorous movements and my grandmother's motionless body was striking. The circle of life and death was in me and around me, near me and beyond me, tangible yet elusive. For a fleeting moment, I saw myself lying in the coffin. I knew at that moment that one day, I too would die. I silently wondered what lay beyond mortal death for my grandmother, for me, for my baby. Was my grandmother looking in on us here, right now? Would the time come when we were all once again united, together forever? I hoped so. I believed so. To think otherwise was beyond comprehension, too frightening. As I set out to complete my advance directive, these memories surface into consciousness. In the process, I am forced to once again come face to face with my own mortality and to make every attempt to accept it with grace and humility.

Alice's first vivid memory of facing her own mortality evoked a powerful and long-lasting effect. For the participants in this study, completing their directive seemed to involve facing and accepting their own mortality. In this chapter, the theme of facing one's mortality is explored in the context of preparing an advance directive. Many authors, both in the scientific and fictional literature, have written about the significance of facing one's mortality. In the context of our conversations, several older adults shared their first experiences of confronting their own mortality. One participant told her story this way. "Well, as a child I had a very bad accident and they were not able to do anything about it medically speaking. I'm now eighty-one and it happened when I was four. From that time on, I had the wish to have my body turned over to the medical schools so that they could find a way to heal what had been my problem. And so this is my first recollection of me thinking about what would happen when I die."

Implicitly, I was both challenged and encouraged by the participants' stories to reflect upon my own experiences with death. Growing up on a farm, the death of animals and pets was a fairly regular occurrence in my youth. Yet as there was always another puppy or kitten or pig that quickly replaced the one that died, I do not think those experiences evoked for me questions about mortality, my own or others. When I was 10, though, my grandmother died and I was forced to confront death in a different way. Soon after my 10th birthday, my grandmother became seriously ill and was hospitalised. When it became evident that she was not going to survive her illness, my parents gathered my brothers and sister and me up, dressed in our Sunday finest, and we drove the 10 or so miles to the local small town hospital to visit my grandmother. My parents didn't tell us that grandma was dying, but as the oldest of the children I somehow knew--maybe it was the expressions on my parent's faces as they exchanged fleeting glances, maybe it was the stillness in the cool autumn air. I don't know how, but I had a feeling this would be the last time I would see my grandma alive. Hospitals at this time had strict rules about visitation, one of them being that no children were allowed, ever. Leaving my mom and my brothers and sister and me in the car, my dad strode with confident steps towards the front doors of the hospital to ask the staff if perhaps the rules could be bent this one time. After we waited for what seemed like forever, we spotted him through the entrance door windows. We knew by his slumped shoulders that our request had not been granted. He told us that the nurses were going to move my grandma's bed close to the window in her room, so that she could see us and we could wave to her. My father then got in the car and drove it around to the back of the building, bringing it to a stop beneath the hospital room where my grandma was located. We got out and stood beside the car gazing up in the direction of my father's pointed finger. My grandmother's silhouette is emblazoned in my mind. I see the second floor window with its white metal frame surrounded by golden yellow bricks. I see a nurse with her stiff peaked cap behind my grandma supporting her as she leans toward the window to wave to us. And I feel the tears stream down my cheeks as I silently wave back. I feel her love and her wisdom, too. In this moment, I know that my grandma will always be with me--that neither windows nor walls nor death will separate our spirits.

Sometime later at the funeral home, I remember sitting by myself on one of the couches situated along the edge of the room and a cousin my same age coming and asking me why I was crying. Wasn't it obvious, I thought, didn't she understand, Grandma was dead and she wasn't coming back? Didn't she know that there would be no more taste testing of her oatmeal cookie batter, that I wouldn't be able to play cards with her at the kitchen table, that Grandpa would be all alone in their big farm house. It was a brutal awakening for me, a difficult time, and the emotions evoked are still very powerful. A box of tissue sits nearby as I write. I wonder if the introduction to death, that first encounter, can ever be gentle. I wonder if there is an easier way to meet death. I wonder why my cousin was not as upset as I was. And I wonder how one's first experiences with death shape one's later beliefs and attitudes about death and dying. Brookes (1997) proposes that "understanding death involves an inward as well as an outward journey" (p. 39). Of your first death experience he states that you should consider the following: "What was its tone? Its color? What connotations and denotations did it suggest for the word *death* that to this day affect the way you shape the word in your mouth, the expression on your face, the slope of your shoulders as you say it?" (Brookes, 1997, p. 39). In response to his queries, I say it out loud--death--and I feel how it rolls off my tongue, I feel my eyes squint together and my brows furrow. I try smiling as I speak the word death. It feels awkward, unnatural, not at all right.

Interacting with Death

Now that I am in my golden years, my interactions with death come more often and more closely together. Not that long ago, I attended five funerals within a four week time period--funerals of long-time friends and family members. My turn is coming soon. I can't say that I'm looking forward to it, I still have a list of things I'd like to accomplish, but I'm not afraid. You may not believe me, but I really have no fear of death. I see it as life's next great adventure. Forgive me if I am repeating myself. (I worry sometimes that I may be in the early stages of Alzheimer's because I can't remember all that I have already told you and because I'm constantly misplacing my keys.) But this is an important point that I want to make sure you understand. I firmly believe that there's something beyond, that death isn't the end but only another beginning. I think that we go to a *different level, exactly where it is I am not sure. It will be a time when I am reunited with family and friends who have gone before me. It will be a time when I am pain-free, worry-free. No longer will I have to be concerned about whether I will outlive my pension, whether it will rain or snow tomorrow, whether the car will start. All of these earthly worries will be extraneous. My father once told me, "you can have anything you want, you can do anything you want, but you can only wear one pair of shoes at a time." I think he was trying to tell me that life isn't about power, fame, fortune, or wealth; it's about living each day to its fullest without regrets. It's unfortunate that in our hustle and bustle society, we don't very often take the time to be quiet, to be introspective, to think about what's really important. I've come to appreciate the time that I've spent contemplating how I've lived my life as I prepared my directive. Having a specific project, a specific goal in mind, forced me to take that time.*

One of the realities that accompany ageing is the loss of family members and friends through death. If an individual comes from a large family as I do, I can only imagine what it must be like to watch one's siblings die, one by one. To be the last left alive ought, I suppose, to be a triumph, but I would suspect it to be a hollow one. To attend five funerals in a month, as Alice describes, would be, I imagine, emotionally draining, almost unbearable. Yet, she seems to take it all in stride. One study participant who had also attended a number of funerals reflected on his experience this way, "well, as I've mentioned we've been to a lot of funerals lately and some of the people who are gone were just tremendous people. In fact, one of them, the service was an hour long, which is awfully long for a funeral. But it almost took that length of time to spell out and give an example of all the things the man had done and accomplished in his life. So you sit there and squirm a little bit and think, man, what have I done with my life? What would people say at my funeral?"

In experiencing and interacting with death and illness while preparing her own advance directive, another participant described being compelled to think about her own mortality. In responding to my question, did going through the process of completing your directive make you think about your own mortality, she says, "ah, very much so, very much. Like my husband was healthy, we thought, the cancer was found accidentally on his lung. How quickly things can change. I also have a brother, he's ten years younger than I am and he had a stroke! And we can't, even four or five years later, understand him when he talks. So I knew that I'm the one left here. After my husband passed away, I'm even more aware of it [her mortality], because I'm the one left for my children. So I try and keep a lot of things, you know, very organised because there's a lot of trauma without it." Alongside an acknowledgement of her own mortality, she has a desire to make things easier for those left behind and believes that an advance directive will assist in this way. For many of the participants, being exposed to death within their inner circle of family and friends seems to be an important facet of coming face to face with their own mortality.

Another study participant recounted an experience that changed her entire outlook on death and dying. She attended an interactive workshop a number of years previously on death and dying where she participated in an exercise where the facilitator took attendees on a guided imagery trip. The facilitator encouraged the participants in the workshop to imagine their own deaths beginning with their doctor telling them "you have a fatal disease and you are going to die." He asked them to envision saying goodbye to three people that they knew and loved and then he took them to a tunnel. He suggested that participants take one person with them for part of the journey, but she chose to go alone. She didn't want to have to say goodbye again. He told them they would be given a word or a phrase as they entered the tunnel. The words she saw come down from the ceiling of the tunnel were "I AM." At the end of this tunnel she saw a man in a long white robe and a beard and he had his hand out in a welcoming gesture. For this woman, the experience was reassuring and alleviated many of the fears she had around dying. At the time of the workshop she described herself as an atheist. Although she did not share with me the meaning that the words, "I am," held for her, the message I took away was that it is enough to be, to exist, that nothing more is asked or required of us. Not everyone will have had an experience with imagery like this participant, yet many reach an analogous conclusion. Scott Maxwell (1968) frames her approach to end of life as a time of discovery. She says, "*A long life* makes me feel nearer truth, yet it won't go into words, so how can I convey it? I can't, and I want to. I want to tell people approaching and perhaps fearing age that it is a time of discovery. If they say--'Of what?' I can only answer, 'We must each find out for ourselves, otherwise it won't be discovery'. I want to say--'If at the end of your life you have only yourself, it is much. Look, you will find'" (Scott Maxwell, 1968, p. 142). I wonder how many of us, regardless of our age, take the time to carefully look inside, to seek our own inner truths, to consider what our own process of discovery might reveal.

It has been said "all religions unequivocally believe in some sort of life or state of being after death" (Anderson, 2001, p. 74). Alice describes this phase as a great adventure. The use of the term adventure surfaced in several of the conversations. As one participant said, somewhat apologetically, "I think that the greatest adventure of life is dying and that may sound hokey or something. But birth and death are remarkable things." Similarly, another said, "it [death] seems like it might be an exciting adventure." In speaking of her mother's death, de Beauvoir (1965) also refers to the term adventure when she writes, "we were taking part in the dress rehearsal for our own burial. The misfortune is that although everyone must come to this, each experiences the adventure in solitude. We never left Maman during those last days which she confused with convalescence and yet we were profoundly separated from her" (p. 99-100). Gadamer (1982) states that "an adventure, interrupts the customary course of events, but is positively and significantly related to the context which it interrupts --thus an adventure lets life become felt as a whole, in its breadth and in its strength--here lies the fascination of an adventure. It removes the conditions and obligations of everyday life. It ventures out into the uncertain" (p. 62). Death seems to fit this description of adventure well. It is an interruption in life's flow and takes one into the vast unknown. However, conceptualising death as an adventure is somewhat problematic for me as we usually think of an adventure as something one must live through to tell the tale, something that one must be able to share with others through communication. Although there have been near death stories recounted in the literature, to date, no one has ever returned to tell us about death in all its fullness and even when we are in its presence, as de Beauvoir reminds us, we are still distant from it. Will we ever come closer to knowing death and what lies beyond? Or is it perhaps one of life's mysteries that is best left untold?

Most participants had spent some time thinking about how they would want their own death to unfold. "Well, I wouldn't want to linger on for a long, long time, you know, I think I'd rather go kind of quickly, maybe not too quickly, cause that's a shock for people, but by the same token, I wouldn't mind just sort of dropping dead though, or going, dying, in my sleep or something like that." A desire to die in one's sleep was frequently expressed. "I actually hope that I can die in my sleep with a heart attack or something. That would be so nice," said one participant. Echoing this sentiment, another said, "I'm just hoping that I will go to bed one night and my heart will stop." By dying in one's sleep, is one hoping to somehow miss the event? When people lie down to sleep at night, do they consider the possibility that they will not wake? A prayer I recall from my childhood does just that.

> Now I lay me down to sleep,
> I pray the Lord my soul to keep,
> If I should die before I wake,
> I pray the Lord my soul to take.

Is imagining how one would prefer to die a useful exercise? Or is it an exercise in futility?

Participants in this study seem to have found a way to interact with death that for most is manageable, rather than disabling or depressing. How they have achieved this equilibrium remains hidden. Perhaps the alternative is simply too difficult to sustain. Muriel Spark (as cited by Anderson, 2001) offers the following insight: "If I had my life to live over again, I would form the habit of nightly composing myself to thoughts of death. I would practice, as it were, the remembrance of death. There is not another practice which so intensifies life. Death, when it approaches, ought not to take one by surprise. It should be part of the full expectancy of life" (p. 21). Maybe it is only by turning our attention to death and incorporating it into our daily practices that we can become more comfortable and accepting of its inevitability.

Accepting Death

If you were to ask me if I have accepted death, I would probably answer yes…and no. Maybe it's because of my background, my life experiences--I've witnessed two people die, my mother and my husband, and there have been some other fairly tragic things happen to family and friends over the years. I wouldn't say I'm callous or that I've got a thick skin, but life brings what it brings and the end of it is inevitable whether you live 40, 60, or 100 years. It's still just a snap of a finger in time in comparison to eternity. If it were up to me, I would like a few more years to see my grandchildren grow up, to see whom they become as adults, maybe even to see the next generation begin their life journeys--my great grandchildren. Just imagine the things they will do and see in their lifetimes--it boggles the mind. And to think that a part of me, well, at least some of my genes, *will live on through them--it's quite remarkable. Perhaps one of my descendants will live on the moon, or discover the cure for cancer, or travel virtually around the world without ever leaving home. Yet, if my time were up tomorrow, that would be okay, too. I'm prepared for death. I've talked with my family. To the best of my knowledge there aren't any unresolved issues. And as I've said before, I'm not afraid of death or of what comes after it.*

In my conversations with these older adults, I was struck by their overall sense of acceptance of death and their general lack of fear of death and what lies beyond. At times this was related to an individual's faith or religious convictions around the existence of an after world. For others the notion of a life after death was not as important. As one man told me, "Well, I've lived a fairly good period of time now, but I really haven't contributed very much except carbon dioxide. So it'll be no great loss to me. I won't know about it anyway." He went on further to say, "there's no fear at all at this point. No, the only thing, to me, it's like when I left home, like I say when I was 17 years old...you're a kid. You don't know a lot of what waits for you when you get where you're going...and this is the same thing. It's more of leaving this behind than going some place else. Because after 71 years, you know you're used to this and you don't know what you're getting next." Another woman said, "I think my life step-by-step as it has unfolded has been acceptable to me and pleasurable enough and when it ends it ends. There are very few really, really strong wishes or convictions that I've had that would make me want to live over and above the years that I am now. I mean, I always, I shouldn't say always, but at least from the time I was seventy I felt, 'Ah! I could die any old day now. I've done nearly all the things that I want to do' and the things that I haven't been able to do are just a matter of time, but they are not that important that I want to live in pain or live with wires and, you know, machines. I would much rather be gone and be remembered as a person that had a real spark of life and it's gone. And the older I get the more I feel that way, definitely! I certainly don't want to be hooked up in any hospital bed, not even over night! Don't even mention it to me (laughs)! That is NOT how I want my life to end (laughs) and I think considering all the nice things they say about you when you're dead, you know, I don't mind (laughs). It [death] can happen any time now while everybody still has a good opinion of me (laughs) and, you know, remembers me as being an active person with all my faculties and foibles and all the rest of it."

Similar descriptions of older adults' attitudes around death and dying exist in the literature. Florence Scott Maxwell at 83 years of age describes her beliefs and fears about death as follows. "*My only fear about death* is that it will not come soon enough. Life still interests and occupies me. Happily I am not in such discomfort that I wish for death, I love and am loved, but please God I die before I lose my independence. I do not know what I believe about life after death; if it exists then I burn with interest, if not--well, I am tired. I have endured the flame of living and that should be enough" (Scott Maxwell, 1968, p. 75). An old woman who is planning her own suicide in the book, <u>As We Are Now</u>, says "it is strange that now I have made my decision I can prepare for death in a wholly new way. I feel free, beyond attachment, beyond the human world at last. I rejoice as if I were newborn, seeing with wide-open eyes, as only the old can (for the newborn infant cannot see) the marvels of the world" (Sarton, 1973, p. 125). Conversely, some older adults remain fearful. One participant in a study examining why older adults do not complete advance directives was reported as saying "every time I start filling out the forms, I cry and stop. It makes it seem like death is coming close" (Winland-Brown, 1998, p. 38). In de Beauvoir's (1965) writing about her mother's death she recalls the words spoken by her mother's friend. "'I can't understand,' said the bewildered Mademoiselle Vauthier. 'Your mother is so religious and so pious, and yet she is so afraid of death!' Did she not know that saints have died convulsed and shrieking? Besides, Maman was not afraid of either God or the Devil: only of leaving this earth" (p. 91). Is there something about talking about and interacting with death proactively that helps to dissipate some of the fear, to make it more manageable?

As participants talked about their thoughts on death, they were remarkably calm, with some even becoming quite animated when discussing the possibilities that lie beyond. My own struggle to accept death is fuelled by much more angst. I vacillate between knowing intellectually on some level that yes I will die and harbouring thoughts in another part of my brain that I am the exception to the rule--that immortality will somehow be ascribed to me. The words of Alexander Sergeyevich Buturlin as spoken in 1915 capture much of what I feel. He is attributed as saying, "I know that I shall die soon and my mind is reconciled to it; but when I think that my body will be put into a coffin, that the lid of the coffin will be screwed down and I will be buried under earth, I am horrified. I am well aware that my horror is unreasonable, that I shall not be feeling anything by then, but I cannot overcome this feeling. Sometimes I also have the feeling--and that is also unreasonable--that I shall not die" (Enright, 1983, p. 26). Even Freud is cited as offering a similar account suggesting "that in the unconscious every one of us is convinced of his own immortality" (Enright, 1983, p. 154). How do beliefs about death and dying develop? How is it that the individuals I talked with have come to acknowledge their own mortality with such quiet assurance, with such a degree of comfort? Or is this assurance a ruse, something they have tricked themselves or been tricked into believing? Is it possible to accept something, but still be afraid? William Hazlitt (1778-1830) suggests that "the best cure for the fear of death is to reflect that life has a beginning as well as an end. There was a time when we were not: this gives us no concern--why then should it trouble us that a time will come when we shall cease to be?" (Enright, 1983, p. 31). He makes it sound so easy.

Gaines (1993), in his novel about a young black man sentenced to die for a murder he did not commit, says of this man's family and friends: "They must believe [in a God, in a life after death]. They must believe, if only to free the mind, if not the body. Only when the mind is free has the body a chance to be free" (p. 251). Like the friends and family of Gaine's character, I find it impossible to imagine that all that remains after death is nothingness. I have yet to come to any conclusion about what the alternative is, but I hold fast to the belief that there must be something. I want the opportunity to be reunited with those who have died before me; I want some assurance that those with physical disabilities on earth have an opportunity to run freely; I want to know that young children who have died have the chance to grow up; I want to believe that there is a way that the wrongs committed on earth can be righted.

