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The Experience of Older Adults Making End of Life Medical Decisions:

Hoping for the Best and Planning for the Worst

by

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## Abstract

### The Experience of Older Adults Making End of Life Medical Decisions: Hoping for the Best and Planning for the Worst

This exploratory study describes the experience of six older adults aged 65 and over in the community who were making end of life medical decisions (EOLMDs). Using phenomenological methodology, open ended, structured interviews were conducted with a purposive sample of six participants.

Analysis of the data revealed five essential themes in older adults' experience of making EOLMDs: (1) "encountering uncertainty", (2) "recalling death and illness", (3) "imagining my end of life (EOL) and beyond", (4) "considering the role of others in my EOL", and (5) "preparing for EOL."

The findings suggest that there is a mismatch in the meaning of this experience for older adults making EOLMDs and the health professionals that help them prepare for EOL. Findings also point to a possible overvaluing of autonomy by health professionals in conceptualizing advance decision-making tools such as Personal Directives.

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## Dedication

This thesis is dedicated to my husband, George, my ‘soul mate’, and to the participants in this study who inspired me with their hope, laughter and optimism.

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## Epigraph

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... already old age is wrinkling my  
skin and my hair is turning from black  
to grey; my knees begin to tremble  
and my legs no longer carry me ...  
oh but once, once we were like young deer  
... what can I do ...

... I know I must die ...  
yet I love the intensity of life  
and this and desire keep me here in  
the brightness and beauty of the sun ...

\*A fragment of a poem by Sappho, a 7<sup>th</sup> Century Greek poet



## **CHAPTER ONE: OVERVIEW OF THE STUDY**

### **Introduction**

On a daily basis, Registered Nurses in community practice face difficult ethical questions that require decisions about the nursing care of legally incompetent patients. As documents such as Living Wills and Personal Directives become increasingly prevalent (Hardingham, 1997; Health Canada, 2000), it is likely that those involved in community nursing will be asked by families to make professional judgments and interpretations about end of life (EOL) care of patients who are unable to articulate these decisions for themselves. It is also likely that clients will ask community nurses to provide relevant information or other support, to enable them to come to end of life medical decisions (EOLMDs). These considerations are particularly important because, as Health Canada (2000) has noted, the involvement of older adults and their families in decision making about life sustaining treatment is a critical element in quality EOL care. In addition, questions about how EOL decisions are made, and by whom, are gaining new urgency as countries such as the Netherlands pass laws legalizing active euthanasia (Schafer, 2001).

But how do nurses make these judgments? What do community nurses need to know to assist patients in making end of life decisions such as those required to make a Personal Directive (PD) or to choose a Do Not Resuscitate (DNR) order? The need for nurses to have an excellent understanding of how older adults experience these EOL decisions is particularly relevant because, as McCulloch (1997) noted, modern North American society often tends to devalue anyone who is not young and productive, and

because there is often confusion among older adults as to what their EOL decisions mean in terms of medical treatment (Falker & Nettles, 1995).

In addition, there is a particular need for EOL questions to be addressed from a nursing perspective. According to the Canadian Nurses' Association (2002) nurses are ethically bound to "aid clients in their expression of needs and values..." (p. 2) such as those involved in making EOL decisions. In addition, the Alberta Association of Registered Nurses (1996) has stated "Nurses can... facilitate better resolution of end of life issues by the dissemination and application of relevant research and information" (p. 20). Research that articulates both the experience of older persons who have made EOL decisions, and the meaning that experience holds for them is a step toward helping nurses assist their older, vulnerable clients in the community.

### **Purpose of the Study**

The purpose of this phenomenological study is to identify and describe the essence (Streubert & Carpenter, 1999) of elders' (age 65 and over) experiences of making EOLMDs about such provisions as life support, DNR orders and Personal or Advance Directives (i.e., legal documents in most Provinces and States that record, among other things, a person's wishes for end of life medical care).

### **Background of the Study**

This study is rooted in my practice as a Registered Nurse (RN) involved with geriatric inpatient care for seven years. Several years ago, on the unit where I practice, I encountered a man with advanced Alzheimer's disease who had come with copy of a Personal Directive. (Note: Some of the details of the following anecdote have been

altered to preserve the anonymity and confidentiality of the client). The directive had been neither signed nor witnessed. However, I soon had larger reservations about implementing this Directive, over and above the legal concerns suggested by its form. The PD was short and to the point; it stated “I do not want any heroic measures if my heart stops.” But what did the patient mean by “no heroic measures”? Did he understand the content, during the time of writing the Directive? More importantly, did I and other nursing colleagues understand his request? How had he come to his decision of “no heroics” and how could I align my practice to best carry out his wishes? These were questions that arose as soon as the man was admitted.

My concerns subsequently became more concrete. The man had a history of cardiac disease and at the beginning of one evening shift, he began to complain (as best as he was able in his confused state) of chest pain. At this point in time, there had been no conversation between the man’s physician and family about a “no code” order. He became increasingly anxious and at one point, approached the desk, clutching his chest, and crying out, “Help me! Help me!” After consultation with my nursing colleagues, the doctor on call was notified, an electrocardiogram (EKG) ordered (which showed some active cardiac problems) and he was treated. But the question remained: Did investigating the possibility of cardiac failure constitute heroic measures? In the minds of some of my colleagues, it did. And if the investigation itself did not qualify as heroic, surely the treatment did. I left work that evening sure in my own mind that I had done the right thing for this patient, although still unsure about what constitutes “heroic measures”.



This incident, and others like it, raised a number of questions that all resolved themselves in a realization. In order to resolve ethical dilemmas like this one, I needed to know what kind of concerns older adults had at the time they were actually making decisions like “no heroics”. I needed to better understand what they experienced as they came to make EOLMDs. Only then could I begin to resolve dilemmas that nurses in the community might encounter when implementing elders’ wishes for EOL medical treatment. I came to believe that to begin to resolve ethical dilemmas like these, a study was needed that focused on older adults’ experiences of making EOLMDs in a way that would preserve the uniqueness of their experience.

One way to begin to understand a human experience and to understand what personal biases need to be “bracketed” is to articulate one's own experience of the phenomenon (Van Manen, 1998; see also Creswell, 1998). Therefore, in addition to the professional experiences of EOLMDs outlined above, I will attempt to account for the personal experiences that contribute to my interest in this subject. At the present time, I am the only child of an elderly woman, age 73, who lives alone and suffers from a number of chronic medical conditions including Chronic Obstructive Pulmonary Disease (COPD) and severe osteoarthritis. As a daughter, I have been called upon in a number of medical emergencies to speak for my mother, and give direction about her end of life wishes. On one occasion, when she had been admitted to an Intensive Care Unit, with complications of her COPD, I found myself in the position of having to defend my mother’s choice to have full resuscitation should her heart stop.

In addition to the above experience, although neither I, nor any of my family have completed a Personal Directive, I had occasion to be involved in my mother's EOLMDs. Over the past 2 or 3 years (perhaps partly because of this work being in progress) we have discussed various scenarios, and she has told me what she would want done in each case. Since that first experience in ICU, her decisions have changed. She is still content to leave the decisions to me, should she be incapable to decide for herself. However, now she is assured that I know her wishes more specifically and know that she feels she has had "a good run" (a full life).

As a loved one of someone making EOLMDs, I experienced these talks as both comforting and anxiety-producing. They were comforting, because I knew my mother was content with her life, no matter what the future held for her. They were anxiety-producing because I faced the possibility of losing someone I loved and because, try as I might, I knew I could not help my mother anticipate every possibility that might arise. This meant that in spite of our talks, potentially, a situation might arise where I still did not truly know what my mother would want done.

### *Bracketing*

This professional and personal experience has evolved a number of beliefs on my part that were bracketed for the purpose of this study. First is the belief that withholding treatment of older adults, especially those with some kind of debilitating medical or psychiatric conditions is becoming more common than it was when I started nursing almost 25 years ago. Secondly, I believe that there is a danger in this trend. That is, despite well-intentioned effort to relieve suffering, there is a danger that nurses can rush

to a solution that involves withholding treatment before the wishes of family and the patient are considered. Particularly in situations where patients are legally incompetent to speak for themselves, I believe that nurses are obliged to have knowledge of and consider the wishes of older adults as to the withholding or giving of treatment. Finally, I believe that in instances of doubt as to what patients might want, that the default should be to provide treatment, even if that means a long potential recovery period for an older adult.

In general, I am biased in favor of a view of older persons as having experience, knowledge and wisdom to offer researchers in particular and society in general about how to meet the demands of life and make important life decisions. I am also biased toward a view that life is innately valuable regardless of age or infirmity. This belief includes the view that active euthanasia is never acceptable and that EOLMDs cannot morally include requests for assisted suicide, nor can nursing personnel morally be a part of such requests.

As much as possible, all of these beliefs and assumptions were identified and bracketed in order to turn to the experience (Van Manen, 1998) of older adults making EOLMDs and rely on intuition and the essences of the experience (Creswell, 1998) during the course of this study.

### **Philosophical and Methodological Underpinnings of the Study**

The philosophical underpinnings of this research are best described by reference to the phenomenological work of M. Merleau-Ponty (1962; 1969). Here, a distinction between phenomenology as a method and as a philosophy should be drawn. The phenomenological method used in this study is based primarily, but not exclusively, on the work of phenomenologist, Max Van Manen and his book *“Researching Lived*



*Experience*” (1998). The use of this method will be addressed in Chapter Three. However, the use of phenomenology in this study goes deeper than mere method. That is, it not only uses the method of phenomenology, but is also rooted in a phenomenological understanding of the world, and hence, it is based on a phenomenological philosophy.