Life experiences, such as those illustrated in Alice's story, seem to have shaped these older adults' opinions on death. Laughingly, one man with severe heart disease describes a conversation he had with his cardiac surgeon. "I felt that if I'm dead, I'm dead. I also have an attitude towards death that says, 'Look!' I said to my doctor before my last heart operation. He suggested that I had only a 10% chance to come through it. And so I told him, 'Well, look! If I don't make it I'm not going to know it and if I do make it you're one hell of a surgeon, so go ahead!'" This same man told of his history as an air force pilot who had been involved in a number of plane crashes, been shot down by enemy fire, and lost several of his mates during the Korean War. He goes further saying, "as I often said when I was in the service, 'I might be gone before I'm 50 (laughs). You know...I'm not even gonna make it until I'm 50.' When I made 50, well, everything I have is a bonus (laughs). But, you know, it's just life experience, there's no traumatic experience that says it's [death is] gonna happen. Just the accumulation of things.... You know, that's it." I wonder about the laughter that is interjected throughout many of the stories that the older adults shared with me. Is it genuine or a way of coping with a topic that is too difficult to tackle head on? Is it a way of deflecting feelings of a different kind? Is it a way of keeping death at a safe distance?

Although these individuals profess an acceptance of death and a lack of fear about its arrival, I am still not fully convinced. It seems that there is some remaining ambivalence, some conflicting testimony in their words. This ambivalence is captured by Scott Maxwell (1968) who is about to undergo a surgical procedure, who says "of course I might die, I had heard of the heart giving out under an operation, it was possible, but then I would meet the great mystery. It almost seemed my chance. A mean way of slipping out though, not fair to the surgeon, and I want to be conscious that I am dying. I did not want to die, but I have lived my life--or so I used to feel. Now each extra day is a gift. An extra day in which I may gain some new understanding, see a beauty, feel love, or know the richness of watching my youngest grandson express his every like and dislike with force and sweetness. But all this is the sentience by which I survive, and who knows, it may matter deeply how we end so mysterious a thing as living" (p. 90-91). It appears that I am not alone in my scepticism. Many years ago, Jean-Jacques Rousseau (1712-1778) is quoted as saying "he who pretends to look on death without fear lies. All men are afraid of dying, this is the great law of sentient beings, without which the entire human species would soon be destroyed" (Enright, 1983, p. 22). Who am I to believe? Does it matter in the end?

Although the participants generally expressed a lack of fear of death and a state of readiness for death, they did not want their lives to be shortened prematurely. As one participant, in reflecting on the content of her directive said, "if you stipulate that you never want to be put on life support, I might get dead quicker than I was supposed to." Another said, "I wouldn't want my life terminated ahead of time if I still had some quality of life." "It [stopping life-sustaining treatment] shouldn't be done precipitously. In other words, it couldn't be that I was just unconscious, so let's pull the plug type of thing" was the comment made by one of the men in the study. All seem to be saying that decisions about life-sustaining treatment need to be made thoughtfully taking into account the context of the situation.

I wonder why someone would want to continue to live here on earth, if they thought there was something better to come after death. I wonder if the words to express our beliefs and attitudes about death exist in our language. In our conversations, I wanted to challenge participants on their lack of fear about death. I wanted to ask them if they truly had no fears, if they were being totally honest with me. I wanted to know if they were hiding something. But such probing questions seemed inappropriate, disrespectful--even potentially harmful. What right did I have to question or try to shake their belief system? My role as researcher is to seek understanding. I wondered if age, simply having lived more years and being at a different stage in life, had something to do with their attitudes and beliefs. The findings in this area are mixed. When Winland-Brown (1998) talked with older adults who had not prepared advance directives, a fear of death emerged as a strong reason for not completing a directive. It may be that age and living more years influence one's acceptance of death, however, age alone does not seem to be sufficient for dispelling a fear of death. Perhaps I have not yet lived enough, have not had enough relevant life experiences, to reach a level of comfort with thinking about my own death. Maybe it is time, using de Beauvoir (1965) words, for me to 'start a fresh chapter' and to think about death anew.

Kavanagh (1972) suggests that beliefs about death and dying are both personal and important to the dying process. He says, "in short, we might easily conclude that nobody knows for certain about an afterlife. Instead, I choose to hold with Kierkegaard that every man knows for himself within his inner soul. Maybe nobody can ever know what to believe for anyone besides himself. Near death, true belief in what you sincerely hold will bring peace and any promise you need for your future" (p. 218). Although this idea of accepting death, of confronting one's own mortality, is difficult for some, its pursuit seems to be of value. As Burgess (1993) suggests, "when we confront our own mortality or assist others to find meaning in their last days of life, we may gain a new perspective on what for us is of ultimate importance" (p. 46). It seems important that I struggle on in my attempts to accept my own death.

Disappearing Death

It seems strange how we, in today's society, try to hide death, to make it disappear. At one time, dead bodies were kept in the homes of their families for days on end and everyone, even small children, came to visit and celebrate the life of the deceased. Now the dead are whisked away to a funeral home. And if you're in hospital, it's sometimes really hard to die. You see, many doctors and nurses, too, don't want to accept death as an outcome--they see death as an enemy and if it can't be conquered then they have failed. I've had friends whom for all intents and purposes were dead, but they were hooked up to machines. So they had a *heart beat, they were breathing, but they weren't alive. Nobody would let them die. And yet, on the other hand, we see lots of images of death on television, in the movies and on the news, but somehow those images don't seem real. They don't seem to have much of an impact on us, on the way we live.*

Megory Anderson (2001) compares the concept of death to the "the elephant [standing] in the living room, while everyone awkwardly discusses the weather" (p. 18). To make an elephant [death] disappear is a trick worthy of a great magician, yet in the last few generations our society seems to have accomplished this with relative ease. How did this happen? Is it a good thing? One participant in describing her own cultural background talked about how "years ago your culture was that you embraced death as a part of life. You know the Old Irish ways where the body was brought into the house and everybody waked the body in the house and then it went to the church and after that, the whole community, your culture, was there to nourish you through that period." Another participant referring to a notice I placed in a senior's centre about this study described how he found death was often a taboo topic. He said, "I do notice in the Senior Centre you can't talk about things like that. Your sheet is up there and I've asked some of the guys and they say, 'Oh, I bought it [an advance directive, living will] at Staples and filled it in or I saw a lawyer and he's done it.' And I know they haven't seen a lawyer. And I know when the man's lying and when he isn't, in most cases. And a lot of them say or some of them say, 'Look! I worked all my life, now it's up to her.' And I don't think they really mean that. I think they're scared to sit down and talk with their wife." This participant attributes the silence to fear, and if his assessment is accurate, individuals will sometimes even lie in order to avoid a conversation about death.

In describing how this avoidance of death has come to pass, Hatfield and McHutchion (1993), suggest that the shift from death in the home to death in the hospital is a defining factor. They state that "in the past two generations we have allowed death to become a hospital experience. Almost automatically this isolation gave death a new and unfortunate aura. Death was hidden. It had to happen in the company of experts. It could not be dealt with in its natural setting, among the family in the community. The family came to feel useless. It induced horror or distaste. The children particularly came to think 'If it's so bad that they won't even let us be part of it, it must be awful'" (Hatfield & McHutchion, 1993, p. 30). As I think of my own experience with my grandmother's death, this last sentence resonates clearly. As I child, I was not even allowed to enter the building, much less the room, or the bed where death was unfolding. They also refer to the family's feeling of being useless or helpless during the dying process, a notion that was discussed at some length in Chapter 4.

As health professionals we are socialised into a world where the sanctity of life holds a special place. Most of our education and research is focussed on extending life. As Hansot (1996) states, "physicians are trained to save lives, and most of us would not have it otherwise" (p. 151). However, when the doctors related information to her about her mother's condition and the likelihood of her recovery, the stories they told her about the success of others in a similar condition "turned into so many cautionary tales. Most of the stories seemed to define success as survival and ended with the patient's departure from hospital. The quality of life after that departure was, at best, moot" (Hansot, 1996, p. 151). It would seem that in some circumstances, health professionals have difficulty differentiating between the terms living and merely surviving. Is there a way to balance our education, practice, and research so that both life and death can be valued and neither declared the enemy?

The media's role in disappearing death is rather paradoxical. Kavanagh (1972), a number of years ago, described his evening television viewing experience over a two week period as follows: "I counted an average of 34 deaths at close range, countless more at a distance. Not one death raised as much as a slight tremor in me. Television feeds our fantasy of forever being a spectator. Even a bloody nose or a fainting spell by a fellow viewer would have aroused more emotion in me than a hundred deaths on the tube" (p. 13). I suspect that the death count on prime time television would be even higher today. Popular television series like Law and Order, ER, Divinci's Inquest, CSI: Crime Scene Investigation, and Third Watch all revolve around stories of illness, injury, and death. In several of these dramas, the person, the victim, almost disappears as the focus shifts to solving the crime or and attending to all the minutiae that are required to complete the puzzle and determine the cause of death. A sense that the case under investigation involved a person with a life, with relationships to others, with a future, is often lost. Is it possible that television and film have diminished our ability to distinguish between what is real and what is fantasy? Computer simulations make this determination even more difficult. Satellite technology has made it possible to beam transmissions of death as they happen to our evening newscasts. During a recent newscast, a reporter warned viewers that what they were about to see was graphic. They then proceeded to show a young boy being shot to death as his father tried to shield him from the crossfire during an armed conflict on the streets of the city that was his home. I remember yelling at the television screen hoping that somehow the reporter would hear me and not show the footage. I turned my head not wanting to see what was happening, not wanting to believe it could be true, but I could not look away entirely. In this instance, I was able to discern that this depiction was authentic, but I wonder if children are able to make that distinction. Although death has not disappeared on television, I think the way in which it has been depicted has somehow desensitised us to it. I wonder if we now believe that everything we see on television or at the movies is illusion. What impact has this had on the way we think and act around death?

The language we use to describe death also contributes to its disappearance. In our conversations, both the participants and myself used euphemisms as a way to distance ourselves from death. We used phrases like "take me home," "go to her rest," "people's form of passing," "ready to go," "pull the plug," "pass away," "the end." Perhaps the most poetic was offered by a participant who used the phrase "waiting for the curtain to fall." One participant described how she found out that her husband was not to be resuscitated. She said, "I had just stepped out of the room when the intern came in and I watched through the crack in the door and they said to my husband, if you have a stroke, we're not going to try and save you and he [her husband] just nodded and smiled, nodded and smiled. He was ready to go." Although the word death is not present in the telling of this story, it is clearly at the heart of this conversation.

Living Life

I consider myself a lucky person. I had a wonderful marriage (even though I never learned to sleep through Stuart's snoring--now I actually find myself missing the sounds that announced his sleeping presence by my side); I've got great kids and grandchildren. I've been very healthy most of my life. I've only had one really close call. When I was in my late fifties I was in a serious car accident (a friend of mine was driving) and had to undergo some complicated surgery. It was touch and go as to whether I'd survive for a few days. But I was--I am--a fighter. As long as I was conscious, I wasn't going to give up. I was determined to get better and the power of the mind is amazing, absolutely amazing. If I hadn't had the will to live, I imagine I would have died. My recovery (after several months of physiotherapy and recuperation) was pretty much complete and I was able to resume all of my previous activities. If I had been older, say in my eighties, I'm not sure if I would have had the same will to go on. Even now I don't think I would want to go through what I did then. I've lived a good life, I've had many happy, fulfilling years and if something awful were to happen and I wouldn't be able to resume my active lifestyle, I'd be much quicker to say, enough, let me go. I have no desire to live to be 100; I'd be bored! My life has always been worth living. And so when it's time, it's going to be worth dying.

When I encounter the word worth, I often think of it as interchangeable with the notion of value. When Alice says, "*it's going to be worth dying,*" I interpret that to mean that there is some inherent value in dying. Kavanagh (1972) expresses a similar idea when he says, "dying well is worth it, because it will insure I lived well, too. I am convinced that our personal failures to unearth, face, understand and accept our true feelings about death keep us from joyful living and dying as we choose. Our failures likewise keep us from treating those we love who are dying with the dignity they deserve" (p. 19). One of the study participants differentiated between getting by in life and living more thoughtfully. He said, "most people are living lives of quiet desperation. It's almost like a grave except it's open at both ends, it's just like a tunnel, they're locked in with mortgages, or marriages, or family matters they can't get out of or jobs they've got around their head because they've got to pay mortgages or kid's university fees. They're not happy but they can't make a change and they're totally frustrated and so many people I talk to, if they'll admit, are like that. Most men don't admit it to other men. Women I think talk more about this but men don't. But if you really get them in a corner, they're not happy about life. So that's where I strongly feel that a person has to think of that third aspect. We are physical beings, we look after our physical needs and we workout and all this sort of thing. And mentally we train ourselves, we go to university and whatnot, but we have that spiritual side of us and if we don't do anything with that and haven't looked into that, then we're a very lean example of what a human being can be." In reflecting upon her past history of cancer and coming to face her own mortality, one participant remarked, "Maybe it's supposed to be teaching me things, and I think in this time I think I've learned a lot about myself and about other people and life and all the rest of it."

Difficult as it might be, reflecting upon one's mortality was perceived as beneficial by a number of study participants. How can this reflection be nurtured? Must one have had a difficult life experience like being diagnosed with cancer or losing a loved one before they are ready to think about their own mortality?

Brookes (1997) suggests that "accepting finality can bring not only such quiet hopes but, in an unexpected way, a kind of truth, of freedom. Life, in fact" (p. 33). Similarly, L'Engle (1980), through the words of a dying grandfather, says "if we knew each morning that there was going to be another morning, and on and on and on, we'd tend not to notice the sunrise, or hear the birds, or the waves rolling into shore. We'd tend not to treasure our time with the people we love. Simply the awareness that our mortal lives had a beginning and will have an end enhances the quality of our living" (p. 59). Scott Maxwell (1968) suggests that "if we have hardly lived at all, it may be much harder to die" (p. 97). And yet another, a man who was dying from amyotrophic lateral sclerosis, shared the following insight, "once you learn how to die, you learn how to live" (Albom, 1997, p. 82). These are strong claims. In essence, they suggest that one can only truly live life to its fullest, after one has accepted death, in particular one's own death, as inevitable. Thus, the observation that completing an advance directive provided individuals in this study with the opportunity to contemplate and reflect upon their own death suggests an added and important benefit to completing a directive that has received little attention in the literature. Such an outcome is difficult to measure in terms of a traditional cost/benefit analysis, but seems worthy of further exploration and investigation. How do we learn to die? How do we learn to live?

In reflecting upon her life, Alice says it has been fulfilling, that she's been lucky. How did she reach this conclusion? Did she complete her own life review while preparing her advance directive? Must I do the same? If Alice were to say, "my life has been awful," would this impact her ability to complete an advance directive? Maybe I am not ready to thoroughly assess my own life. Have I achieved the goals I set for myself? (Some, but not all.) Have I treated people the way I should have? (Not always.) Have I made mistakes? (Definitely.) Maybe I need to re-evaluate my own life goals before I can define how I want my death to occur. Maybe I need to do more living before I can contemplate my own dying. Maybe it is easier if one is older or has been diagnosed with a serious illness to prepare a directive. Maybe one must be nearer to death, to be dying, before you can write a truly meaningful directive.

Sitting Quietly

For me, facing my own mortality, seems a natural thing to do. Maybe it's because of the life experiences I've had, I'm not sure. But I do have friends who I think are hiding their heads in the sand. They just don't seem to be able to accept that death, their death, is a certainty. Maybe they're scared. I just don't see the point of getting all uptight and bungled about it. It's not something to get hysterical about, it happens. I suppose if you don't have faith, if you don't believe in eternity, that would make it more difficult. Maybe if you've never seen someone die, it's more frightening--fear of the unknown is a powerful fear. Do I think there *are advantages to accepting my own mortality? Definitely. It makes me appreciate every day that I have here on earth with my friends and family. I take time to sit quietly, to think, to reflect.*

"In modern society, opportunities are rare for individuals to evaluate their life values and goals, change jobs or careers or emphasize different values" (Burgess, 1993, p. 46). In preparing their advance directives, most participants in this study took time to examine their lives and discuss their values and goals with their partners, their children, their friends. As one participant stated, "I find with today's society, with all this rush and tear and television and the radio and everything we've got, that most people don't have hardly a moment of silence or introspection or time to read or anything and that's pretty sad. And it sometimes takes funerals or accidents to bring them up short and that's too bad because their life might have been quite different had they had more time or made time to stop and think and I think a personal directive can do that." Higgins (1993) writes that "most of us have lived unreflective lives, preoccupied with living, and rarely have thought about the core issues of life and death, and definitely not about our own eventual death. Often, only suffering forces us to face the mystery of being, to ask the age-old existential questions, 'Who am I? Where did I come from? Where do I go?'" (p. 55). In a fictional account of an elderly woman's death, the character Sarton (1973) has created says "I see, now that death is not a vague prospect but something I hold in my hand, that the very opposite is required from what I thought at first. I am asked to listen to music, look at the bare trees divested of all but their fine structure, drink in the sunset like wine, read poetry again" (p. 125-

126). How can we learn to sit quietly, to contemplate life and death, amidst the backdrop of our busy lives? If we are to truly appreciate life, it seems that we must turn our attention to facing our own mortality.

Chapter 6: Talking about Death

> For me, my mother had always been there, and I had never seriously thought that some day, that soon I should see her go. Her death, like her birth, had its place in some legendary time. When I said to myself "She is of an age to die" the words were devoid of meaning, as so many words are. (de Beauvoir, 1965, p. 20)

Conversing at the Dinner Table

I don't remember the first conversation I had about death with my own children, but death was never swept under the rug in our home. My children's first encounter with the permanence of death was probably when one of their pets died. Over the years, we had an assortment of birds, fish, cats, and dogs, and even an injured rabbit rescued from the wild. When a pet died, it received a burial in the backyard with everyone recounting a favourite memory of time spent with the pet. Dusk seemed to be the most often appointed time for these ceremonies. I can recall, too, many lively conversations at the dinner table where we debated the pros and cons of issues like euthanasia, organ donation, and suicide. It sounds kind of morbid, but we even joked about the clothes my husband and I would be buried in. At the time of my husband's death, I was talking with my son and my daughter-in-law about this and David made some comment about the fact that he thought it was difficult, not difficult, that's not the right word. He thought it was odd how we had to make a decision about what kind of suit to put on his Dad when he was being buried. And of course we're making comments like, well what difference does it make--he's going to be cremated anyway, you know. This kind of thing. So then we got chatting about it some more and my son said, "Well don't worry about it Mom. I know exactly what we're going to do for you." And I said with some trepidation, "Really, what are you going to do?" He said, "We're going *to dress you up in your favourite caftan." (I happen to love wearing caftans; they're tremendously comfortable for lounging about! I'm not sure I would have ever thought of being cremated in one, but it wasn't a half-bad idea). So he said, "We're going to dress you up in your favourite caftan. And for your service in church, you know how they put out a picture and all this sort of thing in the foyer of the church, we'll put out your wooden spoon. That will be a symbol of you as a teacher and a mother." Because, you see, I was noted for using the wooden spoon as a motivational tool! I'm also a pretty good cook, so the wooden spoon was used almost every day in my kitchen. We've always been able to talk and joke about these sorts of things openly in our family, so it seemed only natural that I would include my children fully in the process of preparing my directive, another pretty serious topic.*

For participants in this study, preparing an advance directive often seemed to provide an opening for a candid discussion about their death and dying. In conversations between parents and their children about the parent's future death and dying, it was sometimes the older adult who broached the topic with a child; less often it was the child who arrived laden with information on advance directives. These discussions unfolded in a variety of ways--an informal chat at the kitchen table with one child, a formal family meeting with all of the children and their spouses in attendance, a series of conversations that spanned months or years. Sometimes the discussions were difficult, uncomfortable; other times they were gentle, unrestrained. For those in this study who were married, the preparation of an advance directive was a joint project completed by both husband

and wife. All had engaged in in-depth discussions with their spouse and the decision-making process was one they shared. There was not always immediate agreement, but satisfactory resolution was achieved in the end. In this chapter, the theme of talking about death in the context of preparing an advance directive is examined in an effort to reveal insights that may help us to better understand this experience and the role that advance directives may play in these discussions.