Merleau-Ponty, in *“The Primacy of Perception”* (1962), argued that “Our relation to the world is not that of thinker to an object of thought,” (p. 12). Here, he was describing the rejection of the Cartesian world view, a rejection that forms one of the underlying assumptions of this study. I agree with Merleau Ponty’s (1962) perspective, that there is a “quasi-organic relation of the perceiving subject and the world” (p. 12). Put more simply, Merleau-Ponty is saying that the perceiver cannot be separated from the perceived and that there is co-creation of the world by means of the relation between the perceiver and the material world. This is in contrast to the Cartesian view which holds that the mind is distinct from the body (Descartes, p.27), and assumes the material world is constant, measurable and knowable in terms of mathematical laws. It is exactly that world view that is rejected in this study.

### **Researcher's Assumptions and Preexisting Knowledge**

These philosophical underpinnings imply several assumptions that are important to this study. First, if the perceiver cannot be separated from the perceived then I, as the researcher, and the participants cannot be separated from the research process, an assumption not made in quantitative research. Therefore, the participants in this study are understood as co-creators of the results. If as Merleau-Ponty (1962) asserts, “I thus cannot conceive of a perceptible place in which I am not myself present” (p.71) then I am no

more an objective observer than the participants are objects to be observed. It is this holistic, phenomenological understanding of the world that underpins this study.

This phenomenological view includes a view of the human person similar to that articulated by Benner and Wrubel (1989). They reject treating the person as an object and use Heidegger's work to define a person as a "self-interpreting being," (p.41). This idea means that people have a pre-reflective understanding of their lives (Merleau-Ponty, 1964) apart from abstract thought and that consequently, people "become defined in the course of living a life" (p. 41). As a result, people's lives, as reported by themselves, are a valuable source of understanding because "the person grasps the situation directly in terms of the meaning for the self" (p. 42). This study is based on these assumptions about the human person.

In addition to a phenomenological world view and view of the human person, another assumption accepted in this study is the existence of ageism which has an impact on EOLMDs. As Vanier (1999) put it, North American society upholds "the image of the ideal human as powerful and capable (and) disenfranchises the old, the sick and the less-abled" (p. 45). The influence of this ageism on EOLMDs of older adults is understood according to Heidegger's (1962, cited in Benner & Wrubel, 1989. p. 46) definition of *background meaning*, that is, meaning which one learns from birth simply by living in the culture and which determines one's world view. If ageism is a part of the North American *background meaning*, then it assuredly plays a role in end of life medical decision making for older adults.

A final phenomenological assumption of this study pertains to “fictionalized representations” (Richardson, 1994, p.521) or alternative data displays that can reveal aspects of the phenomenon, (e.g. depth of emotion, and the presence of the researcher in the research) that cannot be brought out in more traditional data displays such as summaries, synopses, vignettes, and diagrams (Huberman & Miles, 1994). As Richardson observes, a fictionalized representation of data allows the author to be “somewhat relieved of the problems of speaking for the “Other” because they are the Other in their texts” (p. 521). Such a stance provides the writer and a reader with an opportunity to compare the fiction with a traditional narrative presentation. In this research, since readers and authors (as well as participants and the researcher) are assumed to be partners in making meaning, these goals are fitting and appropriate within the context of this work.

### **Significance of the Study**

The findings of this study should contribute to knowledge that will assist Registered Nurses (RNs) to support clients and their families to make and carry out decisions about EOL care. It is expected to afford insights that will help RNs in community health practice need to guide older adults in completing Personal Directives (PDs) or making other EOLMDs. The findings may also help inform the Canadian Nurses Association’s efforts in regularly updating the Code of Ethics Guidelines. Finally, the findings may be used to guide decisions about the kind of written or institutional resources older adults might need to make EOL medical documents such as PDs.

### **Definitions of Key Terms**

This study uses a number of terms relating to concepts central to the study and to the phenomenological philosophy and method. Below are five of the terms most important to understanding the approach and the results of the research (See also Glossary, Appendix H)

1. Lived Experience- For the purposes of this study, experience is understood as Van Manen's (1998) notion of 'lived experience'; that is, "our immediate, pre-reflective consciousness of life: a reflexive or self-given awareness which is, as awareness, unaware of itself"( p. 35). Van Manen also suggests that an essential part of lived experience is Merleau Ponty's (1968) notion of the sensible. Quoting Merleau Ponty, Van Manen writes, "...The sensible is that: this possibility to be evident in silence, to be understood implicitly' " (p. 36). With this understanding, the purpose of the study is to gather, analyze and articulate the "self-given awareness" that older adults have of making EOLMDs which is implicit in their accounts and make it explicit.

2. Essence- For the purposes of this study, essence is defined as the structure that comprises the experience of a phenomenon and is evident in patterns in the data. It is a view similar to Van Manen's (1998) who concludes:

The essence of a phenomenon is a universal which can be described through a study of the structure that governs the instances or particular manifestations of the essence of that phenomenon. In other words, phenomenology is the systematic attempt to uncover and describe the structures, the internal meaning structures of lived experience. ( p. 10)

3. End of Life (EOL)- This term is understood as the time when life ends and includes the immediate period of illness that leads up to it. Although EOL encompasses the time of dying it may also include some period of time prior to that phase because the period of dying is usually defined by doctors, medically, or by others after the fact of death, as in, “we didn’t realize it at the time, but she was dying” or, alternatively, “the doctors told us she was dying.”

4. End of Life Medical Decisions (EOLMDs)- These are the decisions that participants identified for themselves as being necessary to make decisions about end of life medical treatment and/or to communicate what treatment they might want or not want withheld and under what circumstances. These are the decisions about medical treatment that are necessary to complete an advance planning document such as an Advance Directive.

5. Hope- Hope has been defined variously as “confident yearning” (Weiss, 1971 in McGee, 1988), as “desire with an expectation of fulfillment” (Forbes, 1994) and as “a fundamental knowledge and feeling that there is a way out of one’s difficulty, that as humans, we can somehow manage our internal and external difficulty” (Lynch, 1965 in Farren, Salloway & Clark, 1990, p.43). In the context of this study, Dufault and Martoccio’s (1985) understanding of generalized and particularized hope is most useful. They define *generalized* hope as

as sense of some future beneficial but indeterminate developments.... It imparts an overall motivation to carry on with life’s responsibilities and gives a broad perspective for life...that includes...openness to changing events (p. 380.)

These researchers also draw a distinction between this generalized hope and *particularized* hope that has a more specific object. They describe this kind of hope as characterized by the expectations that

- what exists at present can be improved.
- What a person does not have at this time can be attained or received.
- The desired circumstances surrounding an event will occur.
- Unfavorable possibilities will not occur (p. 380-1.)

Both of these aspects of hope are useful to understand the meaning of making EOLMDs for older adults.

6. Uncertainty- For the purposes of this study, this concept is best understood according to Neville's (2003) articulation of uncertainty. Based on Monat, Averill and Lazurus' (1972) research, Neville proposes that uncertainty has two distinctive expressions: "Temporal uncertainty...defined as not knowing when an inevitable harm will occur, [as distinct from] event uncertainty [which] is a situation where the time of occurrence was known but where the probability of occurrence may vary" (p. 206). In a more general way, uncertainty in the context of this study can also be understood as distinct from professional uncertainty, which is associated with ethical decision making (Neville, 2003; Penrod, 2001). In addition, it can be understood as existing when "individuals are unable to form a cognitive framework for understanding their situation and thus believe they are unable to predict the outcomes of their behaviors"(Weitz, 1989 in Neville, 2003) and when "there is an inability to determine meaning or assign probabilities" (Penrod, 2001).

### Outline of the Thesis

In this chapter, I have described the background and purpose of this research. There is also an outline of the personal and professional experiences that stimulated interest in this area of research and the resulting beliefs that were bracketed during the research. In addition, I examined the world view and philosophy that underpins this study and described the assumptions and definitions that are key to understanding the method and findings of the study.

In Chapter Two a literature review has been provided that examines the current literature on EOLMDs for older adults and establishes a need for a phenomenological study that gives voice to the older adults making these decisions. In Chapter Three, the methods used in this study are outlined in greater detail with particular emphasis on provisions made to ensure methodological rigor. In Chapter Four, in order to provide context, I describe the lifeworld of each of the six participants with reference to this phenomena. This description is what LeNavenec (1993), following Geertz (1973) calls “thick description” (p.83) and is achieved with specific references to interview transcripts and field notes. This Chapter ends with what can best be called a *creative, fictional presentation of the data* (Richardson, 1994) or a *literary tale* (Van Maanen, 1988). This presentation is a compilation of the experiences of all of the participants and is intended to further “thicken” the description of the participants’ experience while, at the same time, making transparent my participation in the conversations that produced this knowledge.

In Chapters Five and Six, the findings are presented. In Chapter Five, a detailed description of the structures of the experience for older adults making EOLMDs is provided. Finally, Chapter Six presents a summary of the research process and a discussion of the findings. This discussion includes implications for the learning needs of both nurses supporting older adults in making EOLMDs and the needs of the older adults themselves. A discussion of topics for future research and their connections to the findings of this study is also outlined.



## CHAPTER TWO: LITERATURE REVIEW

### Introduction

Using Webspirs, Ebscohost, Ovid, and SilverPlatter to search Eric, Healthsource, and Medline, a literature search was completed using the keywords end-of-life, end-of-life decisions, personal directives, advance directives, elderly, older adult, geriatrics and euthanasia. In spite of the urgency, noted in Chapter One, for answers about how to guide elderly patients in EOL decision making, this preliminary review of the literature revealed three salient issues: (1) much of the literature on end of life decision making focuses on concerns of health care professionals rather than on the lived experience of elders; (2) most studies that have examined seniors' points of view on end-of life decision making have examined institutionalized elders rather than elders in the community; and (3) there is a need for more qualitative studies to articulate and describe in detail the experiences of non-institutionalized seniors with regard to end of life decision-making. These three issues will be addressed next.

### Focus of the Current Literature

The literature reveals that many studies to date on end of life decision making have centered on the concerns of health care professionals. For example, there are several studies (Downe-Wambolt, Butler, & Coughlan, 1998; Wenger, Phillips, Tno, Oye, Dawson, Lui, Califf, Layde, Hakim, & Lynn, 2000) that focus on professional aspects of end of life decision making such as the *legal liability* of health care professionals who institute Do Not Resuscitate (DNR) orders. In addition, there are studies like that of Mebane, Oman, Kroonen and Goldstein (1999), which examine *physician attitudes*

toward advance care directives. Other research, such as the study of Huster, Miller and Brown (1999), deal with issues that include a *hospital's and health care professionals' legal obligation* to teach elders about advance or personal directives (PDs). In summary, although there is literature focusing on medical end of life decision making, much of it comes from a medico-legal and/or an institutional perspective thereby affording limited insight into the concerns, views and experience of the elderly population. In my view, the nature of the research leaves nurses with an impoverished view of end of life medical decision making and thereby limits their ability to assist elders in making such decisions.

Studies that **do** ask questions about end of life decisions from an older adult's perspective tend to focus on clients who are ill or debilitated enough to be hospitalized or in nursing homes. For example, Levin, Wenger, Ouslander, Zellman, Schnelle, Buchanan, Hirsch, and Reuben (1999) studied a sample of 413 nursing home residents and 363 family/surrogates to determine if they "...and their families reported discussions about life-sustaining treatment with their physicians, the relationship between such discussions and orders to limit therapy, and predictors of physician-patient communication about life-sustaining treatment" (p. 82). These researchers defined end of life decision making, at least in part, from an older person's perspective. However, their study affords limited insight into the care of an older adult in a community setting because elders who qualify for community care are generally not in a physically or mentally debilitated state as were the nursing home participants studied by Leven et al. Due to the added stress of debilitation, and the perception of many elders that a nursing home is the "end of the

line”, it is reasonable to expect that participants in the study by Levan et al. will have a different experience of making EOLMDs than those who live at home.

A recent quantitative study by Dr. W. Molloy (2000), a professor of Medicine at McMaster University, is open to a similar critique. He compared nursing homes in Ontario which had programs for assisting residents to complete Advance Directives, with nursing homes that had no such programs. His study revealed (among other things) that, as measured by a questionnaire validated as part of the study, the level of satisfaction among residents with access to Advance Directives was higher than that of residents of homes without that program (Molloy, 2000). This study did explore elders’ attitudes toward care; hence it was closer to their experience of making end of life decisions than the aforementioned research that dealt only with medico-legal perspectives. However, Malloy’s study focused exclusively on *institutionalized* elders and, again, one might reasonably expect the institutionalized elders’ experience of making EOLMDs to be different from that of elders well enough to live in the community.

An equally important critique of Molloy’s (2000) research is that like much of the literature on end of life decision making, the study reveals little about an elder’s *experience* of making end of life decisions. In order to assess residents’ levels of satisfaction, Malloy asked his participants to complete a survey that focused on a program for assisting them to make Advance Directives. In his report, there was no mention of any direct questioning of the individual residents, or their perceptions of their nursing home environment. In fairness, there was not any indication that the study intended to give a detailed account of residents’ experiences of making EOLMDs. However, if nurses are to

guide older adults in such end of life planning, they need knowledge about the elder's experiences of such decisions including research findings of what kinds of past and present experiences come into play when elders try to make these crucial decisions. Unless nurses have such knowledge, they may find it difficult to ask the questions or give the support necessary to help elderly clients in the community who want to address this topic.

Why is it important to access elders' points of view about end of life decision making? A critique by Cantor (2000) of a study by Lee, Brummel-Smith, Meyer, et al., (2000) offers some insights. Cantor recounts that even when the older adults in the latter study were asked about their preferences for end of life care, "there was good compliance [on the part of the staff] with very specific treatment requests [of the elders][for example, antibiotic treatment] *but not with [their] requests for types of care* [emphasis added] " (p.1343) such as 'comfort measures only' or 'full treatment/resuscitation'. Cantor notes that Lee et al. "did not answer the most interesting question--why did some patients have their wishes followed while others did not..." (p. 1344). If nurses are to assist patients in making end of life medical decisions (EOLMDs) that are more likely to be carried out, it is necessary to have research that will help nurses to ask the right questions--ones that will not only assist clients in identifying their end of life wishes but also questions that will help assure that the decisions older adults **do** make will be carried out.

Crisham's (1992) research suggests another reason that nurses should be concerned with elders' experiences of making EOLMDs. This researcher identified ethical and moral dilemmas as an integral part of nursing interventions. He states, "Moral

and ethical dilemmas associated with nursing interventions are opportunities for individual nurses and the profession to rediscover and recreate their commitments in nursing” (p. 19). Crisham proposes a model for ethical decision making in which the first step is “*Massaging the Dilemma*” (p.20). In this step, the author advises nurses to describe the ethical conflict, including information about whose interests are at stake, and to define “the dilemma for the individuals involved, describing the crunch of conflicting loyalties, including feelings, laws and regulations, etc.” (p.22). In order for nurses to sort out ethical dilemmas with elder clients who are making EOLMDs, they must first have an understanding of what the dilemmas might be for these people, an understanding that can be supported by research that probes elder’s experience of making EOLMDs.

In view of these points of critique, it appears that more qualitative research on EOLMDs is needed for the following reasons: (1) in order to provide data specifically about elders in the community, (2) in order to ask questions that will make it more likely that older adults’ EOLMDs will be carried out, and (3) to promote nurses’ understanding of the ethical dilemmas facing elders making EOLMDs.

One qualitative study that *does* focus on the perspectives and values of non-institutionalized seniors has noted the need for further research so health professionals can more effectively assist elders in end of life decisions. This phenomenological study by Winland-Brown (1998) examined the reasons of 17 non-institutionalized adults over the age of 65 for not completing Advance Directives. The researcher concluded that denial of death, mistrust of others to carry out their end of life wishes and a lack of knowledge about Advance Directives were all factors in the elders’ experience of making

EOLMDs (Winland-Brown, 1998). I believe that there is a need for more such studies which may afford knowledge about how community nurses could assist older individuals to articulate their values in regard to EOLMDs and to “develop competence in assisting (elders) and their families with the execution of advance directives” (Winland-Brown, 1998, p. 39). Nurses and other health professionals need more qualitative research like Winland-Brown’s that clearly articulates the experience of non-institutionalized elders in making EOLMDs.

The recent study by Carrese, Mullaney, Faden & Finucane (2002), which focused on elders in the community, also demonstrates the importance of more in-depth qualitative work to articulate elders’ views and values around making EOLMDs. In their study involving interviews with twenty three housebound elders, Carrese et al. found that most of these chronically ill participants “preferred not to think about (end of life) at all, let alone make plans, although most had prepared wills and made arrangements for a funeral. Their preparations were for death, but not for the possibility of long serious illness which may or may not be fatal” (2002, online Abstract, p.125). What was it about these elders’ experiences of making EOLMDs that made them eager to prepare for death, but not for the kind of EOL situations, such as those provided for by an Advance Directive or DNR order? What could community nurses do to help older adults overcome their reluctance to plan for EOL? These researchers were unable to shed any light on those questions. Even qualitative studies of older adults in the community show a need for a better understanding of these elders’ experiences of making EOLMDs.

The recent literature clearly demonstrates that the experiences of older adults in the community, struggling to make EOLMDs is a poorly understood phenomenon from a qualitative research perspective. For example, the resistance to making EOLMDs identified by Carresse, Mullaney, Faden and Fucane (2002), and by Windland-Brown (1998) is not well described and the reasons for such resistance is poorly understood. The scarcity of qualitative studies that articulate older adults' experiences makes it difficult to understand older adults' experience and so to assist and support them in making these crucial medical plans.

Having seen the importance of using a qualitative method to articulate the experience of elders making EOLMDs (for the sake of both community nurses and their older adult clients) one must also consider that the phenomenological method used in this research implies a particular theoretical view of the human person, different from that which might be used in quantitative research. This topic is addressed next.

### **Theoretical Perspectives of the Human Person**

Due to the underlying philosophical focus of this study, described in Chapter 1, a review and comparison of two paradigmatic views of the human person is relevant at this point. These two opposing views include (1) the mechanistic view that involves a scientific, medical model as represented by the writing of Bacon, Descartes and other Enlightenment thinkers versus (2) a unified, holistic view as represented by modern nursing theorists such as Parse (1998) and Brunner and Wrubel (1989).

Many current theories of nursing are rooted in a Cartesian model of the human person (Parse, 1998; Brunner & Wrubel, 1998) which can be traced back to the writings

of Rene Descartes and Francis Bacon. In this view, human beings are conceptualized on the basis of a mechanistic model; that is, human beings are considered to be composed of constituent parts which can be "separated" and observed. These observations, so the belief goes, can then be used to deduce laws and relationships of cause and effect. In short human beings are conceptualized as part of the world of natural sciences which "posit methodologies that elicit quantitative data from observable phenomena and reveal causal relationships" (Parse, 1998, p. 1). This view of the human person is a reductionist, causal, view which assumes a mind-body split, and sees human beings as being separable from their environments.

This mechanistic view of the human person also implies a subject/object relationship between a researcher and the "subjects", or people, under study. One can note this implied relationship in the writings of Francis Bacon (1964), where he articulates ideas about truth and the "Idols" that keep men's minds from that truth. Truth, he writes, can only be found by deriving "...axioms from the senses and particular, rising by a gradual and unbroken ascent, so that it (the method) arrives at the most general axioms last of all .... Axioms duly and orderly formed from particulars easily discover the way to new particulars, and thus render sciences active" (p. 12). In other words, if one wants to discover truth, one starts with details, observable through the senses and moves outward, step by step, finally arriving at general laws or "axioms".