During these discussions, both spouses and children indicated that they learned things about the other that they had not previously known. In talking about conversations she had with her son about her advance directive, one participant said, "What you really want is not always discussed as much as it should be. This [our talking about my directive] has made, I believe, my son and I get much closer and he will say sometimes when we are talking, 'I didn't know that, mom. I didn't know you wanted that.' So good, I'm glad we brought it up." One of the married participants similarly indicated that, "we had a lot of talk with each other as to what I should put in mine and what my wife should put in hers and why we were doing what we were doing, if it was any different....There were differences in the sense that I was quite readily able to say who I wanted to be my agent and so on. When my wife got going on hers I noticed I wasn't in the same position as she was in my will and I asked why. She said well when it comes to a woman I think there's certain situations where a man wouldn't feel comfortable, therefore I want my daughter to take control in those areas. I firmly feel that the less the better, the less attempts at heroics, if there's any. If there's no question that the pathway is downhill fast or even if it's straight along for years, if it's in a comatose state, there's no reason I want to be a burden on the system or the family. So, I'll make sure they understand that and I think they know that's what I'd like and my wife was the same. And she's 10 years younger. I was amazed. She too figures that she's lived a very excellent life to this point and if she has to go, well that's fine, don't go on." What is suggested through these excerpts and in the literature (e.g., Coppola et al., 2001; Sansone & Phillips, 1995; Sonneblick et al., 1993), is that family members may not be able to accurately predict the preferences of their loved ones for life-sustaining treatment without having a focused conversation around end-of-life issues.

The story of Alice's caftan and the wooden spoon stimulates many questions for me about symbols. What is a symbol? Why are they important? The definition of symbol which is applicable to this discussion is something that "stands for, represents, or denotes something else" (Oxford English Dictionary, 2002). Chisholm (as cited in Oxford English Dictionary, 2002) is attributed as saying in 1946 that "our distinguishing human characteristic is that we are symbol-users." I think about my own parents and about myself. What would I choose to symbolise their lives? How would I want my life to be symbolised? What clothes would be most appropriate for them, for me, to wear to our last resting-places? How would they, I, want our deaths to be marked? In describing what they valued in life, what was important to them, or how they wanted to be remembered, participants used phrases such as "I try to live each day without regret," "I want to be remembered as a person that had a real spark of life," and "independence, pride, and dignity." One of the participants talked about the discussion he had with his granddaughters who were to inherit his coin collection. He told them, "if you have to sell them, that will be your decision, but remember your granddad loved these coins." For this participant, his coin collection represented something symbolic, beyond its monetary value. In Alice's telling of this story about symbols, there is levity and humour, but when I try to answer questions about what symbolises my parents' lives, my life, to imagine having such a conversation with my parents, tears well up in my eyes. I am evidently not yet ready to contemplate these questions. How can I become better prepared and able to respond to these queries, to assimilate the inevitability of my parents' death, of my death, into my own set of beliefs and practices?

In a book by Remen (1996), entitled Kitchen Table Wisdom, the author talks about the significance of the kitchen table to our understanding of life. She says, "everybody is a story. When I was a child, people sat around kitchen tables and told their stories. We don't do that so much anymore. Sitting around the table telling stories is not just a way of passing time. It is the way the wisdom gets passed along. The stuff that helps us to live a life worth remembering. Despite the awesome powers of technology many of us still do not live very well. We may need to listen to each other's stories once again" (p. xxvii). Participants in this study talked about discussing death around the kitchen table. As one participant recalled, "most of the time, like during supper hour we would discuss certain things and or I would mention it [whatever was on the news--euthanasia, organ donation, etc.] to one of the children as we think about it and when it came to the supper table, we would open it up. You know, one of us would open it up or usually I was the one that would bring up the subject." Perhaps it was not accidental that all but one of the 15 conversations with participants in this study transpired around dining tables. It seemed to be a comfortable place where individuals were willing to talk and a cup of tea could be enjoyed. I think Remen is correct when she suggests that families do not sit down together for supper as often as they once did. The opportunities for sharing stories with one another are more limited. How can we help people gather at the kitchen table once again? How can we ensure that the wisdom of one generation is passed on to the next?

Joking About Death

I'm not really sure why we are able to talk about death so openly. That certainly wasn't the case in my own youth. Although my mother died at home, I don't ever remember having a conversation about her death with my father. It happened. It was finished. End of story. I do recall trying to mention it to him on a couple of occasions and almost instantaneously tears would well up in his eyes and he'd turn and walk away. I soon quit asking, because it hurt me to see my father cry. Christine, my youngest, is a little like that, she's the one who can be counted on to tear up during sentimental TV commercials about the latest long distance telephone rates or the plight of the African elephant. But we seem to be able to joke about it. It doesn't stop us from talking.

Humour was a strategy that many participants utilised both in the context of our conversations about preparing an advance directive and in the discussions they had with their own families and friends. One participant convened a family meeting of sorts to discuss both the contents of her advance directive and her estate will. As she continued, some of her children began chuckling. Before going any further, she asked them what they were laughing about and the story unfolded as follows. "My son said, 'we know this is serious. But we're just using a comic gesture here and there just to break the would-be tension. So that there isn't any tension, we're wise cracking, but we're taking it all in.' I said, 'Well, I'm glad to know that because, (laughs) I mean, if I thought that you were really not interested or something,' I said, 'I really would be concerned.' And they assured me that, 'No, no, they realised that this was something that I was very serious about'....They were just relieving the tension that might build up over such a serious situation, discussion, amongst so many people. They questioned here and there, and apparently the answers, some of the answers, must have suited them (laughs). So I felt very good after having them all here and having the discussion." This participant's demeanour was very exuberant and she laughed often during our conversation. From the description she provided of her meeting with her children, it would seem that they have inherited a similar jovial nature. Another participant described a conversation she had with her son about her obituary. "I've said this, you know, in joking, for example, when you put in my obit [obituary], don't you dare put in a picture of when I was 20 because I've earned this face, you know. And my son just kind of chuckled and he says, 'I know which picture you're getting and it's none of your business.' You know, but I mean, he knows, you know, this is teasing." Similarly, another participant said, "I tease my daughters that I have to be nice to them because they get to choose where I live if I become unable to look after myself."

One of the participants, who had not yet talked with his children about his directive, had some very specific wishes about his future (for instance, he wanted classical music played in his room). In anticipating the discussion with his children he said, "they'll get a laugh when we talk about those things or why this is important to me." Another participant suggested that certain cultures approach death with more humour. She said, "well, there's certainly, in our culture, lots of very humorous stories and songs and writings about people's form of passing....There's Finigan's wake, it's an Irish one that's very funny about the way that Finigan passed on, only he didn't!" Finigan was an Irish man who enjoyed his liquor and after falling from a ladder was thought by his family and friends to be dead. At his wake when a gallon of whiskey is accidentally spilled upon him, much to the surprise of all those in attendance, he is revived (Glover, 1864). The last two lines of the song's chorus capture the recollections of those who witnessed the scene: "Isn't it the truth I've told ye. Lot's of fun at Finigan's wake."

Humour is that quality of action, speech, or writing, which excites amusement; oddity, jocularity, facetiousness, comicality, and fun (Oxford English Dictionary, 2002). Humour is considered to have a sympathetic quality that is allied to pathos (Oxford English Dictionary, 2002). Historically, the word humour was used to describe the four primary fluids of the body (blood, phlegm, choler, and melancholy) which were responsible for controlling one's physical and mental health (Old English Dictionary, 2002). If, as I am suggesting, humour was used by participants as a coping strategy, as a way of dealing with difficult subject matter, the link between the historical usage of the word and its current application becomes more visible. Participants seem to be using humour to help maintain their own physical and psychological well being. I had not considered before a connection between humour and pathos, that humour might be something through which one makes connections and shares emotions with another. I have, however, often thought that those without a sense of humour must be lonely, and this interpretation would seem to support that conjecture. Laughing alone simply does not compare to laughing together with another. What does this mean for the many isolated seniors who are living alone without family members or friends near-by? How can one's sense of humour be nourished? Is there a way that we can help people to incorporate humour into their daily life, particularly as they face difficult end-of-life issues?

Widening the Discussion

After the seminar that Susan and I attended, we talked a bit about the kind of things I was thinking of including in my directive. Over the next few months, I had the opportunity to informally chat with each of my children keeping them informed as I proceeded to complete my directive. I bounced ideas off them. I asked them to read what I had written. I asked if they understood what I was saying and if there were other things they would like to see included. When it was finished (as finished as it can be for the time being at least), I invited them all over, along with their spouses, one Sunday afternoon so that we could go over it in some detail. I wanted them all in attendance, so that any points of disagreement could be resolved at the outset. It seemed to go pretty smoothly.

There were moments of awkwardness, of nervous laughter, especially as we began the discussion, but they quickly dissipated. Dealing with their father's illness and the way his death unfolded was a traumatic experience for us all, so my motivation in completing the document was clear to them and they were all very supportive. When I think back about that afternoon, I have very fond memories--it was a situation in which I felt very close to my children and I think they felt close to me, too. Because we are all so busy, those kinds of opportunities don't happen as often as they should. Scheduling the time to have the discussion was very important for us all. I think involving them in the process of preparing my advance directive has brought us even closer together as a family.

Many participants in this study recognised the importance of sharing the process of end-of-life decision-making with family members and friends, especially the ones who were stakeholders that would be directly affected by the decisions that were made. One participant had not yet undertaken the step of reviewing his directive with his children, but planned to do so in the near future. When I met with him, both he and his wife were at the stage of putting the final touches on their documents. He said, "we haven't met with them [their children] yet, but we will be sitting down with them as a family. And with our family that's easy to do, an evening at home and just discuss it. If you don't do that with a regular will, too, you end up with all kinds of hard feelings later that are unjustified, but if they know your feelings and why you've said what you've said it should clear up a lot of that. And the same thing with the unwritten part of the directive, the side documents that go only to your agent. I'll make sure that they know there is this side document and what it says and why I've done it that way." This individual had been counselled to prepare two documents, one that would be for public consumption and would outline only his basic wishes; the other would be for his agents only and would provide greater details. His purpose in constructing his directive this way was to provide his agent with greater latitude in the decision-making process. The 'side documents' as he referred to them are intended to be used as guidelines by his agents, rather than interpreted as fact.

Kuczewski (1996) suggests that family members should be part of the medical decision-making process and proscribes for them a certain role. He says that family members "take part in the patient's narrative self-discovery that helps her to reconnect with her values and give them meaning as expressed in choices. This self-discovery is not prior to the event of giving consent, but in a sense, is the process of informed consent" (p. 34). He goes further to suggest that in so doing, "a family member, especially one who is often the patient's primary caregiver, may undergo a process of self-discovery and adoption of a new value structure in the same way that patients often do" (p. 35). It is through our relationships with each other (familial or other), that we learn more not only about the other, but also about ourselves. As I participated in the conversations with the older adults in this study, I was continuously reflecting upon my own values, my own life. As I tried to come to an understanding of their experience, I was also seeking an understanding of my self.

Perrin (1997) indicates that "a medical directive is of little use if the individual has merely completed the form without engaging in a discussion of his/her desires with family and physician. It is the discussion of the patient's goals, values, and desires during the preparation of the directive that allows the family and healthcare provider to ascertain what the patient would have wished if the actual situation does not exactly match the anticipated scenario. When medical directives were initially proposed, it was assumed that such discussion would necessarily result" (p. 22). Why has this not routinely happened? Why are healthcare professionals so infrequently involved in the process of preparing a directive with their patients? Given our society's penchant for autonomy and its valuing of independence, bringing others into our decision-making process may require a shift in the way we generally approach life.

One participant had a family friend who was a nurse with a special interest in counselling persons in the preparation of advance directives. The two spent several afternoons discussing various end-of-life issues together. As she says, "it's very difficult for me to remain business-like when she's here because she is like a daughter and we have such good fun together and I've felt bad after she's left that I've, you know, wasted her time. But she enjoys coming, too, I know. I find that she is very precise and has done excellent work with the right questions and the explanations and, you know, if she is as kind and objective to everybody as she is to me, this is fantastic, she's at the right place." Many of the participants in this study were in positions were they had access to resources, both human and educational, to assist them in the process of preparing an advance directive. How can we as health professionals ensure equitable access to such resources for all? Is that one of our roles? Do we need to be more engaged in providing education and counselling around end-of-life decision-making? Are there ways in which we can promote wider discussion of the issues? How do we ensure that everyone has someone they can talk to about death?

Considering a Parent's Death

If you were to ask me whether or not talking about my death with my children was easy, I would probably have to say no. It wasn't easy, but it wasn't difficult either. I don't think any child, small or grown-up, likes to think about the death of his or her parent. A conversation I had a while back with my son is a perfect example. One afternoon David brought me a delightful little book called, The Love of Mothers and Sons, *and I asked him to write a message on the inside cover. We had been discussing my directive earlier that day and he had asked me about an item he was wondering about. So he wrote something about he and I having a good relationship and then finished it off with "And will you please stop talking about your death." Well he was the one who had brought it up! We were both able to laugh about it. That's the kind of lightness that we were able to attack preparing a directive with and I'm very pleased about that.*

One of my neighbours, Mary, has had a much more difficult time talking about death with her two sons. Mary has had some serious health problems in recent years and feels that her death within the not too distant future is a distinct possibility, so she wants her sons to be prepared. But she has met with a lot of resistance. Mary says that her boys will not talk about things like their parents' death or that they want to be cremated. They will not talk about splitting up all of the stuff in the house. She worries that they will think their father is being cheap if *he doesn't spend money on a fancy casket. She has asked each of her sons, Steven and Michael, separately on several occasions if there is something in particular in the house that they would like to have. They are both doing very well financially and always say, "no mom, we don't need anything." Finally, after multiple attempts, she wears Steven down and he says there is one thing that he really likes--the sculpture of the dolphins. With the added ammunition that Steven has made a decision, she once more asks the same question of Michael. He again says, "I don't even want to talk about that!" And his wife says, "But, Michael, my mom has asked me that question, too." And he says, "Well, I don't want to talk about it, but if there was one thing, it would be the dolphins." So now poor Mary has to figure out a way to cut the dolphin sculpture in half! Not long ago, she told me another kind of funny, kind of sad, story that took place when Michael came to visit. The two of them were down in the basement sorting through some things and Mary said, "When I'm gone I want you to just get rid of all the junk in the basement" and Michael turns and says to her, "But where are you going, Ma?" Michael just wasn't getting it. He wasn't ready to accept the fact that his mother will one day die. Mary has pretty much given up for now and doesn't even bother trying to bring up the subject of her or her husband's death. Her husband hasn't been able to help much either, because in his family things like this were never talked about. He'll tolerate a discussion, but he's not really keen to talk about death either.*

For now, Mary has stopped bringing up the subject of her own or her husband's death. To ensure that her sons will have the necessary information and be able to understand the decisions her husband might make on her behalf, should she die before him, or vice versa, they have both written down their wishes in an advance directive and an estate will. One is left wondering, though, why Steven and Michael are having such a difficult time talking about their parent's inevitable, although not necessarily imminent, death. Michael's comment, "But where are you going, Ma?," is almost humorous, as if he thinks his mother is talking about moving to the house down the street. The idea that 'going' is a euphemism for 'dying' is not acknowledged. It would appear that each of her sons has come up with a response to the question: "Is there anything in the house you would like?" in order to pacify their mother and to bring to a close any conversation about her death.

One wonders how a generational pattern of not talking about death can be broken. Mary has attempted to change this pattern in her family, but has been largely unsuccessful. On the other hand, Alice has met with greater success. One wonders how the experience of death and dying is transformed by these discussions. If Mary had been able to enter into a more thoughtful discussion about death and dying with her sons would this change how her own death and dying would unfold? In considering a parent's death, it is almost impossible not to consider one's own mortality. Is the stumbling block that Mary's sons are not yet ready to confront their own mortality? What will need to happen in order for Mary to have greater success in talking to her sons in the future? How can she help her sons face her own and their own mortality?

Although there has been considerable study of the adult child's reaction to a parent's death, only a few studies that focus on the adult child's anticipation of a parent's death were located. Kowalski (1986) suggests that when anticipating their parent's death, adult children may fear becoming orphans, worry that certain issues with their parents will not be resolved, and be compelled to face their own mortality. Fitzgerald (1994), in a grounded theory study with six adult children who had or were anticipating the loss of their parents, identifies three major processes for adult children who are facing the loss of their parents as discerning life and death (asking questions about life and death), evaluating relationships with parents, and preparing themselves to outlive their parents. Several of the older adults in this study describe situations that reflect these fears and processes. One participant believes that the discussions about her death were helping her son to "think of his ends." Alternatively, another participant says, "They [my children] don't want to look at it [death]. When you prepare a will you're preparing for your death...that it exists, that's right. And I know my children have that attitude sometimes....I think it's a thing that says, you know, mom and dad are getting old and who would like to think that mom and dad are getting old." This participant continues to be optimistic that with enough repetition and positive reinforcement, his children will become more accepting of both their own and their parent's inevitable death.

In anticipation of her husband's death from cancer, another participant and her husband both wrote advance directives. She describes her son's reactions to his father's anticipated death this way. "We knew he was leaving, he knew he was leaving. We could connect, we could talk about things. Like my son said he felt very guilty being away for the six years, but as time went on, and the more and more that he had to do things for his dad...then he started to relax, he didn't feel guilty." "We did have a lot of discussion, not only on the physical, but on the psychological, the emotional level for myself and for the children," said another participant. According to Kavanagh (1972), "helping children gain an ease around death prevents the many fearful approaches to life we see in ourselves and in those around us. The main purpose in openly discussing death with children is to enable them to live more freely....The wonder and glory of life is the gist of our message not the morbidity of death" (p. 131-132).