Applied to human research, Bacon's ideas suppose that the researcher, using her senses, studies an object of nature, in this case a human person, and arrives at laws which



apply to all humans. In other words, one person (the subject) studies another (the object) to derive immutable laws about human nature.

According to Bacon (and the prevailing paradigm that underpins quantitative research) researchers are prevented from discovering these immutable “laws” by “false notions” that “so beset men’s minds that truth can hardly find entrance” (p. 13). These are the Idols that Bacon asserts must be removed before nature can be interpreted by his “just and methodical process” (p. 12). The first of these is the Idol of the Tribe which distorts truth by making the individual rather than the universe the measure of all things. This flaw of human nature, Bacon proposes, “distorts and discolours the nature of things by mingling its own nature with it” (p.13).

The second of these Idols, the Idol of the Cave, occurs because each individual has “predispositions” (p.14) of thought that result from peculiarities of thought or education, and so prevent one from observing the truth. Similarly, the third Idol, that of the Marketplace, prevents men from knowing the truth because of “ill and unfit choice of words (which) wonderfully obstructs the understanding” (p.14). And finally, the Fourth Idol, that of the Theatre, consists of dogmas or philosophies, received from previous generations that interfere with knowledge of the truth .

The point about all of these Idols is that they originate in the imagination and perception; they are not part of the physical world, and Bacon asserts emphatically that all of them “must be renounced and put away with a solemn determination” (p.15). In other words, according to what has become known as the scientific approach to knowledge, the

world of legitimate study (including human “subjects”) exists “out there”, separate from the researcher, who does not have any effect on the person studied. This paradigm, or world view, posits a world of subjects and objects, where a methodical study of nature leads to a single “Truth”.

However, just as this study is based on a world view that considers the perceiver and the perceived inseparable, it also takes a view of the human person and the researcher/participant relationship that sharply contrasts that of Bacon. It is a view rooted in the human rather than the physical sciences (Parse, 1998) and shares with Van Manen (1998), Parse (1998), and Benner and Wruble (1989) a number of assumptions about being human. These assumptions include those proposed by Van Manen (1998) that the term “person” means the “uniqueness of each human being” (p.6) and that human science research and, in particular, hermeneutic phenomenology is “an expression of the whole” and “a philosophy of the personal, the individual, which we pursue against the background of an understanding of the evasive character of the *logos* of *other*, the *whole*, the *communal*, or the *social*” (p. 8). This view of the contextual nature of the person suggests a research method that maintains a link between researcher and the people who participate in that research. More will be said about Van Manen’s method in Chapter Three, but for now, it is enough to say that Van Manen views the researcher and the researched as creating knowledge together.

That perspective is also espoused by Parse (1998), particularly her phenomenological view that “the human lives with other, evolving mutually and in cadence with the universe” (p. 20) and “the human is unitary, different from the sum of

parts and is recognized through ways of becoming, co-created with the universe” (p. 22). In other words, human beings are viewed as non-reducible, co-creators of their realities, inseparable from the worlds they live in. In this kind of world, participants are very much co-creators of knowledge in a study such as this one.

Parse’s view of the human person and by implication, the researcher/participant relationship, is supported by Benner and Wruble (1989). They first critique social science models rooted in Enlightenment thinking, and conclude that a human being is an “embodied intelligence” (p. 42), situated in “background meaning” (p. 45) capable of “concern” (p. 47) and “involved in a context” (p. 49). These researchers posit that “because of embodied intelligence, background meaning and concern, people grasp a situation directly in terms of its meaning for the self” (p.49) and that “people are constituted by their worlds and solicited by them” (p. 49). Here, these theorists affirm Parse’s view of human beings as more than the sum of their parts and indivisible; they are co-creators of their worlds.

It is this view of the human person that I share and that underlies assumptions in this study about the relationship between the researcher and participants. In contrast to the view exemplified by Bacon, this view of the human person implies a relationship of interdependence between a researcher, participant and their environment, where the people studied do not become objects of study, but rather are active contributors to the research. Furthermore, from this perspective, the researcher does not become the perfect observer, free of all Bacon’s Idols, but rather acknowledges her biases and creates knowledge in cooperation with participants influenced by the environment.

### Statement of the Problem and the Research Question

Based on the previous literature review, three needs for further research were identified. These are:

1. the need for a qualitative study of EOLMDs which values older adults as co-researchers and focuses on their lived experience,
2. the need for nurses to gain knowledge about the older adults' experience of making EOLMDs in order to effectively meet the needs of this population, and
3. the need for nurses to gain knowledge to deal with ethical dilemmas such as those described in the background section.

These needs point to the problem that is the focus of this study. The central question in this study was: *What is the essence of the experience of older adults' (age 65 and over) in a community setting in making end of life medical decisions?* In this context, "essence of experience is understood to mean the concepts that give common understanding of this phenomenon" (Streubert & Carpenter, 1999).

Initial guiding questions for this study included:

- (1) *How do strong, positive family relationships affect the experience of elders making EOLMDs?* For the purposes of this study, strong and positive family relationships are ones where family members have regular, friendly contact with their older relative and provide social support. As is noted in A Guide to End of Life Care for Seniors (Health Canada, 2000), "social support is an important health determinant throughout life (and) influences an individual's outlook on the end of life--whether the remaining days are seen as a waiting period before death or as time left to continue living" (p.15). This statement

suggests that family relationships play some role in how elders experience making EOLMDs and is the reason for this guiding question.

(2) *What roles, if any, do spirituality and religion play?* For the purposes of this study, *spirituality* will be defined as a sense of the transcendent and/or any conceptualization of a higher power, however participants might conceive of that power (Health Canada, 2000, p. 135-6). Religion will be defined as a formal expression of spirituality through the belief system of some faith community (Health Canada, 2000; Heriot, 1992). Since “all persons experience spiritual needs, whether or not they are part of a formal religious organization” (Health Canada, 2000, p.135), it seemed likely to this researcher that both formal religion and spirituality would play a role in the experience that elders have of making EOLMDs. This question was intended to capture, at least in part, influences from a spiritual perspective.

(3) *Do past illnesses of self and loved ones impact these decisions and if so, how?* Among the questions that arise for elders at the end of life are questions such as “what is my previous experience of death (and) how has it affected my sense of my own death or that of a loved one” (Health Canada, 2000, p. 135). Given this questioning, it seemed reasonable that past illnesses of participants and their loved ones would be significant in the way elders experience making EOLMDs. This question was intended to capture the influence of participants’ past illness experiences on making EOLMDs.

(4) *How do elders interpret the existence of various options such as Do Not Resuscitate (DNR) orders and Personal or Advance Directives?* Since “it is now well-accepted in the field of bioethics, and in health care in general, that the person receiving care should be

the one to make the final decision on the course of treatment” (Hardingham, 1997, p. 8) and since elders are becoming increasingly aware of the need to complete these documents, this question was intended to explore what role (if any) these legal planning tools played in the experience elders had in making EOLMD.

These are the questions that will be addressed in the rest of this thesis. In the next chapter, (Chapter Three) a detailed account will be given of the methods used in this study, followed by findings that will provide some answers to these questions, or as Lincoln and Guba (1985) put it, provide a “working hypothesis” for the study questions.

## **CHAPTER THREE: RESEARCH METHODOLOGY AND PROCESS**

### **Research Design**

Given the nature of the research question, this exploratory, descriptive study uses a phenomenological method which incorporates Van Manen's (1998) theoretical perspective and methods (hermeneutic phenomenology (Van Manen, 1998; see also Fain, 1999)) including the recommended measures of confirmability (Russell, 1999; Streubert & Carpenter, 1999 ). A hermeneutic approach is a specific type of phenomenological approach based on the belief "that language captures the historical, cultural and immediate essence of lived experience as understood by the individual" (Russell, 1999, p. 167). In other words, it is an approach based on the assumption that the essence of a lived experience is accessible through texts like verbatim interview transcripts and participant journals. One major assumption of Van Manen's (1998) method is that "a deeper understanding of the nature or meaning of our everyday experiences" (1998, p. 9) can be achieved by turning to the nature of lived experiences, starting from personal experiences, obtaining experiential descriptions from participants, performing hermeneutic phenomenological reflection and writing (Van Manen ,1998).

In this chapter, I will first discuss the specifics of the study design including the rationale for the choice of a phenomenological approach to the research question. Next, I will describe methods of sample selection, data collection and analysis, recounting first, how participants were selected, followed by approaches and tools used to collect and analyze the data. In the sections on data collection and analysis, a detailed account will be offered of the methods of Van Manen's and other researchers who were used to guide the

design of this study. Finally, I will discuss the methodological issues related to confirmability and how these issues were addressed.

### *Selection of Phenomenology as a Method*

In addition to a need for a study on end of life medical decisions (EOLMDs) from an older adult's perspective, there is also a need for a phenomenological study on that topic. Since the voices of older adults appear to be absent from the research (see literature review) a method and a philosophy that is able to articulate their voices clearly is needed. A phenomenological design was selected for three reasons: (1) the appropriateness of the phenomenological approach to the question and the purpose of the study; (2) the appropriateness of the method to explore nursing topics; and (3) a lack of a "thick" (see Le Navenec, 1993), rich description of elders' experience in the current literature. These reasons for the choice of design will be discussed in turn.

The use of phenomenology is appropriate when the purpose of the study is to explore the meaning of people's lived experience (Creswell, 1998; Van Manen 1998). Other qualitative methods, such as grounded theory and ethnography use a phenomenological approach (Russell, 1999) but their purpose and focus are not as appropriate for a study that endeavors, as this one does, to explore the meaning of elders' lived experience of making end of life medical decisions. According to Russell's (1999) distinction, phenomenology explores the meanings of experience, while grounded theory attempts to "generate theory about social structures and processes" (p.173); and ethnography describes whole cultures, past and present. The three methods also differ in terms of the informants that each use to generate data. Whereas phenomenology explores



the lived experience of individuals (i.e., people who have experienced the phenomenon), grounded theory takes a broader view and includes "all persons involved in a social process" (Russell, 1999, p.172) in order to facilitate identification of basic social processes (BSP). Similarly, ethnography also takes a broader view and includes all people in the culture as potential informants. Of the three qualitative methods, phenomenology, with its focus on individuals who have experience of the phenomenon and its goal of producing a faithful description of the meaning and essence of an experience (Van Manen, 1998) is best suited to answer the question that is central to this study: What is the experience of older adults making EOLMDs?

Phenomenology is also an ideal method to apply to questions of experience that are of interest to nurses because of the fit between the nature of nursing and the underlying holistic world view that is inherent in phenomenology. Nursing theorists and researchers such as Russell (1999) argue that nursing is "guided by a holistic model that reflects the interrelationship of body, mind, spirit, and environment" (p.168). If this is true, as other nursing theorists have also argued (Benner & Wrubel, 1989; Parse, 1998) then, phenomenology which focuses on the lived experience of the elders and takes a holistic perspective, is ideal to provide nursing with a better understanding of the experience of older adults making EOLMDs. A comparison of characteristics of these three qualitative methods are provided in Table 3.1 below.

*Table 3.1 Summary of Differences Between Three Qualitative Methods\**

	<b>Phenomenology</b>	<b>Grounded Theory</b>	<b>Ethnography</b>
<b>Focus</b>	The meaning of lived experience of an individual.	Development of theory grounded in the data.	A description of a culture.
<b>Intellectual Roots</b>	Philosophy	Sociology	Anthropology
<b>Purpose</b>	To describe the meaning of the lived experience of an individual.	To generate theory about social structures and processes (Russell, p.173).	To describe and interpret a culture.
<b>Participants/ Informants</b>	People who have experiential knowledge of the phenomenon under study.	"All persons involved in a social process" (Russell, p. 173).	All persons who are members of the culture under study.
<b>Data Sources</b>	In depth interviews with a small sample (up to 10 participants) diaries, phenomenological descriptions, reviews of art, music, literature.	Interviews with 20-30 people, participant observation, and document review.	Participant observation and interviews over an extended period of time.  (cont.)

<b>Data Analysis</b>	Reflection on the data, dwelling with the data, interpretive identification of themes and structures of experience	Open coding, axial coding, selective coding, and constant comparative analysis.	Description, interpretations, and constant comparative analysis.
<b>Research Outcomes</b>	A full, rich description of the essence of a human experience	Integrated theory, an extension of an existing theoretical model	A well described culture, including descriptions of cultural behavior of a group or an individual.

\*Source: Modified from: Russell (1999, p. 173) and Creswell (1998, p.65)

## *Research Setting and Sample Selection*

### *Selection of Research Setting*

The home setting for the interviews were chosen in consultation with the participants. In the case of Mr. and Mr. Purple (pseudonym) the setting was a senior's apartment they had purchased after the sale of their home. Mrs. Orange (pseudonym) also lived in a seniors' housing complex. All other participants lived in detached dwellings. All participants lived within the city limits of the locale where the study was conducted.

There were three reasons for selecting participants' homes as the site for the interviews. First, the research question focused on elders living in the community, and led to a selection of participants' homes as a natural setting for the interviews. Secondly, the choice of home settings was intended to increase participants' comfort levels during the interview. Finally, the choice was influenced by practical matters of convenience in having extended contact with participants.

### *Sample Selection and Acquisition*

In a phenomenological study, the primary issue in sample selection is to ensure that the participants have experienced the phenomenon of interest (Creswell, 1998; Russell, 1999; Strubert & Carpenter, 1999). Therefore, a purposive sample of six individuals who had 'lived experience' of making end of life medical decisions was selected.

The six participants, all aged 65 and over, were accessed in two ways. First, personally and by letter (see Appendix A), I asked acquaintances and nursing colleagues to recommend clients whom they believed to be suitable to share their experiences of

making EOLMDs. Second, using a snowball technique, I acquired other participants through referral by a few of the participants. For example, two of the participants (Mr. Red and Mr. Purple) were recruited through referrals by their wives. Thus, my sample included two married couples, one widow, and one married women all of whom had experienced the phenomenon under study.

Each potential participant was first given a short explanation (either by phone or by letter) of the research project (See Appendix B) and a list of the inclusion criteria. Nine potential participants were contacted and given a more a more detailed explanation of what their participation would involve. Two declined to participate after they received this information, and one was eliminated because she did not fit the inclusion criteria (she was 63 years old). Next, I arranged a mutually convenient time to meet with the remaining six participants. Through these methods of sampling, four female and two male participants were identified.

At the initial interview, the selected participants were shown a copy of the inclusion criteria and asked to confirm that they met all of the criteria. At that time, I also reviewed the consent form (see Appendix C) with them and emphasized that they could withdraw their participation at any time. I also stressed that their participation might include being asked to respond to an initial report of the findings. All six agreed to participate and signed the consent form. At the time of the second interview, I informally reviewed the terms of consent with them and asked them if they were still willing to be interviewed and to participate in the study. All affirmed their consent. At the beginning of the study, a maximum of seven and minimum of five participants was determined by two

considerations: (1) by the demands of the phenomenological method used for this study, and (2) practical considerations such as available financial and time resources. The minimum and maximum numbers were based on recommendations by practicing phenomenologists (Creswell, 1998; Russell, 1999; Strubert and Carpenter, 1999) who suggest that small numbers of participants are sufficient to accomplish a critical goal of a phenomenological study which is to achieve saturation (Russell, 1999, Strubert & Carpenter, 1999), that is, to exhaust the possibilities of any new meaning in the experience (Merleau-Ponty, 1964).

Rudestam & Newton (1992) advise that decisions about participant numbers in qualitative work “may rely more on what the student ... deem(s) reasonable to develop a convincing argument, independent of statistical testing” ( p.65). With this information in mind, after two interviews with each of the six participants, my thesis supervisor and I judged that the required saturation had been reached based on the repetition in information that participants were giving. We concluded that it would not be necessary to increase the number to seven.

#### *Inclusion Criteria and Rationale*

To be included in this research, participants had to:

1. be male or female age 65 and over. Because the research question asked about the experience of elders as defined by being age 65 or over, this criterion was established to ensure that participants would be in this age group. Both male and female were included to explore the experience of both groups.

2. have made at least one end of life medical decision within the last year. Participants had to have had some experience in making end of life medical decisions. If the experience was recent, participants would be able to better recall important details.
3. be physically and mentally capable of participating in interviews and able to speak and write English. These requirements ensured full participation in the interviews and completion of diaries that were the basis for data collection.
4. be legally able to give informed consent.
5. be living in a community setting. As noted in the literature review, research on elders in the community making EOLMDs had been largely absent. Since elders living in the community are more likely to enjoy good, or at least better health than those in institutional care, one could expect that these two groups would have differing perspectives on EOLMDs.
6. be willing to disclose their affiliation, if any, with a faith community. Based on anecdotal evidence from this writer's professional experience, it was thought that religion and spirituality might make a difference in how older adults experienced making EOLMDs. Hence, it was decided that participants should represent a mix of religious and/or faith groups. Participants were asked for these data on initial contact. The sample included two practicing Roman Catholics, one practicing member of the United Church, two Protestants who described themselves as believers but not church-goers, and one self-described agnostic.

### *Protection of Human Rights*

Prior to the commencement of this study, the research proposal, including a sample consent form (See Appendix C) was submitted to and approved by the Conjoint Ethics Committee of the University of Calgary (See Appendix I for the Letter of Approval). At the beginning of the first interview, I explained to each participant the purpose of the research, proposed methods of data collection, and the steps that would be taken to ensure their anonymity and confidentiality. I also emphasized that participants could withdraw their consent at any time and/or choose not to answer any questions that were put to them during the interviews. They were also assured that data taken from their diaries would be edited for confidentiality and anonymity. I also informed them about their right to be advised of the results of the study. One participant at the time of writing has requested a copy of the final thesis.

#### *Steps to Ensure Confidentiality and Anonymity*

A number of measures were taken to ensure confidentiality and anonymity of the participants. The participants were assigned a pseudonym which was used in all paper and electronic documents, with the exception of some of the Contact Notes (CNs). In the latter case, after the initial contact, the actual names of the participants and any other identifying data were whited-out. The sample of transcripts provided in Appendix E has been edited for any information such as addresses, relationships or names of family members which might make it possible for a reader to deduce a participant's identity. As a courtesy, community nursing agencies that assisted in gathering potential participants will be informed of the results of the study. However, this information will consist of



conclusions only and will contain no personal or identifying information. Participants' personal data were shared only with the researcher's faculty advisor at the University of Calgary to the extent required to fulfill the requirements of a Master's Thesis in the Graduate Division of Educational Research in the Faculty of Education.

#### *Steps to ensure secure handling of data*

All data (hard copies and audiotapes) have been secured in a locked filing cabinet in the researcher's home for the duration of the research and will be held there for five years as required by the University of Calgary.

#### *Methods of Data Collection*

Data collection was guided by the phenomenological method articulated by Van Manen (1998). He offers a number of strategies for generating data including the three used in this study: in-depth interviews, participant diaries and field notes which encompassed observation, personal reflection and the use of literary sources. These three modes of data collection were used over an eighteen month period (from January, 2001 to August, 2002) to ensure sufficient information was collected to provide a "rich full, insightful description of (the) human experience" (Fain, 1999, p.172). These three methods are discussed next.