In describing the older adult's experience of talking about death with their children in the context of preparing a directive, there were three approaches that seemed most evident--avoidance, acquiescence, and acceptance. Avoidance represents a desire not to talk about their parent's death; acquiescence suggests that the parent's death is acknowledged, that no objection is raised, and that the conversation is tolerated, but it is limited; and acceptance suggests that the children welcomed and regarded the discussion as favourable. These categories are neither exhaustive nor mutually exclusive, rather they represent three sub-themes that appeared in the data. Across all three--avoidance, acquiescence, and acceptance--there is a sense that facing a parent's death is not easy or natural--that it is a significant event for all involved, perhaps even especially for adult children. Kavanagh (1972), in his book entitled Facing Death, describes one adult child's experience this way: "A handsome corpsman in the navy, intense and terror-eyed, Van told of his perennial need to anticipate his parent's death. He was obsessed with their imagined death and his equally imagined grief. Nightly, he pictured them in caskets, waked and buried them, unable to sleep until he pre-felt his untested grief" (p. 89). Clearly for some, anticipating a parent's death is a difficult and disturbing process. Although the children were not interviewed in this study, we see glimpses of these difficulties in accepting a parent's death in Michael's comment "Where are you going, Ma?" and in David's admonition "Will you please stop talking about your death." Another participant who brought up the topic with her daughter said, "when I first mentioned the directive to her she got all teary-eyed and said, 'Oh, Mom,' and I just said, 'Hey it's a fact of life, you live, you die, and I have to do this.'" I can empathise with these comments, because even though I live some 3000 kilometres away from my parents and see them infrequently, I too find it hard to imagine a world without them. In the opening quote of this chapter, de Beauvoir (1965) has eloquently captured the difficulty that children of all ages have in imagining a parent's death in this phrase about her mother, "her death...had its place in some legendary time." How do we help adult children accept that the legendary time is now?

Imposing Limits on the Discussion

As I prepared my own directive, I talked to several of my friends about the process. It's interesting how we have all approached it somewhat differently. One of my friends, Isobel, has had two bouts with breast cancer. She has completed an advance directive and shared its contents with her four children, but she did not include them very much in the process. Instead she talked with a close friend who *is a nurse and also a breast cancer survivor. She believes that her friend is in a better position to understand how she is thinking and feeling than her children. She believes she is protecting her children by limiting the discussion about her death with them, but I'm not so sure. Sometimes I wonder if she is shutting them out, creating an insurmountable gulf between them. I think there are some real benefits to having open discussions with your children. For me, I think it has brought our family closer together. Everyone feels that they have an important role to play, that they can help, that they can say what's on their mind and be heard.*

Isobel's rationale for leaving her children out of the decision-making process is to protect them, but one wonders whether or not this action will achieve the results she hopes for or if instead it may actually create, as Alice suggests, an insurmountable gulf between mother and children. In this situation, it would seem that Isobel is almost forcing her children to avoid entering into a discussion about her end of life. In an effort to protect them from hurt and harm, is she actually preventing them from engaging deeply with her about her death and dying? Who will be at Isobel's bedside when she is dying? How will her children feel when someone else is making decisions about their mother? With another of the participants, it was the children who set a limit to the discussion around death. In this particular instance the discussion was centred on the participant's estate will. He said, "when we had our wills made and we gave them a copy of our will. We said, 'This is the will.' And my daughter said, 'I'm not even going to open this, I don't want to look at it. I'm going to put it away, I know it's there.' And I told her, she's the executor. And she said, 'I don't want to look at it, I don't even want to think about it, ok?'" So the participant said, okay, and the matter was closed. From what other participants shared and what is written in the literature, it seems important that the communication channels remain open. How can we keep the conversation going?

Talking to No One

A friend of my husband, John, left home when he was very young and has been on his own ever since. He never married and for as long as we have known him, he has been estranged from most of his family. He is a very private man and didn't really talk with anyone before or while he was preparing his directive. In fact, the only reason I know that he has a directive is that it came up in the conversation when he was over for dinner one night. I mentioned that I was preparing my directive and he said that he had signed one too. From the little that he said about it, I got the sense that under no circumstances did he want his life to be prolonged in any way. He had lived his life fiercely independent, and it seemed that he wanted to die that way too. It seemed so sad to me that he had no one to share these sorts of decisions with. As he had lived all of his adult life alone, I was now picturing him dying alone, too. I guess it fit with his lifestyle, I guess it was the right thing for him, but it still seemed sad to me, it didn't seem quite right. There was no one whom he could count on to speak up on his behalf.

For those participants who didn't have a spouse or children, it was a niece or nephew, a sibling, or a trusted friend that was usually involved in discussions with participants about preparing an advance directive. These participants chose individuals they thought would have an understanding of the purpose of advance directives and have some knowledge of death and dying--two nurses, one lawyer. As one participant shared, "we talk, you know--about things so that she knows. And we will continue to talk. Well, I think because she's a nurse I thought that she would be, you know, in a good position to [understand]....And also we're probably closer than I am to some of my other nieces and nephews because she lived here for six years and we spent, you know, quite a bit of time together at that time and so, you know, she's probably the closest to me." They selected individuals whom they believed would accept this role willingly. Only one older man completed his directive as a solitary act. His only communication with others about his wishes was to provide a copy of his directive to his family doctor. After meeting with him, I wondered if his decision to participate in this study fulfilled an unmet need or desire to talk about what he had done, about his own death, with another.

When I began the process of completing my own advance directive, I, too, approached it as a solitary act. I gathered a variety of templates, was very familiar with the legislation, and thought I had everything necessary to complete the project in hand. That is my usual approach to performing tasks, collect what you need and just do it. I think I am a capable, self-directed person. I do not like to be dependent upon others. However, as I sat in front of the computer staring at the blank screen, I was immobilised. My mind wandered and images of how I might die flashed before my eyes--I am flying down a steep ski slope out of control. Icy wind is lashing at my cheeks. My ski poles are flailing helplessly through the air.

A treacherous rocky cliff looms just ahead....The traffic light changes to green. The walking signal illuminates. I confidently step off the curb. I hear the crunch of bones. My body is brutally heaved into space....The scorching heat of flames surrounds me. In the smoky darkness I begin to panic. I can't find the door--An alarming shiver runs through my body, making me tremble from the top of my head to the tips of my toes. I am no longer connected with the computer and the keyboard or the task at hand. Instead, I am leaning back in my chair, staring out the patio doors leading to my balcony. The sun has started to burn through the heavy fog that silently hangs in the cold winter air and clear blue sky is slowly unfolding. The branches on the trees are still. Every few seconds a car passes by and I hear the muted sound of its engine. Maybe it is too quiet here in my living room. I get up from the chair and turn the radio on, just loud enough to provide some background noise. Now that I am up, I refill my water glass and get a snack from the kitchen. Almost an hour has gone by since I began this task. Progress has been painstakingly slow. Is it possible that completing an advance directive requires the input of others, that it is not easily done alone and in isolation, that talking about death is an essential aspect of the process? If so, what happens to those who have no one with whom to dialogue about death? How can we, as healthcare providers and healthcare recipients, begin to widen the discussion? How can we learn to talk more openly about death? How can we ensure that everyone has the opportunity to talk about death?

Chapter 7: Choosing an Ally

> 'Don't leave me in the power of the brutes.' I thought of all those who have no one to make that appeal to: what agony it must be to feel oneself a defenceless thing, utterly at the mercy of indifferent doctors and over-worked nurses. No hand on the forehead when terror seizes them; no sedative as soon as pain begins to tear them; no lying prattle to fill the silence of the void. (de Beauvoir, 1965, p. 94)

Naming an Agent

In Alberta's legislation, individuals can name in their directive, someone or more than one person--what they refer to as an agent--to make decisions for them should there come a time when they are no longer able to make decisions for themselves--like if the individual is unconscious or has Alzheimer's disease. This seemed a sensible thing for me to do, because no matter how many specific instructions I include in my written directive there may be a situation that I haven't thought about or the circumstances might be different than what I had envisioned. With so many advances in technology happening so quickly, you never now what's going to happen tomorrow, let alone five years down the road (Have you heard the latest?--There are computers now that you can wear on your wrist that are the size of a watch. Computers didn't even exist when I was born. I can only imagine what is yet to come!). So you want the agent to have some flexibility to interpret what you have written. I've given them carte blanche in any decision that they make as long as they think it is in my best interest at the time. I've even given them the power to make decisions about determining my mental capacity. I may be going out on a bit of a limb with that one, but I figure they ought to know my usual state of mind better than any physician. So in *consultation with a physician, they can decide whether or not I am acting as my usual self or if my mind is slipping and I am behaving out of character.*

Naming an agent was perceived by participants as both a back up and an adjunct to preparing a written directive. In this chapter, the experience of selecting an agent is explored under the theme of choosing an ally. The term ally, as described in Chapter 4, signifies a person or organisation that acts in co-operation with another to work toward some common goal. As a back-up, participants believed that their agents would act in such a way as to reinforce and uphold the written statements they had made; as an adjunct, participants believed that their agents could provide supplemental information that would contextualise their written statements. In both circumstances, the agent would be acting in support of the maker of the directive's goals. As Alice clearly identifies, another reason for naming an agent is to deal with the issue of uncertainty. Illnesses that are today considered terminal and life-threatening may in a matter of years (and before Alice has a chance to update her advance directive accordingly) become treatable through the development of new medications, surgical procedures, and so forth. Alice has provided her agents with the freedom to make decisions that they think are best given the current set of circumstances and their knowledge of her values and approach to life and death. As one study participant reflected upon the role of an agent, he said, "he knows you well enough as to know what you would desire and then he can make the decision and you are literally giving him that flexibility and that power. If you're confident in who you appoint as agent it shouldn't bother you." Another participant indicated that "you've got to choose a person who's going to be there. If you choose, in my opinion, an outside party, who do you choose? Who would you choose? You know, say we'll choose a good friend; friends come and go! They move away. You have to be sure that it's going to be somebody who's going to be available and there at all times."

Situations have been described in the literature and the popular press about advance directives that were either ignored by healthcare professionals or where the treatment provided was inconsistent with written or verbal instructions (Edson, 1993; Hansot, 1996; Teno, Licks et al., 1997). In the widely published Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) undertaken in the United States, as few as 35 percent of physicians were aware that their seriously ill and hospitalised patients had prepared directives and that they were present in the patients' charts (Teno, Lynn et al., 1997). Clearly, there was a breakdown in communication and subsequent lack of knowledge about patients' wishes around life-sustaining treatment in these situations. In these circumstances, an agent might have played an important role in ensuring that the physicians providing care were aware of the documents and familiar with their contents.

Perhaps even more disturbing are those situations where treatment proceeds in a direction that is in opposition to the written wishes that an individual has provided and are known to healthcare providers. The rationale for providing treatment that clearly contradicts an individual's wishes does not usually represent any malicious intent on the part of care providers. Sometimes health professionals initiate treatment because they believe that the individual will survive if they receive life-sustaining treatment and that it is their duty to treat, to provide at the least an opportunity for continued life. Sometimes it is provided because the healthcare providers do not believe that the individual understood the potential consequences of what he or she had written. In both of these instances, an agent who has engaged in meaningful discussions with the maker of the directive may be in the best position to intervene and advocate on behalf of the patient.

Advocating on behalf of a patient may not be easy, however, indeed it may be very difficult. Elisabeth Hansot (1996), a 57 year-old professional woman, who was her mother's agent describes her experience of acting on her mother's wishes this way. "I am astounded that I had so little inkling of how hard it would be to help my mother have the death she wanted....When we talked together about how she wanted to die, she was clear, consistent, and matter-of-fact. She hoped for a swift death and wanted no unnecessary prolongation of her life....I believed that I could make decisions on her behalf as she would want them made if she were to become incapacitated. As it turned out, I was woefully unprepared for what was in store for her and for me" (p. 149). Elisabeth came up against the 'power of the brutes' that Simone de Beauvoir speaks of in this chapter's opening quotation. In the hospital setting, the physicians in charge of Elisabeth's mother carried the bulk of the power and a five-day battle ensued. Her physician, according to Elisabeth, "found it nearly impossible to accept that my mother would prefer death to living with hemiparalysis and a tracheotomy." De Beauvoir also speaks of the difficulty she had in ensuring her mother's wishes were enacted.

"When I reached home, all the sadness and horror of these last days dropped upon me with all its weight. And I too had a cancer eating into me--remorse. 'Don't let them operate on her.' And I had not prevented anything" (p. 57). I wonder if the individuals whom the study participants have selected as agents are prepared for combat. I also wonder if there is another way to approach these difficult end-of-life decisions that does not engage the war metaphor--that does not define the situation as us against them, life against death. Is there a way to reconceptualise the conflict or even better to prevent a conflict from emerging? Until such a shift in our stance occurs, choosing an ally will remain an incredibly important aspect of ensuring that one's wishes for end-of-life sustaining treatment will be respected.

The concept of power within the context of end-of-life decision-making is one that raises for me many questions. Who holds the power, or in other words, who has the ability to do or act (Barber, 2001)? Who ought to hold the power? How can one overcome power differentials? How can one obtain power? Is the trend toward legalisation of advance directives, an effort to correct an existing power imbalance, to ensure that the power is in the right hands? Even the language of the law suggests that power is an integral notion in the area of substituted decision-making (e.g., power of attorney). It would seem reasonable to include power within the war metaphor. Is it not the most powerful who win wars? How does power impact relationships? Can an authentic relationship exist in the context of a power differential?

Healthcare professionals were rarely named as agents, however several, as did Alice, indicated that any assessment of competency be undertaken in consultation with a physician. The determination of competency was one area where participants believed that healthcare professionals had special expertise. As the data analysis proceeded in this study, the lack of involvement of healthcare professionals crystallised in a number of ways--in initiating discussions, in participating in discussions, in the process of preparing directives, and in their enactment. There is a general perception that healthcare professionals, in particular physicians, have different beliefs and goals around the provision of life-sustaining treatment than older adults. For this group of participants, quality of life was generally of greater significance and value than quantity of life. Several indicated that they were concerned that physicians would provide treatment that was more aggressive than they desired. As Alice stated earlier, she has *"a lot of reservations about the medical profession...[she's] seen first hand some of the things that they do, in the name of the Hippocratic Oath, or whatever. There are times when they don't know when to stop."* One of the participants thought that there had been a bit of a shift in attitudes in recent years. He said, "there's more acceptance now, I think, in the younger medical doctors but at that time [in the 1980s], I think they thought 'my job is to save lives. I don't care if he's a vegetable, he's alive.'" Although the participants recognise that this mindset is important in sustaining continued progress and advances in medicine, they did not want it to apply to them in the situations that they have described.

Selecting the Best Agent

I remember the lawyer talking about some of the qualities he recommended in a healthcare agent. First of all, he suggested that you need someone who is going to be readily available and there when you require them. Second, he said that you want someone who knows you well, who knows the things you value, and is knowledgeable about your directive and what's contained in it. And without saying, it has to be someone that you trust, someone that you know will respect your wishes, and someone who will be able to make the tough calls if needed.

For me, the obvious choices were my children. I've put my son, David, first on the list. He'll be the primary contact for decisions about my health care. David is very level-headed, bright, able to face serious issues head on--he's just a tremendous iron solid person with no weaknesses in any mental or emotional areas that might jeopardise the care I would want. I think having only one individual identified as the key contact has the added benefit of improving communication between the healthcare providers and the family. The healthcare team will know whom they need to be relaying information to and hopefully that process will be streamlined. I can imagine it must be very frustrating and time-consuming for physicians and nurses to keep repeating information to one family member after another and to have to answer the same questions over and over again (I know it's frustrating and tiring for me when I have to repeat myself). This way my son will be in the position to pass the information to other family *members, in particular my daughters, and to gather and consolidate all of their questions.*

Susan and Christine will be my alternate agents in case David is unavailable and they will also be the ones in charge of decisions about where I should live and whom I should socialise with and those sorts of things. Those are areas where they feel more comfortable. They know the kinds of things I look for in a place to live (clean toilets and bathtubs, lots of windows, flowering plants). But I expect all of the decisions to be shared amongst the three of them. They seem okay with this idea. I've mentioned this before, but it is really important to me that they continue to be friends after I'm out of the picture. It is my hope that knowing what I want ahead of time and having these discussions will help to achieve that goal.

If an individual's autonomy is to be respected, it is vital for a surrogate decision-maker to be knowledgeable about the patient's desires and willing to act accordingly (Sansone & Phillips, 1995; Yamani et al., 1995). Although the adult children's perspectives were not directly accessed in this study, one gets a sense from participants, that they believed their children for the most part were well-equipped and prepared to assume this role. As Alice relates, David is "*level-headed, bright, [and] able to face serious issues head on.*" Another participant said, "I'm quite sure my kids will respect them and I don't know who else would be very much involved. I think they'll be right there if I'm very ill." The tendency of older adults with children to name their children to be their agents was reflected in this group of participants (Sansone & Phillips, 1995). There is some evidence to suggest that surrogate decision-makers take their role seriously. In a survey by Sansone and Phillips (1995) on the topic of advance directives, 168 surrogate decision-makers of older adults received a questionnaire by mail. Responses were received from 153 individuals, an incredibly high response rate, which suggests that the topic was one of significance to this group. Seventy percent of the respondents were adult children. The engagement of most of the adult children in formal and informal family meetings and discussions and in posing thoughtful questions to study participants suggests that this group of children also approached the role of surrogate decision-maker with a high degree of sincerity.

In the following quotation from a study participant, the many factors that were considered as she contemplated her decision about who would be the best individual for her to appoint as her agent are described. "I think I appointed my son because, in general, men are the ones who usually have the authority of making decisions and signing for this and that and the other, more so than women. And my second child is my daughter and she has cerebral palsy and I don't think that she would want to have that responsibility put on her. And also he has a phone and answering machine, whereas she doesn't, well, she does too, but she never listens to it, darn it! And you have to phone her at least three days in a row and she might get around to it the fourth day and figure, 'What did you call me the other day for?' 'Well, why didn't you phone me back the first day?' 'Well, I didn't find out!' So, I mean, I definitely don't want her to be in charge! And the third child is the other daughter who is quite capable....[but she] has lived far away from home since she graduated from university and went up north to work. So, I mean, I would not name her because she is never in the city." Another participant named both a primary and alternate agents. Projecting himself into a time of future incapacity he explained, "I thought if I'm in that kind of a basket case [incompetent] I don't care whether it's my wife, my son, or my daughter making the decisions or facing the issues if they're capable and at this point they are. That's why I wrote whom I did down. It's my wife and saving her, my son, and then on down with my other two daughters after that. And I guess my wife isn't as logical, but after that all three children are equally competent I would say. They are all in the city but who knows where one of them might be at a given point of emergency and so the advice was to always have other alternates." Another participant discussed how her husband had made his decisions about appointing agents. "My husband had appointed myself and if I wasn't able to, then it would have been my son. Personally we spoke about it that our son would, of course, speak to his sisters. One is, like our little one, the one who is going through the divorce, she is quite emotional, and she takes things a little [harder]. And the other one was expecting a baby so we didn't want to put the burden on them. BUT it was understood that they would have a discussion. The girls definitely were not gonna be kept out of it or in the dark. But our son was to make the definite arrangements. That was only if I wasn't capable."