The first mode of data collection was semi-structured, in-depth interviews. An interview guide (see Appendix D) was used. Using this semi-structured approach, an initial interview and one follow-up validation interview was conducted with each participant. The purpose of the initial interview was to establish rapport and to obtain basic information about the participant's background and his or her experience of making

end of life medical decisions. The validation interview gave both researcher and participants an opportunity to clarify and expand on data from the first interview. The length of the interviews ranged from 65 minutes to approximately 150 minutes. All interviews were tape recorded and subsequently transcribed verbatim. In all cases, the participants were interviewed alone except in the case of Mr. Red, whose wife was present in the next room in an open plan living/dining room. Observations contributed by Mrs. Red during this interview were recorded in the Contact Notes as those of a general informant (i.e., one who has valuable, but peripheral information to offer) as opposed to participants who were key informants (i.e., the primary sources of data for this study).

A second method of data collection was that of participant diaries. Using guidelines suggested by Van Manen (1998), participants were asked to record thoughts, feelings and reflections on EOLMDs after each interview and at least once a week. Although none of the participants wrote in their diaries this regularly, all but one recorded at least two entries by the time the diaries were collected after the second interview was completed. This source of data allowed access to the reflective thoughts of participants. (Van Manen, 1998).

The third mode of data collection was field notes. The following five types of field notes were compiled throughout the period of study as suggested by LeNavenec (1993) and Schatzman and Strauss (1973).

1. **Observational Notes (ONs)** - contain descriptions of events and the environment available through watching and listening. These notes included observations of things like a participant's home, their physical appearance or nonverbal behavior.

These notes were the basis, in part, for the individual sketches found in Chapter Five, Participants' Lifeworlds and Experiences section.

2. Contact Notes (CNs) - include notes on correspondence, telephone conversations or other communication with the participants or general informants who have significant information to offer.

3. Personal Notes (PNs) - consist of a journal of the researcher's reflections. Entries were made after each of the initial interviews and at various times during the research project (Creswell, 1997, p.122). and included the researcher's thoughts and feelings about "the meaning and significance of the field experience" (LeNavenec, 1993, p.76).

4. Methodological Notes (MNs) - include reflections on methodological approaches, with a view to maintaining methodological integrity and auditability (Lincoln & Guba, 1985). These notes were used to record topics that needed follow-up during the next interview as well as ideas on how to address those topics (LeNavenec, personal communication, September 28, 2000). In addition, they were used to record consideration of the methods of data analysis ultimately used to provide triangulation of methods (Lincoln & Guba, 1985)

5. Theoretical Notes (TNs) - contain material used to formulate "mini-propositions" (LeNavenec, 1993) derived from preliminary analysis of the data as it emerged during participant contacts, and served as a basis for later analysis.

## Data Analysis

### *Some Reflections on Qualitative Data Analysis*

In this study, data analysis was conceptualized as inductive analysis; that is, a search in the data for themes, categories and patterns (Janesick, 1994). It was an ongoing process which began after the first interview (PNs June 30, 2003) and continued up to the time of writing. Data analysis was an iterative process that involved becoming immersed in the data, interpreting the data, then, returning to it throughout the study period. This dwelling with the data (MNs, November 23, 2002) had as its goal a full and exhaustive description of the experience under study (Creswell, 1998).

### *Methods of Analysis*

#### *Initial Identification of Categories*

All interviews were taped and subsequently transcribed verbatim by the researcher and one assistant. Participants' diaries were transcribed as well. The first round of analysis was guided by Van Manen's (1998) approach to thematic analysis which includes an understanding of *themes* as "structures of experience" (p. 79.) Such a method of analysis with its focus on experiential structures was chosen as a particularly apt starting place for answering questions about older adult's *experiences* of end of life decisions. (MNs, May 15, 2002). The steps of Van Manen's (1998) thematic analysis which I used include:

1. Uncovering themes - Preliminary themes are identified in the data, keeping in mind that themes are "only fasteners, foci, or threads around which the phenomenological

description is facilitated” (Van Manen, 1998, p. 91), and that no theme can exhaust the meaning of a phenomenon.

This step was accomplished in the field notes by notations that described first thoughts about common themes arising in the data. An example of one of these preliminary themes was the one of “No Heroics”, which became evident after the first three interviews (TN, Aug. 7/01).

2. Isolating thematic statements- In order to uncover and isolate experiential structures, Van Manen (1998) suggests three approaches be used together: (a) the *holistic or sententious approach* where the researcher focuses on the text as a whole and asks, “What sententious phrase may capture the fundamental meaning or main significance of the text as a whole?” (p. 93); (b) the *selective reading approach* where the researcher reads or listens to a text several times and asks, “What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experiences being described?” (p. 93); (c) and the *detailed reading approach* when the researcher looks at every single sentence or sentence cluster and asks, “What does this sentence or sentence cluster reveal about the phenomenon or experience being described?” (p. 93).

This step was accomplished by first reading the texts of each interview and writing a phrase at the bottom of each transcription that seemed to sum up the main theme(s) that the participant was expressing about end of life medical decisions. Then, a selective reading was done by making marginal notes beside each instance of a participant's description of end of life medical decisions.

3. Composing linguistic transformations - Here, Van Manen (1998) suggests that thematic statements be captured in researcher-written paragraphs based on notes, reading and other research activities. The purpose of this step is to gain insight by creating phenomenological focused *summaries* of the data.

In the first round of analysis, there was an attempt to capture common themes by writing summaries of the themes found in all the interview texts. This first round of analysis resulted in an articulation of Categories of data which included the following:

- Having to think about past experiences with death and illness
- Considering others (e.g., views of family members)
- Considering end of life possibilities/scenarios
- Making preparations and decisions
- Considering personal values/quality of life
- Identifying categories that do not directly contribute to the understanding of the question (MNs, June17, 2002).

#### 4. Interpreting through collaborative hermeneutic conversations

In conversations with participants, data were analyzed by allowing participants to reflect on the experiences that had been gathered by the researcher through interviews and other methods of data collection. As Van Manen (1998) points out, themes identified by the researcher become the objects of study and thus allow deeper meaning and other themes to be discovered. This fourth step was accomplished in the second round of interviews by asking participants to comment on initial themes and asking how those themes described their own experience. For example, since the theme of "no heroics"

seemed to feature prominently in the first round of interviews, in the second round, participants were asked to comment further on what "no heroics" meant to them.

### *Expansion, Development and Refinement of Categories*

After the initial categorization of the data, I encountered a problem in data analysis. Since "the aim of developing a category system is to ensure that all of the meaning units in the text are accounted for" (Bernard, 1994, p. 114) there was a problem in that the last category mentioned above, (categories that do not directly contribute to the understanding of the question) contained much information that related indirectly to participants' experience of the data. An example of this kind of information was participants' mention of other EOL decisions that were not medically related, such as making burial decisions and powers of attorney. Therefore, the category system as it stood, did not account for all the significant data (MNs, June 27, 2002). To solve this problem, an expansion of the categories was accomplished in the following way:

1. First, copies of the transcripts were cut into sections and pasted onto 3x5 index cards. A complete thought was deemed to be a section. In cases where I asked a leading question, the question was included in the section to provide context. In cases where I had reflected the participant's thought back, the comment was omitted from the section.

2. An initial sort of the cards was done according to Lincoln and Guba's (1985) "look alike, feel alike" method of initial categorization.

3. The index cards were then pinned to display boards, grouping cards according to the initial sort, and a heading was given to each group of cards that attempted to capture the meaning of all of the cards in the group. In naming the groups, an attempt was

made to stay as close to the participants' wording and point of view as possible so as to give voice to THEIR expressions of experience. This was done until all the cards were accounted for.

4. Adjustments were made, sometimes reassigning a card to a different group that seemed to better encompass its meaning, and sometimes adjusting the wording of the group heading to better capture the meaning of the cards in the group.

Through this process, the initial five categories were expanded to eleven and a brief defining description of each category was constructed. These categories included:

1. A good/best end
2. What I would want/ accept at EOL
3. When to "pull the plug"/ When I don't want to be kept alive
4. Making things easy for those left behind
5. Communicating with others about EOLMDs
6. Having seen some of the things that can happen to me and others
7. Playing it by ear
8. Personal and religious beliefs
9. Other EOL decisions
10. Background information
11. Extraneous information

At this point in the data analysis, demographic information and family history was considered background information. This information, was eventually captured in Chapter Five: Participants' Lifeworlds and Experiences. Extraneous information



(category number 11) was included general comments such as those about weather, news items, etc. that served to build rapport but did not directly address the research question or interview probes.

### *Testing of Categories*

To test the constructed categories against the data, I asked two nursing colleagues to examine two transcripts and assign the above categories to test for "a reasonable match between two people reviewing the category system" (Burnard, 1994, p. 114). Here, testing is understood as a "hermeneutic conversation on the themes and thematic descriptions of phenomena ..." (Van Manen 1998, p.100). In this approach to understanding phenomena, testing is the art of questioning for the purpose of "allowing the author to see the limits of his or her present vision and to transcend those limits" (Van Manen 1998, p. 100).

The result of this test was that both readers affirmed my coding of the material with two notable exceptions. Parts of the transcripts that I had coded as background material, particularly segments relating to family history were coded by both the outside coders as belonging to the category "personal and religious beliefs". For example, I coded as background a segment from the first interview with Mrs. Green that read, "I've been an avid reader all my life. And [my] parents, [were] the same way. My mom and dad ... not my dad, but my mom believed the same way I do." Both coders categorized this segment as belonging to the "personal and religious beliefs category." As a result of this testing, some data segments were re-categorized as part of the "personal and religious beliefs

category" and the category was renamed as "The Impact of Personal and Religious Beliefs" to better capture all the data in that category.

The other major change to the categories as a result of the testing was that the two readers interchanged categories three and two; that is, that they did not seem to make much distinction between a coding of "What I would want/ accept at EOL and "When to pull the plug/let me go." As a result, these two categories were collapsed into one. See Table 3.2 for a list of categories and sub-categories at the end of this stage of analysis.