Although most participants had identified someone to be responsible for making decisions for them should they become incompetent, they did not want them to bear any legal or other consequences for making decisions on their behalf.

As one participant stated, "we [husband and wife] absolved them [their children] of any liability in making these decisions. That may bother some people, it doesn't me." In her written directive, another participant wrote, "I recognise that this appears to place a heavy responsibility upon you [her agents], but this directive is made with the intention of relieving you of such responsibility and placing it upon myself in accordance with my strong conviction. I hereby absolve my physician or any physician taking care of me, from any legal liability pertaining to the performance of my requests and demands." To date, there have been no legal challenges to the Personal Directives Act in Alberta so the strength of these clauses remains untested.

In a large Canadian study of outpatients of all ages, patients indicated that they were most likely to have discussed their preferences for life-sustaining treatment with friends, spouses, and children (Sam & Singer, 1993). Interestingly, when selecting a surrogate decision-maker the order shifted, with individuals most likely to choose spouses, children, and then friends. That one is most likely to talk about these kinds of decisions with friends, but least likely to select them as surrogates is a rather perplexing phenomenon. Perhaps the dialogue between friends is a safe space and less threatening place to test out ideas and work through decisions of this nature, so that later discussions with a spouse and/or children proceed more smoothly. This would be something akin to a dress rehearsal where one has the opportunity to work out some of the finer details and make adjustments as needed before the curtain is raised on opening night. Scott-Maxwell (1968), an 83 year-old woman, writer, and Jungian psychologist describes her discussions about death with a good friend this way: "With one friend of my own age we cheerfully exchange the worst symptoms, and our black dreads as well. We frequently talk of death, for we are very alert to the experience of the unknown that may be so near and it is only to those of one's own age that one can speak frankly" (p. 31). Many of the individuals in this study did talk to friends during the process of preparing a directive, but a chronological sequencing of the timing of these discussions was not evident. Only one participant named a friend (a nurse) as her sole agent. In selecting a nurse, this participant believed she was choosing someone who was knowledgeable about end-of-life issues. As she said, "As a matter of fact, the agent that I have chosen is a nurse and certainly deals with end of life VERY often. And so she gave me all of the possible scenarios, about if you're this way they'll do such and such, and if you're this way they'll do something else, and whatever, whatever....I am leaving that [decisions about my end of life such as stopping life-sustaining treatment] up to my friend who is certainly more qualified than any of my children to assess my situation. I definitely knew that I didn't want my children to have to say, 'pull the plug' and then feel guilty about it. She was my best choice, I believe." A second named a family member and a friend. In preparing her advance directive, this participant had consulted a lawyer. She said, "I wouldn't have thought of choosing somebody if it hadn't been for the lawyer. That's one thing. My sister was my first choice. And I know that she would abide by my wishes and that's partly because that's part of the family values that we have, that everybody makes their own decisions, people don't make decisions for somebody else. The other person I chose and I know she would be faithful and would make herself available is a friend."

Participants were also very clear about the persons that they did not want to be their surrogate decision-makers. As one participant stated, "we have some more distant relatives that I would cringe to think about appointing as an agent because of their inability to face some serious issues in life, especially life and death." Isobel, to whom Alice referred to in Chapter 6, chose not to select her children as her agents because she did not want them to be in the difficult position of making end-of-life decisions for her. She believed her friend who was a nurse and had breast cancer was better equipped and intuitively more able to make such decisions. In Isobel's words, "she can empathise with every single feeling that I have...and understands completely." Another had some reservations about choosing a good friend, because she had recently witnessed her friend having difficulty in dealing with life-sustaining treatment decisions around her own mother's death. She believes her friend's mother underwent some invasive tests and procedures that were unnecessary and unwanted, and she wonders if this friend would be able to be a strong advocate for her. This same participant had thought about naming a husband and wife as her agents, but her lawyer advised against this because of the possibility that the couple might at some point become separated or divorced. The lawyer postulated that a situation for potential conflict could arise and that she might get caught in the middle. Yet another thought it was important to select someone who was younger as "someone younger, really, can cope with it better, too. Like...as you get older you can't cope with stuff, you shouldn't have to, you know...It's hard enough to look after yourself as you get older without having to look after other people." Somewhat ironically, this individual is an agent for two of her friends who are a few years her elder.

In Chapter 4, I discussed how the term 'agent' seemed to lack any notion of relationship, that it was a rather cold and business-like term. During our conversations participants talked about their agent's duty to respect their wishes. This sense of duty, however, seemed to stem from the relationship the agent had with the older adult rather than from the signing of a legal document. The notion of relationship was important throughout the process of naming, selecting, and trusting an agent to act on their behalf. No one selected a stranger or a paid professional in their employment (e.g., lawyer, doctor) to be their surrogate decision-maker. Because of the educational material they had accessed, participants were familiar with and used the term agent often in our conversations. There was a sense that their agents would be close by, ready, and willing to do battle. Are the agents well equipped or does the healthcare system still have the bigger guns?

Trusting Your Agent

I am so fortunate to have three children who are available to go to bat for me whenever I need them. When I see myself on my deathbed, now what I see there, what I believe, I see it, I visualise myself incapable and I'll have three warriors at my disposal and they will do the best they can. I trust them with that. Because I believe that if I didn't trust them the whole idea, the whole directive, would be futile. You have to accept that they will do what you want. It's certainly *better than not having anyone standing up for your best interests. I can't imagine what it is like for someone like my husband's friend, John, to have nobody he can trust to make decisions for him. He is relying solely on the piece of paper he has signed to be his spokesperson, to relay his last wishes. I can only hope that his advance directive ends up in good hands, the right hands.*

Selecting an agent, indeed the entire process of preparing an advance directive, seems to revolve around the concepts of trust and fidelity. Fidelity "addresses issues of mutual faithfulness between individuals....Under the principle of fidelity, one is held to the promises that one makes" (Winters et al., 1993, p. 22). Participants trust their agents to make decisions in accordance with their wishes or in their best interest if there are no written directions that apply to a specific situation. Participants trust that the documents will be provided to relevant decision-makers. Participants trust that health professionals will act in accordance with their written instructions. Only one individual in this study did not name an agent or substituted decision-maker. This reflected his independent lifestyle, his desire to make his own decisions and to not be dependent on others. His reasons reflect those identified in the literature, in particular, a preference for independent decision-making (Sam & Singer, 1993). Another reason identified in the literature for not selecting an agent is not having anyone available within one's sphere of relationships that would be suitable (Sam & Singer, 1993). This may also have been a factor in this participant's situation, as he was not close to most of his family members.

Participants expressed confidence in their agents to make the decisions that were in their best interests. When I asked one participant if she had any concerns that she might change her mind about what she wanted if she were to become incapacitated, she said, "I think I've left a good margin of variation there. But, again, I would have to put my trust in the agent, in consultation with the doctor, to know whether I am still as lucid as I want to be. You know. Is it the pain that's talking or is it the bottom line? There are so many variables, depending on the degree of demise, I guess. It would be up to the agents to know whether I am making the right decisions or not, if I start changing my mind, if I say, 'Go ahead, break my ribs!' or whatever." Another participant was certain that her wishes would be followed. "I know that my daughter, the one that's away. She'd come down here like a thundercloud if she thought they weren't doing [what I wanted]. Oh, yeah, oh, yeah, she would come down and say, 'Look! Every one of those things has to be carried out! THAT'S mother's wishes.' Yeah, oh, yeah, she's very, very much aware that people's wishes should be carried out. She's very aware that this is how I feel." Another participant, based on her agent's history expressed her confidence this way, "she's been through this with her own dad, and if she can make those decisions for her dad she can make them for me."

In discussing the trust he placed in his agents to follow his directions and advocate on his behalf, one participant told the story of a situation in which his advance directive had already been utilised. He said, "I know after discussing with my children that my daughters wouldn't have any hesitation of acting on my behalf, too, and supporting her [his wife]....[If a situation were to arise they would be able to say] 'I don't want you to touch him! Leave him alone, he doesn't want you to touch him, so leave him alone.' As a matter of fact when I went in the hospital this time and I was in respiratory arrest my daughter made damned sure [they knew about my directive]....She went out and checked the chart and made sure it's [the directive] on there. You know, and so I don't have that kind of worry."

In preparing an advance directive, there is an ongoing tension between the notions of trust and distrust. As it is defined in the dictionary, as a verb, trust means "to have or place confidence in" (Webster, 1984, p. 736). In making the decision to prepare an advance directive one is in many ways acknowledging a distrust of the healthcare system, of healthcare providers, perhaps even of family members. We are not confident that the 'other' will make decisions about how we want to be cared for that conform to our own wishes. Yet, paradoxically, in preparing an advance directive we trust that others will respect our written wishes. In choosing an individual to act as our proxy decision-maker, we are explicitly placing our trust in them to carry out our wishes.

In my conversations with participants around naming and selecting an agent, I was provoked to consider whom I would trust to make decisions on my behalf. Who do I not want to be part of that decision-making process? The answers to these questions are not self-evident. If I were to make a list of my closest family members and friends and rate them on some sort of trust scale, would that help me to choose an agent? Is trust the overriding consideration in selecting a proxy decision-maker? Suppose I have compiled a list of my most trusted friends and relatives, those with whom I have the closest relationships and get along with the best. What would I do next? How would I open up this discussion about advance directives? Would I call up a good friend and invite her over for a coffee, telling her I want to talk about my future incompetence? Would I phone one of my sisters and say: 'Have you got an hour or two, I want to tell you what I want done if I ever become incapacitated?' I picture them both turning to their husbands and, in unison, saying 'Dianne's gone off the deep-end for sure this time.' Or maybe I should discuss this with my parents. Maybe that would be an opportunity for them to tell me how they want their lives to end as well. But no, they have their own remaining elderly parents, six other children and assorted spouses, ten grandchildren, and still counting. Would they be upset if I did not choose them as my healthcare agents? Either way, I do know that I do not want them to be burdened with additional responsibilities. Parents should not have to contemplate their own children's death. It does not seem right, or good, or natural. Selecting an agent is not an easy task for me. How many others have struggled with this aspect of preparing an advance directive? How can we help individuals to choose an ally?

Chapter 8: Getting It Done

> Reflection on death has taught me that fulfillment in life can only come from defining clearly what we want before death. (Kavanagh, 1972, p. 17)

Gathering Information

The morning after the information session I began the process of completing my own directive. The Alberta government produced a series of pamphlets with information about advance directives, so I phoned the number the lawyer had given us and ordered my free copy. Although there are many ideas running through my mind, I don't start putting anything on paper right away. I am waiting until I have a chance to review the pamphlets. I also want to touch base with my family doctor about my own health status. Although I am pretty healthy now, I have had the occasional angina attack (my dad died of a heart attack as did several of his brothers and sisters), so I want to talk to her about the most likely scenarios that might occur for me given my own and my family's history. I've also been keeping my eyes peeled for articles in the daily paper and in the senior's publications that I receive. So far, I've clipped out a few and tucked them away in the file clearly labelled: Alice Dawson-Advance Directive.

Several weeks go by. My package from the government has finally arrived (that was just the first in a number of delays in completing this project). I am anxious to get started, so I skim through the materials quickly. There is one pamphlet that talks specifically about how to prepare your own directive: "Choosing Now for the Future" the title loudly proclaims. I retreat to my favourite stuffed reading chair (the one I told you earlier that I want to take with me wherever I go) with a cup of green tea to read this brochure more carefully. It *provides the bare bones, a skeleton, so to speak, of what should be contained in the written directive and gives lots of information about points to consider, but it becomes quickly apparent that I will have to do most of the writing myself. I guess I was hoping that there would be a template and all I would have to do was fill in my name. But that would be too easy, wouldn't it? And after all we aren't all the same, we all have different ideas about how we want our life and death to unfold, so now that I think about it that goal was rather unrealistic from the outset. Actually, it's probably a good thing that there is lots of room for personalising your directive. If we all wanted the same type of treatment at the end of life we wouldn't need advance directives, would we?*

Alice is a practical, organised person and has been very thorough in her approach to completing a directive. This thoughtfulness in preparing an advance directive was evident with most of the participants of this study. The older adult's experience of preparing an advance directive, thus far, has been explored through the themes of protecting self and others, facing one's mortality, talking about death, and choosing an ally. In this final chapter of analysis and interpretation, the theme of 'getting it done,' which describes how older adults moved from consideration of preparing an advance directive to actual completion of one, is discussed. In the literature, surprisingly little is written about this aspect of advance directives. Consequently, it is the experiences of the older adults in this study that dominate this discussion.

Participants gathered information about advance directives primarily through three avenues--reading written materials, attending public seminars, and consulting one-on-one with various individuals.

Reading Materials. Participants obtained written information about advance directives from a variety of sources: the government, bookstores, neighbours, and even the Internet. In conjunction with the enactment of the Personal Directives Act, the Government of Alberta prepared the set of brochures that Alice refers to as part of a public education program. A number of study participants had obtained this series entitled, Choosing Now for the Future, which included: a guide to writing your personal directive, the responsibilities of service providers under the Personal Directives Act, and the duties and obligations of an agent in a personal directive. One participant recalled, "the priest here asked me if I would help look after funerals and, you know, talk with the people and help prepare and then be there at the funeral. And I did this for two years. And during this time it came to my attention that there was a lot of grief [conflict as to what should be done such as burial versus cremation] that wasn't necessary for the families. And the whole idea of personal directives was just new, what four years ago, five years ago, and I sent for the books." Another participant said, "I'd thought a lot about a directive even before it was called a personal directive, when they called them living wills. But it just seemed so nebulous until the Government made the Act ongoing so I, it took me quite a while to gather the material. I looked in so many places. As a matter of fact, when I was visiting Florida a friend was going into the hospital and was made to sign a personal directive before he went in." Although the PSDA (Patient Self-Determination Act) requires healthcare organisations in the United States to ask patients whether or not they have an advance directive upon admission into their facility, there is no requirement that individuals must complete an advance directive. This participant, however, perceived that non-completion of an advance directive was not an option for her friend. Did her friend feel coerced in any way? Is this an instance where an individual behaved compliantly in order to not jeopardise subsequent care? How do we balance the provision of information and encouragement of advance care planning without forcing individuals to make decisions about their future healthcare wishes that they may not be ready, able, or want to make?

Attending Seminars. Alternatively, or in addition to gathering and reading information about advance directives, a number of individuals attended educational sessions about end-of-life advance care planning. According to one participant, "the senior citizens group brought a lawyer in. For the life of me, I can't remember his name. I do know he was a lawyer and he was excellent, and I took copious notes. Both my wife and I went. We came home and we followed the instructions he had laid out, and he said you can see a lawyer or you can do it on your own. So we decided to make a living will on our own. And we pretty well followed everything that the lawyer had told us. He gave us the bare bones, it was a skeleton. We didn't copy it from anything, we just did it on our own." Another participant indicated that "I attended a few sessions at different places. I think one was put on by the Good Samaritans Society, I attended that and then we had people come and talk to us. I say we, the church. We also had someone come and talk about inexpensive funerals."

Another participant indicated that she "went to various seminars. There was a whole evening there and they had literature and handouts and everything and that was kind of my start and then I went to, maybe, another couple of seminars that I obviously can't remember, where they had a whole sheaf of paper!" During her nursing career, one participant indicated that she went to seminars on topics related to end of life, but not specifically to any about preparing an advance directive. She said, "I went to a lecture that was put on by the law faculty on euthanasia and so they were talking about euthanasia and sort of clarified to me the difference between legally killing somebody and prolonging their dying, and so that was useful, too. And, probably, one of the things that was the MOST helpful was I went to a workshop on death and dying. And the person who did the workshop had done a lot of work with Kubhler Ross [an expert who has published widely in the area of death and dying]." Around the time of the enactment of the legislation in Alberta, there were public education seminars about advance directives put on by various organisations and individuals including a number by the Office of the Public Guardian. Although there has been some continuation of such seminars, the frequency seems to have decreased. In personal communication with an employee at the Office of the Public Guardian, she indicated that they now only do seminars upon request and that requests had dropped off in recent years. Without a regular schedule of informational seminars about advance directives, one wonders how subsequent cohorts of adults will become informed about them. Should healthcare providers be playing an active role in filling this potential educational void?

Consulting Others. Thirdly, some participants consulted with others, experts and non-experts, prior to or during the process of completing their own directives. Lawyers were most often consulted for expert advice on the legal aspects of preparing an advance directive. One participant stated, "it didn't appear to be something I wished to fill out on my own. I wasn't sure of the wording or anything, so my financial advisor has a number of other professionals that they call on for various things and he suggested a lawyer whom I went to and had one made up." Several also conferred with religious advisors and friends. As one participant recalled, "I went for a walk with a friend and we talked about it. But making the decisions wasn't hard, handling the emotions that were associated with it--that was the hard part, to keep my emotions out of my thinking. And then when I finally did go to a lawyer, talking with him, was really very therapeutic. And he wrote a beautiful living will and said it much better than I think I had. When I went back and read it over he asked if he had captured it [what I wanted] and he had done it even better than I could have." Another indicated, "I immediately got hold of some of the forms and went through them and discussed them with my minister at the time, and he was the one that had signed my first living will. And that would have been many years ago, here and gone. I guess, it would be almost 20 years ago when I did my first living will or whenever they came out. And I have not changed my mind in any way about my future and the older I get the more I am convinced that I do not want to prolong my life by any of the new gizmos that they come up with. I mean they're coming up with things all along and they have all these replacements. I do not feel that I want to be kept alive through a whole lot of medical intervention, I just don't feel that way about my life."

One participant, along with his wife consulted with an individual from the Office of the Public Guardian. In describing his interaction with this individual the participant said, "she's very, very personable and just full of stories and I guess one of the most knowledgeable people in Alberta in this area. She has lots of stories to tell about what happens if you don't have good planning of a personal directive in place. She gave us each about 20 minutes of personal one-on-one time to fine tune what we had developed from all the written material and forms and guidelines that she'd given us. She has her own guideline called 'Workshop on Making a Personal Directive: It's more than a living will.'" Others hesitated to consult individuals outside the family. As one participant stated, "I guess I'm more of the old school of taking care of yourself and doing what's necessary and only bringing one of the so-called experts when you need to, as a last resort almost in some cases." Another said, "I just didn't see any point in involving a lawyer for something if it's not necessary."

As participants talked about how they gathered information about advance directives, it seemed that serendipity played a significant role in their access to information. Coming into contact with key individuals appeared to happen somewhat by accident. I wondered about the many seniors who have fewer resources and more limited access to information. Do they have the same opportunity to consider, plan, and control what happens to them at the end of life? Do advance directives represent another instance of discrimination? I was also struck by how several participants indicated that they tried to keep emotion out of the decision-making process. I found this somewhat ironic. Life and death situations are among the most emotional that one can encounter, yet the expression of emotions is suppressed. Why are we so uncomfortable in acknowledging emotion? How can we embrace and incorporate emotion into our end-of-life decision-making?

Personalising the Data

During my annual physical examination, I mentioned to my doctor that I was completing a directive. She thought that it was a good idea. Our discussion about it was pretty short--she was already at least an hour behind in her appointments. But basically she said that given my history of heart disease, the potential for me to have a heart attack was definitely there. And the statistics she shared with me about CPR (cardiopulmonary resuscitation) were pretty grim. So one of the things that I've included in my written directive is that I do not want to be resuscitated. I actually think a quick death by a massive heart attack would be a pretty good way to go, it would be even better if it happened silently in my sleep. She also said that, given my age, it was unlikely that many of my organs would be in good enough shape to be donated, but I've stated anyway that I am willing to donate any organs that are usable. I won't have any further use for them, so this seems like a reasonable gesture. I've also been toying with the idea of donating my body to science, but I haven't made a decision about that yet. I think the idea *is a good one, but I can't get past the idea of twenty-something young men and women standing over my body and dissecting it piece by piece.*

After gathering general information about advance directives, participants integrated the information into their own personal situations. One participant with a history of breast cancer had a discussion with her doctor about her prognosis. She described her conversation with her doctor like this, "Yeah, I definitely asked her, you know, on a scale of one to ten what are my chances, where do I sit on that scale if ten would be the best outcome. And she told me about a four. So I said, 'Wow! That's not very good!' And she said, 'Well, you asked.' So then we had further discussion." This same participant also asked one of her friends who was a nurse for detailed information about possible end-of-life scenarios. "I just sat her [my friend who was a nurse] down and said, 'I want you to tell me all about this and I want you to tell me what will happen if my heart stops or, you know, I can't recollect everything.' But we went through it considerably." Another participant also had a discussion with a friend who was a nurse. "She gave me a form and asked me to write my impressions down and then we discussed them. There was tube feeding and there was intravenous. There were all three, air, food, and hydration, we talked about hydration quite a bit. And I, you know, we talked about how inhumane it was if somebody was thirsty not to give them a drink." Yet another recalled, "Well, I had some ideas of my own. If I were so ill that it seemed unlikely that I could recover or at least recover completely mentally then I wouldn't want all the ICU things done that would save me. And also I felt strongly that my children shouldn't feel obliged to keep me in their own home if I were unable to live on my own. If it came to that, there are public and private facilities, but I hope they come and visit me."

Several of the participants had the perception that their physicians and other healthcare providers were too busy to take time for lengthy discussions about the future. As one participant stated, "I just handed it to him [the doctor], he was very busy, I'm sure he's filed it and read it, he knows how I feel." Another, speaking of a recent hospitalisation said, "I'm just thinking how busy they were. They had trouble looking after just the physical needs." This perception may be another of the reasons why older adults rarely initiate discussions about end of life with their physicians. Are we as health professionals really too busy to talk about important life and death issues? Or do we use our busyness as an avoidance strategy--a barrier we construct so that we do not have to talk about death?

One of the personal decisions that a number of participants struggled with was the issue of organ donation. Within the Alberta legislation, agents do not have the authority to make determinations about organ donation, so if individuals want to donate their organs it must be specifically and clearly stated within their written directive. For one participant, it was during the preparation of his advance directive that he was stimulated to consider donating his organs. He said, "I've got an organ donor authorisation here [in his directive]. That particular section I had never really confronted before. And it took a little talking with my wife as to whether we should do it and why and so on and so forth, but we've gone ahead with it. But certainly when you think of agreeing to cornea transplants and other organs, it's not pleasant, but, you know, it's something you can face. You don't have to put it in if you don't want to but we did....If one of my family needs a kidney and I'm still around and it's compatible I've given them the okay to do that." Another participant indicated that organ donation had been discussed in her family previously. She said, "we'd have the discussion on donating organs if it came on the news, cause we'd listened to the news as we were eating our supper. And so we were always very open in these situations. And because it's easier as the time comes, everybody knows what to be prepared for. The children are used to knowing that if something happened to mom and dad, say that it was at the point where the organs would be used or whatever, it's not a surprise to them." Expressing his opinion on organ donation, one participant said, "everybody should, if they can, donate their organs if they die. I can't because medically my organs are shot. But to me this is what you do. You've got your organ donor card, you sign that, you've got the directive, you sign that, you've got your wallet. Then your family knows what's to happen." One individual had decided to donate her body to science indicating that "I have been obese all my life and if by taking my body apart they could find something that caused this--perhaps there is research that could be done." For the older adult, organ donation is a phenomenon that did not exist during their childhood or early adult years. Does this impact their awareness or understanding of the process of organ donation? Do many think they are too old--that none of their organs would be of value? Should organ donation be addressed separately, outside of the context of an advance directive? Is it perhaps lost among the many other end-of-life decisions that can be addressed in an advance directive?

Despite being an aspect of preparing an advance directive that seems quite important, obtaining specific information about their own health status and the most likely scenarios that they might encounter given their past medical history is something that only a few participants pursued. Singer (1995b) suggests that this is a role for the person's own doctor. He suggests that "in his or her role as health educator, the doctor may raise the issue of advance care planning with his or her patients...and direct the patient to the appropriate tools to support the process. The doctor could also tailor the information about health states and treatments to the person's own particular health situation" (p. 6-7). How can older adults and their physicians be encouraged and supported to engage in such discussions?

Writing and Rewriting (Typing and Retyping)

I'm a relative computer novice, but I have been enjoying learning how to use the computer, so I figured typing up my directive was a good opportunity to practice my word-processing skills. This way, too, I could easily access and update the document and make changes and print off copies whenever I needed them. My directive has evolved over time and now has three sections. In the first section, I have included my statement of values. In the second, I have included written directions. And in the third, I have named my agents. Although it's only a little over a page in length, it was the first section that took me forever to write (and that had nothing to do with my pathetic typing speed). I'd keep going back, changing a few things, setting it aside for a few days (that sometimes stretched to weeks) and then rereading and rewriting some more, until it felt right. It was very time consuming and emotional, at times, too. On more than one occasion, as I sat *in front of the computer, I had to stop because tears blurred my vision. Preparing my directive made me think about my husband and his death. How can I explain to you what it feels like to lose your best friend, your lover, the father of your children--the pain is unbearable, it hurts so deeply. And then as I take a few deep breaths, the anguish passes, and I'm able to carry on. It was really hard for me to try and sum up on a page or two what I was all about, but I persevered. Let me read for you what I came up with for the first paragraph of my personal statement:*

> I have tried to live my life with dignity and I need to be allowed to die the same way. Death, to me, is a reality as much as birth, growth, maturity and old age. It is the absolute certainty of life and for me, I think of it as life's greatest adventure! If I am faced with an endlessly painful end, I insist on my right to die how and when I wish. I need to die with some dignity left intact, without inflicting prolonged distress on my children, or indeed myself!

I think from this you can get the gist of my thoughts on life and death and what I believe is important. I think you have to put some thought into writing your own personal statement, to express your feelings--that may be the most important step of all.

When it came to deciding what to include in the written portion of their directives, participants used a variety of approaches ranging from one individual who simply signed a living will form he purchased at a bookstore to others who spent hours, days, and weeks revising the content. A sample advance directive representing the type of content most participants included is presented in Appendix G. The appointment of a health care agent, information about how and when the directive comes into effect, the powers of the agent, personal decisions, and access to documents and information were topics frequently addressed. As one participant said about preparing her written values statement, "I wrote and I wrote (laughs), and I wrote and I crossed out and I changed and I did this and I did that and it took me, probably, weeks." Some individuals included very specific individualised instructions in their directives. For instance, one participant had family members who were alternative therapy practitioners (e.g., Reiki). Because of her religious beliefs, this participant was adamant that she did not want to be the recipient of any of these alternative modalities. She said, "I have that quite detailed in my personal directive, because he [her agent] would not be able to control [the actions of] the rest of the family members without proof that it's what I want."

Several expressed satisfaction in the process of authoring their own advance directives. As one said, "I did this myself. I have it on my word processor. The doctor and lawyer seemed to think that it was okay. He never changed it. He used what I had written." Within the context of advance directives, there is a parallel that can be drawn between the terms author, as a writer or the originator of an event, and authority, as the power or right to enforce obedience (Barber, 2001). In authoring their advance directives, individuals are exercising their autonomy and legal right to control what happens to them. Given the potentially significant outcomes related to the enactment of an advance directive, one operates on the assumption that the written statements contained within an advance directive reflect the thoughts and ideas of a well-informed author. When an individual or an agent presents with an advance directive, how do we ascertain whether the statements are those of an informed author?

I think back to another of my attempts at authoring my own directive. I retrieve from my burgeoning file of information another example of an advance directive. Maybe it will capture the essence of what I want to tell the world about the way that I want my life before death to unfold. Maybe.

> I, _Dianne Godkin_, of _Edmonton_, being of sound mind, make known my wishes. If the time comes when I can no longer take part in decisions for my future, I have chosen one or more option(s) as indicated by my initials. If I have an incurable condition, as determined by two or more physicians:
>
> _____ 1. I direct that I be allowed to die naturally without medical intervention.
> _____ 2. I direct that I be allowed to die with comfort measures such as nursing care and relief of pain.
> _____ 3. I request no cardiopulmonary resuscitation nor admission to an intensive care unit.
> _____ 4. I request to live my last days at home rather than in a hospital if this is agreeable with my family.
> _____ 5. I donate any of my tissues that are of value for transplants.
> _____ 6. Other
>
> These statements are made after careful consideration and are in accordance with my strong convictions and beliefs. I have asked ____________to be my healthcare agent to make treatment decisions on my behalf. This permission shall remain effective in the event that I become incompetent or unable to make decisions for myself. If my healthcare agent is unavailable, another person will be identified in accordance with local legislation.

This seems pretty straightforward. All I have to do is put my initials beside the statements I agree with. I read the first one: I direct that I be allowed to die naturally without medical intervention. What exactly does this mean? What is a natural death? The only natural death that I can think of is one that occurs as a result of old age, where your heart just tires out and you die quietly in your sleep. But I am not old, at least not that old. And if I die in my sleep, I will not need an advance directive. I go on to number two: I direct that I be allowed to die with comfort measures such as nursing care and relief of pain. Is nursing care a comfort measure? How do I explain the grimaces of pain on the patient's face, as I, a nurse, slowly turn her from side to side to prevent the development of pressure sores? How do I explain to a young boy that this injection that causes him to hurt is necessary? How do I tell family members that their loved one is deceased? I scan down the list to number four: I request to live my last days at home rather than in a hospital if this is agreeable with my family. Yes, I think I'd rather die in familiar surroundings than in a cold, sterile hospital room, but my family all live at least 3000 kilometers away. Would I expect them to come and stay with me until I die? I have good friends who live close by. Would I expect them to put their lives on hold to care for me on my deathbed? The answers are not clear to me. Some choices others might have, I do not. The written words of others do not adequately reflect how I want my life before death to transpire. I will have to use my own words. But I am too tired now and my head hurts, I cannot think about this any more today. I close the document, not even bothering to save what I have typed. I will try again tomorrow. But tomorrow never seems to come. How is it that this day has arrived for others?

Historically, there have been many rituals associated with death and dying. Over time, many of these rituals which were often associated with religion have disappeared; many people are no longer affiliated with a religious faith

(Anderson, 2001). According to Anderson (2001), "rituals have the ability to bring people an experience of something greater. They create a safe space and time in which we can touch the deeper issues of our existence. They have the power to bring to the surface and resolve very deep feelings and unnamed blocks that have been buried in our unconscious" (p. 40). For the participants in this study, advance directives seem to have allowed participants to look inside themselves and to reflect upon some of life's greatest questions. Is it possible that preparing an advance directive is an end-of-life ritual for the 21st century?

Keeping it Simple

I've kept my written directions fairly simple and brief, because I don't want my children to be bound too tightly by what I've written. For example, although generally speaking, I don't ever want to have a feeding tube, I haven't written that down, because a situation might arise where a feeding tube would be appropriate for a short term and I would recover fully if this was done. But my children know that under most circumstances, I do not want a feeding tube. Based on my conversation with my doctor, I have included a statement that I do not want to receive cardiopulmonary resuscitation if my heart stops beating as a result of heart disease or some other traumatic event. I have also indicated that I do want to receive pain medication and other comfort measures, so that I can die as comfortably and peacefully and as pain-free as possible. If I have a treatable condition (something like a broken hip or pneumonia) and there is a good possibility that I will be restored to my previous health in a relatively short time, I do want to receive the full range of possible treatments (that might include *hospitalisation, surgery, or antibiotics). One of the things we talked about a lot at our family meeting was the kind of treatment I would want if I was terminally ill. There's no question that if the prognosis is grim, I don't want to be a burden on the system or my family. In that situation, the less attempts at heroics, the better--I firmly feel that in this sort of scenario, less is better. So I've written it in my directive this way: "If I am terminally ill and, in the opinion of my physician and other consultants, have no known hope of recovery, no matter what is done, I do not wish my life to be prolonged by artificial means or intrusive medical treatments." And as I mentioned before, I've also included a statement about donating any usable organs. Along the way as my advance directive started to take shape, I kept asking myself the questions: "Does this do what I want it to do? Will it perform the way I want it to perform?"*

Study participants sought to make their directives straightforward and simple. As one participant stated, "well the main directive is pretty basic but areas like 'do not resuscitate' and what type of accommodation I would like and all that, we didn't put that down in the directive because we were advised not to for a number of reasons. That's the simplicity of our document." Another participant referred to her neighbour's directive as she completed her own. As this participant said, "she gave me some of the stuff that she'd had completed and I just sort of looked at that and whatnot. But mine just is a one-page thing and it just states my agent and that's it. I haven't gone beyond that....I think one of the reasons I've kept it simple at this stage is I don't feel I'm going to need it for a while yet, you know, and it's subject to change." Another participant tried to keep the language she used simple and clear. She said, "well, again, like I say, it's not written out in any scientific way but, to me, my statement is adamant enough and my agent knows me well enough and knows any situation that could arise." Keeping it simple is another of the paradoxes around advance directives. How can a document that purports to describe how one's death and dying is to unfold in any way be construed as simple?

Following the Rules

I thought about taking my advance directive to my lawyer to have him review it, but in the end I was satisfied that I had followed all of the regulations. I didn't see any sense in spending money if it wasn't required. Actually I think that the ability to complete an advance directive without legal counsel is great, especially for seniors on a limited budget. It means that anyone can complete a directive, it's not limited to only those with the necessary financial resources. If you want to do it, there really is no excuse not to complete a directive.

Unlike Alice, some participants were concerned that their directives might not conform to the legal requirements and thus included a lawyer in the process. As one participant said, "So after we did decide [to prepare a directive] I contacted my lawyer and I, you know, had it prepared, these documents. And, you know, once they were prepared and signed I gave each of my children a copy." Another participant stated, "well, I let the lawyer tend to the necessary tickety-boo stuff, but I wrote a personal statement that expresses my feelings, my wishes, and how I want to be taken care of if I become terminal....I had asked him initially 'Essentially what has to be in a directive?' and he said, 'The best thing for you to do is to make your personal statement,' he says, 'so that it's very clear as to what your wishes are and you're not waffling around.' And if you want non-care to a certain degree or whatever, you have to make your thoughts known. So this is what I hope I've done."

Having a lawyer involved gave some participants a sense of security. As one participant stated, "I felt very secure knowing that this was the newer and officially acceptable way of having my wishes being put, you know, put to paper and signed. So I felt much more secure knowing that this was something that the government had initiated and would accept." Several participants considered completing their advance directive as part of a package of documents required to adequately prepare for end of life that included estate wills and power of attorney. As one participant reported, "when we went to have our wills updated, we asked him about the living will. He said it was called a personal directive. And he did it, it's very simple, simple rules, we more or less told him what we want, like not prolonging life, that we want to be comfortable. And so we had that done. Not hoping we would have to use it, but we did, and it was very helpful and very comforting not only for me but for our son."

Reflecting on the Process

I remember the evening that I finished composing my written directive, including my statement of values. It was a cool November evening and already long past dusk when I finally printed a copy and shut down the computer. I felt great! It made me feel good that it was on paper and I'm happy about it, that it's done. I think I feel more comfortable because it's in place. Just like a person feels *more comfortable and has a sense of security once their will is finally figured out and written up. The time to completion, from that first meeting in February when I made the decision to this day, has been more than eight months in length. I remember thinking at the time of the information session, that this was a simple job for an afternoon or evening. I was a bit off on that prediction. It wasn't that I spent all that time between February and November working on my directive, but I found it was a process that couldn't be rushed. I needed time to gather information and facts, to talk to my children, to talk to my family doctor, to write and rewrite, and perhaps most importantly of all, to sit quietly and think and reflect. After it was finished, there were just a few minor housekeeping items to attend to--making and distributing copies for my children, my family doctor, my minister, my lawyer.*

During our conversations, one of the topics that we discussed was how participants felt upon completion of their directives. One of the most frequent responses was simply relief that "it's done." As one participant said, "well, what struck me was once it's done, that's it." Another said, "that's what I want and I'm happy about it, that it's done....Yeah, that's right, I don't have to prepare any more, it's done, yeah." Another common response of participants was that completing an advance directive provided them with a sense of comfort. One participant said, "it just made me feel great. I really feel comfortable and pleased that we had it all done. Yeah. Actually, yes, I guess you could say security. Because particularly at that time I was running into another operation and that, our wills were done, my directive was there and I went into the operation feeling, 'well, I've done everything I can, now they do what they can, if they can't do it that's fine.' You know, I don't know what happens after you're dead but that's it, you know. So I felt very comfortable, very comfortable." Another common response was that it made participants feel good, positive. "Yeah, it made me feel positive that I had taken care of myself and my own wishes, while I am still competent to make those decisions," said one participant. Another said, "I felt good. This was the way I wanted the world to unfold in the future and it was down on paper now and they'd better not ignore it."

In reflecting on the process of completing a directive, one participant, like Alice, remarked, "well, initially you think the directive is a simple thing. You just write down, 'I don't want to be resuscitated, don't do a damned thing, ok.'" Another expressed, "I think you have to put some thought into it. And I think you have to express your feelings and make that personal statement. I think that personal statement is the most important thing of the whole business." Yet another said of the process, "it was an interesting one. You know, being able to do it, to try to think about what things would be."

There is the suggestion in the literature that "participating in discussions about personal goals about future care may alleviate some of the frightening uncertainties related to the disease and the patient's prognosis" (Neumark, 1994, p. 771). Additionally, one author states that "involvement in choice-of-care decisions is critical to many patients for whom maintaining a sense of control is vital to their quality of life" (Griffin, 1993, p. 39). In the quote by Kavanagh (1972) that opens this chapter, he suggests that delineating what we want to happen prior to our death is a prerequisite to a fulfilling life. Most participants expressed an unwavering certainty about controlling how their end of life would unfold, something that is inherently uncertain. Another paradox is that the completion of an advance directive as an expression of one's autonomy cannot be done autonomously. If one does not involve others, at least to the extent of informing them that a directive exists, where it is located, and its contents, there is no mechanism for the individual's wishes to be respected.