Table 3.2 Summary of Categories and Sub-Categories of Data

	<b>Code: EOL= End of Life ; EOLMDs= End of Life Medical Decisions</b>
<b>Categories of Data</b>	<b>Sub-Categories of Data</b>
<b>1.0 Recalling Past Experiences with EOL and Illness</b>	1.1 Recalling the worst that can happen. 1.2 Recalling the best I have seen
<b>2.0 Encountering the Uncertainty of the EOL Situation</b>	
<b>3.0 Hoping for the best possible EOL situation</b>	3.1 A good/ideal EOL 3.2 What I want/would accept at EOL
<b>4.0 Preparing for the worst EOL situation</b>	4.1 Internal Preparations
	<i>4.1.1 Thinking about what I don't want/when to pull the plug</i>
	<i>4.1.2 Thinking about expectations of others at EOL.</i>
	<i>4.1.3 Encountering procrastination about EOLMDs</i>
	<i>4.1.4 Understanding the difference age makes.</i>
	<i>4.1.5 Thinking about personal/religious/family values and beliefs</i>
	4.2 External Preparations
	<i>4.2.1 Preparing to make things easy for those you leave behind</i>
	<i>4.2.2 Communicating about EOLMD with others</i>
<b>5.0 Making other EOL decisions</b>	
<b>6.0 Background</b>	
<b>7.0 Extraneous information</b>	

### *Conceptualization of Essential Themes*

The next step in data analysis was to re-conceptualize the categories into themes. Van Manen (1998) refers to this step as "composing linguistic transformations" (p. 95) and "determining incidental and essential themes" (p. 106). For the latter process, Van Manen (1998) proposes that "in determining the universal or essential quality of a theme, our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is" (p.107). With this definition in mind, Van Manen's (1998) four essential themes of Lived Space, Lived Body, Lived Time and Lived Other were used as a guide to reflection on the categories. This last step in analysis led to a definition of five essential themes. These are:

1. Recalling Death and Illnesses
2. Imagining My EOL Situation and Beyond
3. Considering the Role of Others in my EOL
4. Preparing for EOL
5. Experiencing Uncertainty

### *Data Transformations and Summary of Steps of Analysis*

Some researchers assert that each transformation of data, especially a written transformation, is an interpretation by the researcher and thus, a form of data analysis (Denzin, 1994; Huberman & Miles, 1994; Richardson, 1994). Therefore, it is fitting that the stages of analysis be summarized with the accompanying data transformations that occurred, which are as follows:

1. Transcribing the tapes - During this stage, the taped interviews were transcribed verbatim by the researcher and one assistant.

2. Initial Categorization of Data - Transcripts and diaries were analyzed according to Van Manen's (1998) method which afforded identification of six initial categories for the data.

3. Development, Refinement and Expansion of Categories - Transcripts were again analyzed using the methods described above to refine the categories until they accounted for all the data in the transcripts. This step resulted in expansion of the number of categories to eleven.

4. Testing the Categories - The categories were applied to two selected transcripts by two outside reviewers and myself. The categories were adjusted as a result to seven in number as described.

5. Conceptualizing Essential Themes - The categories of data were recombined using Van Manen's four existentials to capture five essential themes.

6. Writing phenomenological descriptions- The writing of the research report is seen as a linguistic transformation of the data (Van Manen, 1998) and therefore a part of the method of analysis. (For a more detailed discussion of writing as part of the method see Chapter Four). During this phase some final adjustments were made to the wording of the five essential themes.

### *Methodological Issues*

With the assumptions and world view that underpin this study, concepts such as internal and external validity, reliability and generalizability usually associated with

quantitative research are not appropriate. However, qualitative methods such as phenomenology are often criticized for a lack of scientific rigor (LeNavenec, 1993). To address the issue of rigor, this research was based on Lincoln and Guba's (1985) concept of trustworthiness. First, a discussion of Lincoln's and Guba's measures of scientific rigor in qualitative research will be presented, followed by an explanation of how this study met those measures.

Lincoln and Guba (1985) argue that traditional measures of validity, reliability and generalizability found in quantitative research are not appropriate for qualitative work (See also Russell, 1999; Streubert & Carpenter, 1999). Instead, they propose measures of trustworthiness. Trustworthiness, as conceived by Lincoln and Guba (1985), consists of four elements, which should be established for qualitative research:

1. Truth value or "how ...one establish[s] confidence in the "truth" of the findings" (p.290).
2. Applicability or "how ...one determine[s] the extent to which the finding of a particular inquiry has applicability in other contexts or with other subjects (respondents)" (p. 290).
3. Consistency or "how ...one determine[s] whether the findings of an inquiry would be repeated if the inquiry were replicated with the same (or similar) subjects (respondents) in the same (or similar) context" (p. 290) and
4. Neutrality or "how ...one establish[s] the degree to which the findings of an inquiry are determined by the subjects (respondents) and conditions of the inquiry and not by the biases, motivations, interests or perspectives of the inquirer.

Although these four elements have been established in quantitative research with measures of internal validity, external validity, reliability and objectivity respectively, Lincoln and Guba (1985) propose a set of parallel measures for qualitative work. These are credibility, transferability, dependability and confirmability. Each of these will be discussed in turn along with techniques for meeting each of these requirements.

1. Credibility - the measure of truth value which equates with positivistic measures of internal validity. In qualitative work, credibility is achieved by a number of techniques which include prolonged engagement, persistent observation, triangulation of sources, methods and investigators, peer debriefing, negative case analysis and member checks (Lincoln & Guba, 1985).

2. Transferability - is a measure of applicability which parallels quantitative measures of external validity. In order to establish the applicability of a study, Lincoln and Guba (1985) have concluded that ...

the naturalist can only set out working hypotheses together with a description of the time and context in which they were found to hold ... he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility. (p. 316)

Therefore, they recommend meeting the requirements of this measure by thick description. This kind of description includes a "holistic and lifelike description that is like those that the readers normally encounter in their experiencing of the world" (p. 359) as well as a "thorough description of the context or setting within which the inquiry took

place ...[and] a thorough description of the transactions or processes observed in that context that are relevant to the problem ..." (p.362).

3. Dependability - is a measure of consistency that these researchers equate to positivistic measures of reliability that are met with an audit for 'dependability'. The latter is a test that is met if readers are "able to follow the decision path of the researcher and arrive at the same or comparable (but not contradictory) findings, given the researcher's data, perspective, and situation" (Russell, 1999, pp. 176-177).

4. Confirmability- is measure of neutrality which is met when a reader can follow the methods of data transformations, data reconstruction from the raw data and can identify "materials relating to intentions and dispositions" (Lincoln & Guba, 1985, p.320) of the researcher. These researchers recommend meeting this requirement through keeping a reflective journal in order to identify the researcher's pre-knowledge, suppositions and the development of ideas and through descriptions of bracketing (setting aside of identified biases and previous knowledge).

### **The Researcher's Responses to Issues Related to Trustworthiness**

The following sections outline my response to issues of trustworthiness as described by Lincoln and Guba (1985). A summary of these issues and the techniques used in this study to increase trustworthiness are outlined in Table 3.2.

#### *Credibility*

In this study, credibility was increased by:



*Triangulation of methods and data sources*

This study used two types of triangulation: (1) It drew on the two sources of data described in the section on data collection (triangulation of sources) ; and (2) the analysis of data using two additional qualitative methods of data analysis as a check (triangulation of methods).

Although Lincoln and Guba (1985) do not describe a process for triangulation of sources, they do specify one example of triangulation of sources where an "interview respondent's recollections about what happened at a board meeting (is verified) by consulting the official minutes of that meeting ... ". This suggests that themes found in multiple sources, for example, both interviews and diaries help to meet the requirement of credibility.

In addition to triangulation of sources, was a triangulation of methods. In addition to the steps of analysis, mentioned above, two additional methods, those of Burnard and Parse, were used as a check to see if similar themes could be found in the data. The two methods, outlined in Table 3.2, were adapted and applied to the data with the result that the five essential themes listed above were found by the researcher.

*Table 3.2 A Summary of Burnard and Parse's Methods of Data Analysis\**

Parse's Method	Burnard's Method
Extract essences (core ideas in participants' words) from transcribed descriptions.	Clean the text by removing "dross", that is, text that does not further understanding of the participant's point of view.
Synthesize essences (putting a core idea into the researcher's language)	Divide the texts into meaning units that is a phrase, sentence or group of sentences that conveys a single idea.
Formulate a proposition from each participant's description.	Develop a category system, that is, look for patterns in the data and identify themes under which the meaning units can be grouped. This step involves assigning a letter to each theme
Extract core concepts from the formulated propositions	Order themes. Using the sort feature on a word processing program, order the themes and adjust the categorization of the meaning units as necessary
Synthesize a structure of the lived experience, that is, describe relationships between the propositions.	Interpret the patterns in the data.

*\*Source: Parse, 1990; Burnard 1994*

*Prolonged Engagement and Persistent Observation*

The data were collected over a period of 18 months. There was a minimum of three contacts with each participant (an initial phone contact and two interviews) with a period of at least three months between the first and second interviews. This time period allowed building of a trusting relationship, one of the purposes of prolonged engagement according to Lincoln & Guba (1985). This trust is illustrated, for example, by Mrs. Purple, who confided in me that she was prepared to die "whenever the good Lord was ready to take me."

One limitation to this study is a challenge to credibility that arises because I had worked with elders before undertaking this study and so bring what Lincoln and Guba (1985) call "distortions" that arise from working as geriatric nurse. For example, I initially interpreted participant's comments about postponing making a Personal Directive as "avoidance", a concept from my work life that I obviously had not bracketed. Although the identifiable biases were bracketed (see Chapter 1) I cannot say with any degree of certainty that the contact period was long enough to recognize all such distortions, or if, indeed, any contact period would be adequate to recognize and bracket them all.