Preparing one's advance directive is a relatively unique experience. There are few situations in which we consider our wishes for our projected future selves in such a systematic manner. Additionally, there are few undertakings that have the potential to impact one's life and death in such a permanent and personal way. Completing an estate will is somewhat similar in that one must face his or her mortality, but differs in that it is only enacted after the death of the maker. As well, its impact is felt only on those left behind and does not directly affect the maker. Planning for retirement also has some similarities. In planning for their financial security, individuals take into consideration their values and priorities in life. However, it does not necessarily require people to confront their own mortality. Advance directives implicitly require individuals to do both--face their own mortality and imagine their future and responses to unforeseen situations. Are these demands humanly possible? Perhaps it is because both of these tasks are difficult if not impossible for many, that the rate of completion of advance directives is relatively low. Can completing an advance directive really put one's mind at rest about his/her pending death? Is this a false sense of closure, wishful thinking? Maybe. Are there any guarantees that preparing a directive will help one to die well? Perhaps not. But does it really matter? Could it be that the process of preparing an advance directive is more important, more meaningful, more comforting than the actual outcome of a death that precisely mirrors one's prospective wishes? Perhaps it is the opportunity to reflect on one's life and to share those reflections with family and friends that is of ultimate value and significance.

Looking Toward the Future

I know that there are lots of people who attended the session at the church who haven't yet written their own directives. And I think that is unfortunate. What convinced me to do it, I think, were the compelling, and often tragic, stories where I heard about what can happen if you don't have good planning in place--stories that the lawyer shared at the information session, stories that my friends told me about people they knew and loved, and probably most of all, my own personal recollections of my husband's death. I'd be naïve if I thought that completing an advance directive would guarantee that my death will unfold exactly as I would like it to, that I will be able to control everything that happens to me. And that's okay. My directive is important to me, but it's probably even more important for my children. I wanted to make it as straightforward and simple as possible for them. I want them to be comfortable. I don't want them to have to face challenges at a time when it's already challenging enough.

I think completing a directive improves your life in other ways, too, ways I'd never expected. As you think through these things it brings you face to face *with your own mortality and the number of days you might have left. Hopefully it will make those days that are still coming better days--more valuable days and better lived--and relationships better treasured than they might have been otherwise. I look forward with great anticipation to the days that lie ahead--to receiving the bouquet of dandelions freshly picked by my youngest granddaughter, to learning the steps to the latest line dance, to celebrating life.*

As our conversations drew to a close, I often asked participants if they had any parting thoughts or additional comments about their experience of preparing an advance directive. On a number of occasions, within their final words was a message of encouragement for others to "get it done." One participant said, "I've enjoyed talking with you and sharing things with you. Parting thoughts, well, I think everyone should have a directive and even the young people who are invincible, you know. Because what you really want is not always discussed as much as it should be." Another who had completed his directive shortly after finding out about their existence said, "I haven't been putting this off because we just discovered it and did it, but if people do know about personal directives and aren't doing it, I think they're dragging their feet." And still another said, "I think everybody should know about it and everybody should discuss it with their children or if they don't have children, their partner, or if they don't have a partner, a very close friend. And if they're lacking all of that then their minister if they're religious, and if they're not I kind of figure, their lawyer otherwise (laughs). But I feel that everybody should give some thought to their final days and what condition they might be in during those final days and what they would like to happen to them should they not be able to say it then." How can we help others to get it done? How can we help ourselves to get it done?

Chapter 9: Drawing Out Conclusions and Implications

> We no longer completely trust the system or the professionals who handled our end-of-life dilemmas....We have lost sight of how life could, and should, end. It is time to give back to our dying a human, or a humanly understandable, face. (Ahronheim & Weber, 1992, p. 14, 27)

Introduction

Since I first began conceptualisation of this research project, there have been a number of studies completed and papers published suggesting that advance directives have failed to live up to their original expectations (e.g., Ditto et al., 2001; Prendergast, 2001; Teno, Lynn et al., 1997). At the time of their introduction, advance directives were considered by many to be a panacea for resolving end-of-life decision-making dilemmas that were occurring on an increasingly frequent basis. New life-sustaining technologies, along with rising health care costs, an ageing population, raised consumer awareness about health matters, and increasing health care litigation being among the factors contributing to this rise. It was thought that preparing a directive would ensure that appropriate and individualised end-of-life treatment and care would be provided. It was thought that everyone, once they were informed about advance directives, would immediately sit down and prepare one. Advance directives were also thought to be financially advantageous as they would result in significant cost-savings for the healthcare system. Although the implementation of advance directives has not consistently met all of these lofty goals, the analysis and interpretation of the data in this study lead me to suggest that there are other benefits to completing an advance directive that have not been adequately appreciated or examined. The findings also provide insight as to why some of the approaches to implementation of advance directives have been relatively ineffective at either increasing completion rates of advance directives, or more importantly, improving end-of-life care. In this final chapter, I begin by outlining, in the form of summary statements, the major findings of this study. Although knowledge generated through an interpretive inquiry is not generalisable as participants have not been randomly selected from the population, the findings provide much food for thought and point the reader in certain directions. The implications for practice, education, policy, and future research that flow from the findings are described. I conclude by suggesting that completing an advance directive is a means through which one may apprehend or come to know death.

Summary Statements

Protecting Self and Others.

In this study, the older adults' motivation for completing an advance directive primarily stemmed from the following: 1) *protecting one's self* from the inappropriate use of life-sustaining technologies, overly zealous healthcare professionals, and pain and suffering at the end of life, and 2) *protecting others* from the burden of making difficult end-of-life decisions, paying for unnecessary expenditures, and feeling helpless. These older adults were hopeful that preparation of an advance directive would minimise conflict and promote positive relationships among family members and help them to remain friends during the end-of-life decision-making process and following its completion. Protecting children in this way protects family relationships for the future.

Facing One's Mortality. Facing one's mortality was an integral aspect of preparing an advance directive for these older adults and contributed to their ability to appreciate and live life to its fullest. Reflecting upon their own life and death was for most of these older adults a positive and fulfilling experience.

Talking about Death. Talking about death was not always easy or comfortable, but it was an important component of preparing an advance directive for these older adults that resulted in the strengthening of family relationships, the sharing of values and beliefs about end of life, and a renewed valuing of life, itself. Talking about death was at times an emotionally charged experience for these older adults and those they chose to talk to about their death.

Choosing an Ally. Choosing an ally, an individual(s) to be one's spokesperson and advocate, was a complex and important undertaking that required a thoughtful assessment of persons within these older adults' sphere of relations. Older adults chose individuals with whom they had a close relationship, who were readily available, and whom they perceived as level-headed and capable.

Getting It Done. Getting it done, or in other words completing an advance directive, was a time-consuming, thought-provoking endeavour for many of the older adults in this study that required awareness, information, and careful and reflective contemplation. Completing an advance directive was not accomplished autonomously. Healthcare providers were conspicuously absent from all aspects of the older adults' process of completing a directive. The larger community, however, including the media, churches, and senior's centres played an important role in raising awareness of advance directives and transmitting information.

Integration of Findings into Healthcare Practice

One of the most striking findings of this study is the relative invisibility of healthcare providers throughout the older adult's process of completing an advance directive. Emanating from the outcomes of this study, with additional support from other reports in the literature, a number of implications for healthcare providers are outlined in this section. The implications are relevant to a variety of healthcare professions including nurses.

Examine One's Own Attitudes and Beliefs About Death. In 1997, McKenzie made the following suggestion to physicians regarding advance directives: "The first practical advice would be 'physician know thyself.' I have a personal directive for myself and I review it every year....If you have not written a personal directive for yourself or assisted a close family member in doing so, you will discover some blind spots in terms of your personal biases" (p. 3). Through conducting this research and in attempting to prepare my own advance directive, I learned that completing an advance directive is not necessarily a straightforward or simple task. Although not every healthcare provider may wish to prepare an advance directive, the findings of this study confirm that there are benefits to be gained for one's self and others from examining one's own attitudes and beliefs about death. Anderson (2001) restates this notion more emphatically indicating that health care professionals must "resolve their doubts [about death] to help patients resolve theirs" (p. 275). Shook (1992) concurs stating that "the informed and knowledgeable professional has evaluated personal issues of life and death and feels comfortable and confident when informing patients and families about their rights" (p. 34-35).

Study participants believed that many of the healthcare professionals with whom they had come into contact perceived of death as the enemy and that healthcare professionals, at times, had difficulty accepting the deaths of their patients. Without exception, participants shared traumatic stories about family members or friends who had suffered at the end of life, they believed, at the hands of healthcare professionals whom had provided treatment that in their estimation was unnecessary and even harmful. There is an urgent need for healthcare professionals to examine their own attitudes and beliefs about death and to consider conceptualisations of death other than that of the enemy. There is a need for healthcare professionals to hold simultaneously in a delicate balance both life and death as valuable outcomes. The findings suggest that exploring one's own attitudes and beliefs about death may result in a greater appreciation of life.

Be Informed and Involved. As reported in the literature, and reaffirmed by participants in this study, the involvement of healthcare professionals in the completion of advance directives is limited. There is a general consensus by both healthcare providers and older adults that the input of healthcare professionals during the process of completing an advance directive can be both helpful and substantive. Participants in this study who had talked with a friend or family member who was also a health professional (most often a nurse) valued their knowledge and expertise and found what they said to be helpful in the process of completing their directive. Participants asked questions about the types of treatment they might be expected to receive at the end of life and the likelihood of successful outcomes following their application. Some also had queries and concerns about areas such as nutrition and hydration and their relationship to comfort and suffering during the dying process. It would seem that health professionals would be the most appropriate persons to provide this type of knowledge and information.

At a recent in-service to hospital staff about advance directives, one of the nurses in the group indicated, and others nodded in agreement, that nursing staff rarely looked at patients' advance directives when copies were placed on their charts. I found this both curious and alarming. Healthcare providers are legally and ethically bound to provide care that is in accordance with an individual's wishes as outlined in an advance directive. The finding in several studies that care provided at the end of life was inconsistent with what patients requested in their advance directives is less puzzling given this anecdotal information. It is unclear how widespread this practice of overlooking advance directives by healthcare professionals is, but it certainly requires further exploration. When I asked the nurses why they did not look at the patients' directives (much less engage in a discussion with patients about the contents of their advance directives), there were several responses including: "not enough time," "documents too long and complicated," and "the social worker deals with directives, not us." When an individual presents with an advance directive, it would seem to offer an excellent opportunity for healthcare professionals to enter into an open and informed discussion about death and dying with their patients and to clarify any unclear statements that might be contained in their directives. Entering into such a discussion may reveal concerns and/or misconceptions that a patient has about their own end of life and these could be proactively addressed. Nurses, as they generally have the most sustained interaction with patients, are well-positioned to take part in such discussions and to act as patient advocates as needed (Perrin, 1997).

Healthcare professionals should be concerned about the delegation of the preparation of advance directives to a singular profession either within or outside of the healthcare system. Currently it would seem that lawyers, social workers, religious leaders, and public guardians are playing pivotal roles in the preparation of these documents. Each of these professions brings an important and beneficial perspective to the process. However, owing to their lack of clinical background and education, one wonders whether persons in any of these professions are qualified to counsel patients about end-of-life treatment issues. It is unlikely that they are familiar with the types of care and treatment specific patients might expect to receive at the end of life and the likely prognosis given their individual health status and medical history. Singer (1995b) suggests that advance care planning is neither a medical or legal process, but rather "a social process that occurs in families, and the role of professionals should be to respect, support and facilitate it" (p. 8). For the participants in this study, it would seem that all of these elements--medical, legal, and social--were important aspects of completing an advance directive and that for the best outcome each should be attended to in the process. Instead of limiting their role to respecting, supporting, and facilitating the process of completing advance directives, healthcare professionals ought to be involved in initiating discussions about end-of-life care, providing information that is appropriate, relevant, and individualised, and regularly reviewing advance directives with their patients to ensure that the contents remain current and applicable. Above all, healthcare professionals must be respectful of the time and thought that individuals have put into the completion of their advance directives. Ignoring these documents because one is too busy, believes it is someone else's responsibility, or does not agree with the concept or contents of the directive is not an acceptable response, ethically or legally. If healthcare professionals have concerns about the instructions contained within an advance directive, they have an ethical and legal responsibility to enter into a dialogue with the patient or agent in order to achieve a satisfactory resolution for all. Individuals trust healthcare providers to abide by their wishes. Erosion of this trust has negative implications for everyone.

Reconceptualise Purpose of Advance Directives. Advance directives have been described as the solution to the problem of making decisions about life-sustaining treatment for incompetent patients (Singer, 1995b). This conceptualisation, I would argue, fails to acknowledge the complexity of both 'the problem' and 'the solution.' I would agree with Singer (1995b) who states that "advance care planning is not about legislation, lawyers and doctors, but rather about relationships, communication, and families" (p. 9). For many participants in this study, there were no lawyers or doctors involved in the older adult's process of completing an advance directive, but references to relationships, communication, and the involvement of families were prevalent and considered of paramount importance. For the participants in this study, completing an advance directive was not just about making end-of-life treatment decisions in conditions of incompetence, it was about reflecting upon the existential questions of life and death.

In response to published studies that report a relatively low completion rate of advance directives despite implementation of a number of different and often intensive programs designed to increase completion rates, Fins (1997) suggests that advance directives, in and of themselves, are not to blame. He suggests that "shifting responsibility away from ourselves indicates our own denial of death and avoidance of much needed dialogue at the bedside of dying patients. It is too easy to scapegoat advance directives when it is clear that advance directives are going to be only as good as our efforts to obtain them [and use them]. Advance care planning will become effective only when we are more comfortable discussing end of life care and when we understand the cultural determinants that have made American medicine so hesitant to accept human finitude" (p. 520). One of the messages that I believe is implicit within Fins' response is that we should conceptualise advance directives not as a quick fix, as an effortless solution to a simple problem, but rather we should consider their development and implementation as part of a consolidated and comprehensive approach to caring for patients at the end of life, one that takes time and thoughtfulness. Certainly for participants in this study, completing an advance directive was by and large a thoughtful process that unfolded over time, in some cases months and years.

Make Room for Discussion of Death. A number of studies have indicated that older adults are willing participants in discussions around end of life and advance directives, however, healthcare professionals may need to be the ones to broach the subject. By introducing the subject of advance directives, healthcare professionals legitimise the topic as one worthy of discussion. Individuals, including those in this study, often perceive that health care professionals are very busy and do not have time to enter into such a discussion about the future. Several participants in this study expressed appreciation for the opportunity to talk about their experience of preparing an advance directive. One participant near the end of our conversation stated, "when I read the piece of paper that mentioned your exercise and what you were going to be investigating I thought what am I going to say. I didn't think I'd have anything to say and obviously your questions are bringing out deeper things." As Heydemann (1997) suggests, "personal directives allow us to converse about dying, to share our thoughts and feelings about death, and to take responsibility for very essential life/death decisions at a time when we are fully capable and in the midst of life itself....They will foster partnerships between family members and health care providers, so that we can walk more comfortably into the future" (p. 6). Although this recommendation requires a time commitment by health professionals, there may be many long-term gains to be made by engaging in such discussions sooner rather than later. Although difficult to measure, early and ongoing discussions may, in the end, actually save time. If healthcare providers have an understanding of the values and beliefs of a patient, when the patient becomes incompetent and unable to participate in the decision-making process, healthcare providers may not need to spend time finding and interviewing multiple family members and friends in an attempt to determine the patient's desired level of care. Additionally, if a patient has clearly indicated for instance that they do not want to be given any chemotherapeutic agents in the context of terminal illness, it would not be necessary for healthcare professionals to undertake time-consuming reviews of the literature and other sources to establish a chemotherapy treatment regime that would be applicable to this patient's medical condition.

Making room for discussions about death requires that healthcare professionals see patients as individuals who are situated in a particular context and web of relations. From my conversations with older adults about advance directives in this study, it seems important for healthcare professionals to: 1) provide an opening for discussion of end-of-life issues, 2) communicate sensitively, 3) be at ease when talking about death, 4) be comfortable with emotion, 5) maintain a sense of humour, and 6) minimise the impact of ageist attitudes. For many seniors who are alone and separated from their families, healthcare providers may be the only persons with whom they have regular contact. With this group of isolated older adults, the importance of initiating discussions about death and dying is further accentuated. Healthcare professionals who are uncomfortable talking about death have a responsibility to seek out opportunities to develop their knowledge and skills in this area.

Foster Healthcare Provider-Patient Relationships. When an individual presents an advance directive during their hospitalisation, it may symbolise, as the opening quote for this chapter and participants' stories implied, their distrust of healthcare providers and the healthcare system. Participants in this study expressed a concern that healthcare professionals have been socialised to act in a certain way to sustain life at all costs that is in opposition to the participants' personal beliefs that generally privileged quality over quantity of life. Healthcare professionals need to be aware of the possibility that patients are wary of their motives and they may need to work hard to re-establish a trusting provider-patient relationship. When the general public is asked to rate their level of trust of a number of professions, nurses are among the most highly rated (e.g., the January 1997 POLLARA Public Trust Poll reported that 79 percent of Canadians trust nurses a lot). As nurses are often in the most direct contact with patients, they are in a good position to foster the development of trusting relationships between healthcare providers and patients. In a number of intervention programs to increase completion rates including the SUPPORT study, an element that was missing from the intervention was the notion of fostering relationships. Instead there was an emphasis on information giving, answering questions, and documenting results of discussions (often by a stranger who was not involved in the patient's ongoing care). In this study, in the process of completing an advance directive, participants involved people with whom they had an established and long-term trusting relationship, most often family and friends, sometimes lawyers and religious leaders, and less frequently a nurse or physician.

Support Family Involvement in the Process. The importance of family members in the process of preparing an advance directive and in the role of agent was central for study participants. Kuczewski (1996) suggests that "interpreting our values usually involves the feedback of those close to us and often the advice of persons with professional expertise....If we assume that values do not simply emanate from some ineffable core within us but take shape through interaction with our environment, the family is a natural part of this process" (p. 34). Studies have shown that "involving the family in the execution of the documents, while giving priority to the older person's preferences, alleviates the fears of future family conflicts" (Winland-Brown, 1998, p. 40). As healthcare professionals we have a role to play in supporting family members through the process and encouraging intergenerational dialogue. Although not directly addressed in this study, there is some evidence in the literature to suggest that agents may have difficulty and meet resistance in carrying out the wishes of their loved ones. Providing agents with additional information to assist them in negotiating the healthcare system might help to alleviate some of these potential difficulties. Healthcare providers also have a responsibility to provide agents with relevant information about their loved one's medical condition and treatment options, allow agents to share information about their loved ones with healthcare practitioners, and provide an environment that is supportive and free from coercion.

Develop and Implement Best End-of-Life Practices. In addition to supporting those individuals and their families who enter into the process of completing an advance directive, healthcare professionals have an ethical responsibility to improving end-of-life care in its entirety. The major concerns around end-of-life care raised by study participants were the control of pain during the dying process and the appropriate use of life-sustaining technologies. Thoughtful practice and continued research into the provision of end-of-life care, including pain management, is warranted.

Educational Considerations

Professional Education. The findings of this study suggest that there is a need for education around death and dying in both healthcare professional education programs and in continuing education programs for practising healthcare professionals. There also appears to be educational needs around the purpose and utilisation of advance directives, including healthcare provider responsibilities and obligations. Incorporating an educational component that assists individuals to examine their own attitudes and beliefs about death, including facing their own mortality, has been shown to be a worthwhile endeavour for both nursing students and nurses (Deeny, Johnson, Boore, Leyden, & McCaughan, 2001; Mok, Lee, & Wong, 2002). Educational strategies such as problem-based learning approaches using realistic scenarios and drama have been effective in creating more positive attitudes toward death and increasing self-awareness (Deeny et al., 2001; Mok et al., 2002). Although an analysis of current educational practices in various health professions around death and dying and advance directives is beyond the scope of this study, the findings of this research and other literature suggest that what is currently being taught is insufficient for providing optimum end-of-life care.

Public Education. The older adults in this study were exposed to or sought out a variety of opportunities to educate themselves about advance directives. There is some evidence to suggest that these educational opportunities have declined in recent years. As many, indeed most, older adults are in contact with healthcare professionals several times a year, healthcare professionals are well-positioned to help older adults, especially those with limited resources, financial and otherwise, access educational materials and opportunities to learn about advance directives. In most studies that used educational interventions in an effort to increase the completion rates of advance directives, the information presented to individuals was given by persons unknown to them, in standardised formats, with limited opportunity for one-on-one consultation, and rarely with follow-up activities or interaction. The lack of both continuity and individualisation of material is problematic. Given the continuing nation-wide shortage of organ donors, one of the items that ought to be included in any discussion of advance directives is the question of whether or not individuals wish to donate their organs. Only a few study participants had addressed this item in their directives, but those participants who had thought about organ donation and discussed it with their family members were willing to donate their organs. Attending to this matter is particularly important in the context of the Alberta legislation in that it does not allow agents to make decisions about organ donation unless they have been specifically addressed in the advance directive.

Policy Applications

Government Policies. In legislation regarding advance directives, including the Personal Directives Act in Alberta, there is no obligation requiring "the physician and the patient to work together prospectively, in anticipation of possible hospitalization or admission to a critical care unit, to identify the patient's beliefs and values concerning terminal care, quality of life, aggressive treatment to sustain life, interests of family members, and other issues" (Doukas & McCullough, 1991, p. 145). Policies which encourage and support routine discussions about advance directives between healthcare providers and patients would be potentially beneficial and should be developed and evaluated.

Institutional/Organisational Policies. Within organisations and facilities, there is a need for policies which address how advance directives are discussed, stored, and implemented. One study participant's experience with nursing staff refusing to follow the instructions of his advance directive, unless accompanied by a written order by his physician, is indicative of this need. The in-service experience that I encountered where nurses stated that they did not routinely attend to the contents of the advance directives of patients further substantiates the necessity of developing policy to guide practice in this area. These policies need to be compatible with the legislation governing advance directives in the specific jurisdiction and should involve professionals from a variety of disciplines (e.g., health, law, social work, theology). Including individuals who have written their own advance directives and encountered difficulties in their enactment in the development of policy would help to ensure that problem areas and concerns from a consumer point of view are acknowledged and addressed.

Areas for Future Research

Flowing from the implications above, a number of areas for further study and potential research questions are proposed in the areas of practice, education, and policy.

Practice. Conducting longitudinal studies that follow individuals who have completed advance directives through to their death and/or enactment of their advance directives would provide information about the directive's impact on the provision of end-of-life care. Is the care provided consistent with the individual's previously stated wishes? Does preparing an advance directive impact an individual's ability to live life to its fullest? Investigating the experience of agents who have been called upon to make decisions for their loved ones would add another dimension to our knowledge. It would also be interesting to longitudinally follow agents along with the makers of directives. Do agents have a difficult time convincing healthcare providers to follow the wishes of the individuals who have prepared the directive? If healthcare providers disagree with the instructions provided what do agents and healthcare providers do?

In recent years, there have been several studies that examined through surveys and questionnaires, the attitudes and opinions of healthcare providers who have worked with individuals with advance directives. Baker (2000) found that social workers, who were employed in nursing homes and hospice settings, had more positive attitudes toward advance directives compared to those working in other locations. The healthcare providers who participated in a survey by Neuman and Wade (1999) reported high overall satisfaction levels with advance directives despite concerns that few patients had completed a directive and a lack of confidence in the surrogate decision maker's ability to make decisions that accurately reflected the patient's wishes. Detailed and informative descriptions of healthcare providers' lived experiences of working with specific patients/clients who have advance directives are conspicuously absent from the literature. What do healthcare providers find helpful or problematic when they encounter advance directives? How widespread is the practice of routinely ignoring the advance directives of patients and what are the roots of this behaviour? Examining the current attitudes, behaviours, and practices of healthcare professionals around advance directives has the potential of improving the provision of end-of-life care and treatment and enhancing the dying experience for seriously ill patients.

In addition to qualitative studies that would provide a better understanding of the various facets of advance directives, there is a need to develop and evaluate educational and intervention programs to both raise awareness and assist individuals in the process of preparing an advance directive. These programs need to address deficiencies that have been identified in other programs such as the establishment of an ongoing relationship, individualisation of content, repetition of information, and opportunities to revisit decisions. The potential value of advance directives as a vehicle through which individuals might reflect upon their own mortality and the life they have lived has not been described in any detail in the literature. That completing an advance directive might be a transformative process that stimulates a renewed interest in living life to its fullest is a tremendously interesting benefit and one worthy of further exploration and investigation. The conceptualisation of completing an advance directive as a ritual that one might engage in to prepare for death is another avenue for study. As well, continued research into the actual provision of end-of-life care is warranted.

Education. The outcomes of incorporating educational material around end of life, including opportunities to reflect on one's own attitudes and beliefs about death and dying, into professional educational curricula need to be further studied. The predominant role that the media has in shaping our values and beliefs and acting as a source of knowledge is also something that requires further examination. There may be ways that healthcare professionals can utilise the media as an educational tool. Similarly the role of other community organisations such as churches and senior's centres in disseminating information and influencing attitudes and behaviours requires study.

Policy. Institutional and organisational policies that are developed in the area of advance directives require monitoring and evaluation for their impact in changing end-of-life care. Given that Alberta's policy governing advance directives has now been in effect for five years, evaluation of its impact on the provision of end-of-life care would also be of interest and provide useful and practical information. To determine the legislation's relative effectiveness, outcomes from local provincial studies could be compared to those in other jurisdictions.

Conclusion

In completing this study, I was seeking to understand the older adult's experience of preparing an advance directive. Through the writing of Alice's story and the voices of study participants, I learned of the older adult's desire to protect themselves from the actions of healthcare professionals, from technology, and from pain and suffering. Their enduring need to protect others, including family, healthcare professionals, and society from being burdened with making difficult end-of-life decisions, shouldering expenses related to unwanted life-sustaining treatments, and the feelings of helplessness that may accompany witnessing the older adult in pain and suffering, was clearly evident. In completing their advance directive, participants talked about coming to terms with death, more specifically, their own death. Their approaches to facing their own mortality and accepting their own death as inevitable were forthright, practical, and to my surprise and delight, often uplifting and amusing.

Most participants engaged in in-depth and ongoing conversations about death with their family members and friends. This pattern of open communication was long-standing in many of the family situations. The importance of maintaining and sustaining relationships even beyond their death emerged as an underlying factor that motivated their decision to complete an advance directive. Choosing an ally, someone to champion their cause, was also an important part of the advance directive process for all but one of the study participants. Although the ability of agents to accurately predict the wishes of the makers of directives has been measured in a number of studies and a discouraging level of concordance has been shown in some instances, this was not a concern for these older adults. What was important to them was that they trusted their agents to do their best. They felt comfortable that they were in good hands. For older adults without family members to talk to or appoint as an agent, preparing an advance directive may be a more difficult process.

Most participants entered into the process of completing an advance directive without fully realising the complexity or nature of this undertaking. Many were surprised that the process took as long as it did, that it involved reflecting upon how one was living one's life, that there were so many options and choices to be considered. Yet, they entered the process wholeheartedly--proactively seeking out educational information, written material, the input of family and friends, and on some occasions the opinions of experts. All expressed satisfaction with what they had done, a sense of accomplishment and completion. Contrary to what one of my initial subsidiary questions implied, I discovered that preparing an advance directive in many ways actually has more to do with living well than dying well.

In seeking a phrase that would capture the older adult's overall experience of preparing an advance directive, the one that I kept returning to was that of 'apprehending death.' To apprehend means to become cognisant of, to recognise, and to understand; it also means to anticipate, to imagine, and to fear (Oxford English Dictionary, 2002). Completing an advance directive requires first an awareness and recognition of the existence of advance directives and their purpose. It demands individuals to project themselves into the future, to imagine their own incompetency and death, and for some there is an undercurrent of fear--fear of pain, fear of the unknown. Contrasted with the term 'comprehend' which denotes the embracing or understanding of something in its entirety, 'apprehend' denotes a clear understanding, but one that leaves some parts unknown (Oxford English Dictionary, 2002). In that we do not know, cannot know, and perhaps should not know, what the death experience encompasses in its totality, comprehension is impossible. Yet for those who have been in death's presence, something is known of it; while all of its intricate features cannot be grasped, one can recognise the contours of death's "human face" (Ahronheim & Weber, 1992, p. 27). We can apprehend its meaning to a certain extent. I feel, too, that in completing this study, I have apprehended (but not fully comprehended), the older adult's experience of preparing an advance directive. I now feel better prepared to contemplate my own death, to try once again to complete my own directive, and to assist others in doing so, too. I am ready to live life to its fullest.

In recognition of the participants' contributions to shaping this study and its outcomes, for their willingness to share of their time and experiences, it seems only appropriate to give Alice the final word.

I've enjoyed talking and sharing with you my experience of completing an advance directive. I've tried to present my story honestly and completely, to leave nothing unsaid, no stone unturned. I hope you will take some time to contemplate your own death and dying and examine the way you are living—maybe you'll even consider preparing your own advance directive! I hope you'll talk about death with your family and friends--they are what is truly important in life--not *work, not money, not a bigger house, or a new car. I hope that you will enjoy life to its fullest and experience all of its joys and few of its sorrows. And for you and for me, I hope that when death knocks at our doors we will go gently into the night.*

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Appendix A: Recruitment Poster

Title of Research Project: Preparing an Advance Directive

Investigator: Dianne Godkin, RN PhD(c)
Faculty of Nursing, University of Alberta
Phone: 492-9045

Supervisor: Dr. Vangie Bergum, Professor
Faculty of Nursing, University of Alberta
Phone: 492-6676

Are you an older adult who has completed an advance directive (e.g., living will, personal directive)?

Would you be interested in participating in a study about advance directives?

I am a nurse who works with older adults. I am conducting a study to better understand what it is like for older adults to prepare an advance directive. This study is part of my doctoral program in nursing.

You will take part in a conversation with me. We will talk about what it was like for you to prepare a directive.

The conversation will take place in your home (or an alternate location) at a time that is good for you.

You are eligible to take part if you are 65 years or older and have completed an advance directive.

To find out more about the study, please call me at 492-9045. After we have talked further, you can decide if you would like to take part.

Appendix B: Recruitment Advertisement

I am conducting a study about the experience of preparing a personal directive (advance directive, living will). This study is part of my doctoral program in nursing. You are eligible to take part if you are 65 years or older and have completed a directive. To find out more, please call Dianne at (780) 492-9045.

Appendix C: Information Sheet for Participants

Title of Research Project: Preparing an Advance Directive

Investigator: Dianne Godkin, RN PhD(c), Faculty of Nursing, University of Alberta; Phone: 492-9045

Supervisor: Dr. Vangie Bergum, Professor, Faculty of Nursing, University of Alberta; Phone: 492-6676

Purpose of the Study: The purpose of this study is to understand what it was like for you to prepare an advance directive.

Background: In a directive, individuals outline their wishes regarding future health care. Health care providers work with individuals who have completed advance directives. Health care providers need to better understand what it is like to prepare an advance directive.

Procedure: You will take part in a conversation with me. We will talk about your experience of preparing a directive. The conversation will take place in your home (or another suitable place) at a time that is good for you. Our conversation will be audio-taped and typed. You will be asked to provide some information about yourself (e.g., age, marital status). You will also be asked for permission to make a copy of your written directive. This will take between one to two hours of your time. During the next year, you may be asked to do one of the following:
1) take part in a second interview;
2) read the interpretive writings and provide feedback; or
3) take part in a group discussion.

Benefits and Risks: There are no health risks to taking part in this study. Some individuals may find it uncomfortable to talk about this experience. Others may find the discussion helpful.

Voluntary Participation: Your participation is voluntary. You may refuse to answer any questions. You may withdraw from the study at any point in time. You can withdraw by telling me.

Confidentiality: Your records will be stored in locked filing cabinets. Access to records will be limited to my committee members, the typist, and myself. In reports of the study, you will be assigned a false name.

Additional Contacts: If you have any concerns about any aspect of this study, you may contact the Patient Concerns Office of the Capital Health Authority at 492-9790. This office has no affiliation with study investigators.

Appendix D: Consent Form for Participants

Part 1 (to be completed by the principal investigator):

Title of Project: *Preparing an Advance Directive*
Principal Investigator(s): *Dianne Godkin, Faculty of Nursing, University of Alberta, 492-9045*
Supervisor(s): *Dr. Vangie Bergum, Faculty of Nursing, University of Alberta, 492-6676*

Part 2 (to be completed by the research subject):

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No
Do you give permission to the investigator to contact you in the future to ask if you would be willing to participate in a follow-up study? An ethics board will review any follow-up studies before they are conducted.	Yes	No

This study was explained to me by: ______________________________

I agree to take part in this study.

______________________________ ________________ ________________________
Signature of Research Participant Date Witness (optional)

______________________________ ________________________
Printed Name Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

____________________________________ ______________________________
Signature of Investigator or Designee Date

Appendix E: Guiding Interview Questions

1. Can you tell me how it was that you came to decide to complete a directive?

2. Can you talk about your reasons for completing a directive?

3. How did you prepare to complete the directive?
   a. What information did you gather?
   b. Who did you talk to?
   c. Who did you involve in the process?
   d. How did they react/respond to their involvement?
   e. Did you have any concerns about completing a directive?

4. How did you decide what to include in your directive?
   a. Can you tell me about some of your decisions?
   b. What did they mean to you?
   c. Do you have any concerns that you might change your mind? That the decisions you have made now might not be the ones you would want if you were incapacitated?
   d. Do you have any concerns that your wishes might not be respected?

5. Did you select someone or more than one person to be a health care agent?
   a. How did you come to a decision about who to choose as your agent?
   b. What criteria did you use?
   c. What do you see as the qualities or characteristics necessary in a good agent?
   d. How did you discuss your decision with your agent?
   e. How did they respond?
   f. What questions did they have?
   g. Did you have any concerns that the individual you selected wouldn't be able to follow through on their commitment to you? That they wouldn't be able to follow through with your decisions?

6. What was this process like for you? What thoughts ran through your mind?
   a. How was this process the same or different from completing an estate will?

7. Did completing the directive make you think about your own mortality?
   a. What does it mean to you to die well?
   b. What does a good death look like to you?
   c. How would you describe your own beliefs about death and dying?

8. Are there any other aspects of preparing a directive that you'd like to talk about?

Appendix F: Demographic Information Form

Age: ______________________________

Gender: ______________________________

Level of Education: ______________________________

Marital Status: ______________________________

Number of Children: ______________________________

Proximity of Children: ______________________________

Relationship to Children: ______________________________

Career Background: ______________________________

Culture/Ethnicity: ______________________________

Date of Directive: ______________________________

Estate Will Completed: ______________________________

Appendix G: Sample Advance Directive

1. Appointment of Health Care Agent

I, ________________, appoint ________________ as my agent to make decisions on my behalf.

2. Coming into Effect

This directive will have effect only when I lack capacity to make a decision about any personal matter, and I will lack capacity when my agent signs a written declaration to that effect after consulting with a physician or a psychologist who has completed a declaration as required by the regulations to the Personal Directives Act.

3. Agent's Powers

I give my agent powers to make all decisions relating to the following:
a) my health care, including providing consent, accepting or refusing any or all medical care;
b) where I am able to reside and with whom I am able to live and associate;
c) what social and recreational activities I am to engage in; and
d) generally, all day to day matters including decisions respecting nutrition, hygiene, clothing, and safety.

I have discussed my values and beliefs with my agent and trust in his/her ability to make a decision that I would be comfortable with.

4. Personal Decisions

My agent must instruct my health care service providers based on the following guidelines:

4.1 I do not wish my life to be prolonged by artificial means when I am in a coma or a persistent vegetative state and, in the opinion of my physician and other consultants, have no known hope of regaining awareness and higher mental functions, no matter what is done.

4.2 In the event of a mild stroke or mild dementia, I want all major treatments such as CPR, life saving surgery or antibiotics to continue, but would only want a ventilator, dialysis or tube feeding on a short-term basis.

4.3 I wish to be kept comfortable and free from pain. This means that I may be given pain medication even though it may dull consciousness and indirectly shorten my life.

4.4 If I am unable to care for myself, I do not wish my family to be burdened with my care. I wish to be cared for in a private or publicly-funded facility.

4.5 I have signed an organ donor card and authorise my agent to inform my caregivers of this to hasten the process of organ harvesting after my death.

5. Access to Documents and Information

I authorise and permit my agent to access all confidential documents to which I am entitled personally including, but not limited to, full access to my medical records, Revenue Canada records, any safety deposit boxes I may have as well as all personal financial information.

6. Other

In the event that my instructions in this Personal Directive are ambiguous or insufficient, I direct my agent as follows:

a) to make the decision that my agent believes I would make in the circumstances, given my agent's knowledge of my wishes, beliefs and values; and

b) if my agent does not know what decision I would make, to make the decision my agent believes in the circumstances is in my best interest.

This directive is made after careful contemplation. I hope you who care for me will feel morally bound to follow its mandate. I recognise that this appears to place a heavy responsibility upon you, but this directive is made with the intention of relieving you of such responsibility and placing it upon myself in accordance with my strong convictions.

Dated, Signed, and Witnessed

I make this personal directive on the 1st day of January, 2002, at Edmonton, Alberta.

Signed: ____________________
Witness: ____________________
Date: ____________________