It was, however, long enough to recognize at least some of the distortions introduced by the participants. For example, participants consistently interpreted questions about end of life **medical** decisions as questions about end of life decisions **in general**. This recognition led me to attempt to account for this distortion and this

accounting eventually became a critical part of the findings (see Findings, Chapter Seven):

### *Negative Case Analysis*

Lincoln and Guba (1985) describe negative case analysis as "a process of revising hypotheses with hindsight" (p.309) which "requires that the researcher look for disconfirming data in both past and future observations" (p. 310). The goal of negative case analysis is to "continuously refine a hypothesis until it accounts for all known cases without exception" (p.309). Negative case analysis was used in this study in the construction of the sub-category of "Encountering Procrastination" (4.1.3 in Table 3.1). Initially, this sub-category of the data was found in the transcripts of only three of the participants. On further analysis, it was found that participants' comments about putting off the making of Personal Directives often came in connection with a discussion of specific EOL situations that participants were trying to envision. It seemed that the procrastination they encountered was a manifestation of the uncertainty they experienced when they envisioned EOLMDs. (TN, July 28/02) This insight required reexamination of the transcripts to see if this category appeared in some form in all the participants' descriptions.

### *Peer Debriefing*

Another technique used in this study to increase credibility was peer debriefing whereby peers not involved in the research were asked to review a study with an aim to "explor[e] aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind" (Lincoln & Guba, p.308). The two nursing colleagues were not only

asked to code transcripts but also to offer feedback on the definitions of data categories. Since both were practicing geriatric mental health nurses, they qualified as peers who were knowledgeable about the area of inquiry (Lincoln & Guba, 1985). Feedback they offered brought a new category of data to light that, up until that point, had been classified as "other" or data that seemed important to the question, but did not seem to fit in any of the existing categories.

In addition, a more formal method of peer debriefing was used near the end of the study period. Two other colleagues, with knowledge of qualitative research were provided with a draft of this thesis along with samples of raw data (transcripts of the interview, samples of field notes ) and asked to answer two questions: (a) Was the phenomenon under study recognizable from the data they were provided with and (b) if not, why not. The result of this process was that one peer debriefer asked for more exemplars from the transcripts. With this addition, both debriefers were able to recognize the phenomenon.

#### *Member or Participant Checks*

One final measure used in this study to assure credibility is the use of member or participant checks. Lincoln and Guba (1985), describe it as "the most crucial technique for establishing credibility" (p. 314) and a way to ensure that participants can recognize their own experience in the descriptions.

Participant checks were done in two ways. First, meanings and descriptions that were ambiguous in the first interview were followed up by having participants check my interpretations. For example, in the first interview, Mr. Red described a desirable death as

a "natural death" which I interpreted as one that would not be long and drawn out and would not involve technological interventions during the dying period. During our second meeting, I checked my interpretations with him to find that a "natural death" could also be preceded by a chronic illness. In this case, the "natural death" was not an ideal or desirable death.

A second, more formal participant check was completed toward the end of the study period. At that time, I prepared a preliminary report which consisted of a description of each of the five essential themes that had been uncovered and a diagram that depicted relationships between the themes. These were presented to two participants and they were asked to answer three questions: (1) does the diagram and the description accurately describe your experience? (2) is there anything significant in your experience that the visual and written descriptions do not account for? (3) if yes, what in particular do the descriptions NOT account for? The result of this consultation with Mrs. Orange and Mrs. Green was that both participants acknowledged their own experience of making end of life medical decisions in the preliminary descriptions. Mrs. Orange, in response to the second question observed that "Seniors prepare for life, not for death" (CN, July 9/03) and Mrs. Green commented that the description in the preliminary report of "hoping for the best and preparing for the worst" especially captured her experience.

This participant check brought to light another limitation of this study. Given the purpose of member checks, which is, to test that phenomenological descriptions are "adequate representations of [participant's] own (and multiple) realities" (Lincoln & Guba, 1985, p. 314), credibility would have been strengthened by doing this formal check

with all of the participants. However, the demands imposed by limited time and resources made it necessary to abbreviate this method of establishing credibility which results in increased reliance on the other measures outlined in this section.

### *Transferability*

The best way to assure transferability is by use of thick description, that is, a "data base that makes transferability judgments possible" (Lincoln & Guba, 1985. p. 316). In this study, thick description is understood as hermeneutic description, that is, interpretive description that increases understanding of lived experience (Van Manen, 1998).

With this understanding in mind, thick description is provided in three ways. First, detailed descriptions of each of the five participants and the research settings given in Chapter Four provide the context necessary for the reader to make judgments of transferability. Secondly, detailed descriptions of the five essential themes uncovered are provided along with supporting quotes and exemplars from the participants in the findings section.

The last method used in this study to provide thick description is a nontraditional presentation of data in the form of a literary nonfiction piece that depicts the meaning and lived experience of making EOLMDs as uncovered in this inquiry. This presentation contributes to transferability because it gives the reader an additional opportunity to judge whether the conclusions are consistent with her own experience, one of the tests for assessing phenomenological research (Van Manen 1998; Russell, 1999).

*Dependability/Auditability and Confirmability*

Lincoln and Guba (1985) have concluded that dependability and confirmability are best established with techniques which make a study auditable, that is, techniques which make the process of inquiry and the conclusions of the study available to critique.

Two ways in which this study makes critique possible is in providing a detailed description of the research process and by providing samples of raw data (unedited transcripts, participant diaries and field notes). A detailed account of the transformations of data and the research methods have already been provided in this chapter. In addition, samples of the interview questions used to begin the interviews appear in Appendix D. This, with samples of unedited transcripts and participant diaries found in Appendices E and F respectively are offered as an audit trail to provide the reader with the data necessary to assess the dependability and confirmability of the conclusions. Below is a summary of the measures taken to establish trustworthiness in this study and a comparison to measures traditionally used in positivistic research.



*Table 3.4 Summary of Techniques to Assure Trustworthiness\**

<b>Element of Trustworthiness being measured</b>	<b>Measure in Positivistic Research</b>	<b>Measure in Qualitative Research</b>	<b>Technique used in this study</b>
Truth Value	Internal Validity	Credibility	<ul style="list-style-type: none"> <li>✓ Triangulation of sources and methods</li> <li>✓ Prolonged engagement and persistent observation<sup>1</sup></li> <li>✓ Negative Case Analysis</li> <li>✓ Peer Debriefing</li> <li>✓ Member Checks</li> </ul>
Applicability	External Validity	Transferability	<ul style="list-style-type: none"> <li>✓ Thick description: <ul style="list-style-type: none"> <li>• Descriptions of participants and research contexts.</li> <li>• descriptions of the four essential themes that were uncovered?</li> <li>• literary nonfiction presentation of data</li> </ul> </li> </ul> <p>(cont. next page)</p>

			(cont. from previous page)
Consistency  AND  Neutrality	Reliability  AND  Objectivity	Dependability/ Auditability  AND  Confirmability	✓ Audit trail: <ul style="list-style-type: none"> <li>• Detailed description of the research "process."/0</li> <li>• Provision of samples of raw data forms</li> <li>• Provision of sample entries of a reflective journal</li> </ul>

\*Source: Lincoln and Guba, 1985

## Conclusion

The purpose of Chapter Three was to give a full account of the research process and methods used in this study, including its appropriateness to the research question and its faithfulness to the world view which underpins this study. This approach affords insights for the development of the new paradigm of nursing that Parse (1998) asserts is needed:

...to posit the idea of nursing grounded in the human sciences is to make explicit an alternative to the traditional practice of nursing as a medical model grounded in the natural sciences ... (p.1)

The account provided in this chapter is intended to lay a foundation for this study, grounded in an alternative, human sciences view of nursing. With that in mind, the next three Chapters will provide a "rich, full description" by presenting the lifeworld of each participant, with a creative nonfiction presentation of the data, and by describing the meaning and structures of the lived experience of making EOLMDs.

## **CHAPTER FOUR: THE LEWELWOLDS AND EXPERIENCES OF PARTICIPANTS**

### **Introduction**

In Chapter Three, the need was emphasized to provide an audit trail, to evaluate the adequacy of the thick description, including contextual features, and to assure the trustworthiness of this study. The next two chapters are intended to provide those elements in two ways. In Chapter Four, the reader will be provided with a summary of each participant's lifeworld (Van Manen, 1998) and in Chapter Five, a thorough description of each of the essential themes that came out of those life worlds will be discussed.

The summaries that follow, compiled from observation notes (ON) , personal notes (PN) and transcripts, give a general description of participants' physical surroundings, their family backgrounds, their current state of health and other pertinent details. In addition, themes from the data from each participant which informed the explication of the essential structures will be described. Finally, a summary of participants' experience of making end of life medical decisions (EOLMDs) is given.

### **Some Reflections on Writing**

Lincoln and Guba's (1990) view is that the narrative in case studies provides a way for the reader to judge both the process and the product of a qualitative study and thus provides a way to assess trustworthiness; it is a view I share. With this emphasis on writing, it is fitting that a more detailed account be given of the views of writing assumed in this study.

*Writing as a method of inquiry*

In this study writing is understood as a way to discover and uncover meanings in the data not previously or completely understood. As Richardson (1994) points out, "Writing is ... a way of knowing, a method of discovery and analysis." Thus, the writing and rewriting of the following case studies is viewed as a transformation of data (Van Manen, 1998) and a final step in data analysis.

Inherent in this view is that writing is part of thinking, or "a great way to discover what we are thinking as well as to discover gaps in our thinking" (Wolcott, 1990, p. 21). Writing can therefore be said to be socially constructive (Richardson, 1994), that is, as a part of the shaping of participants' experience so it can be understood by others.

**Reports of Participants' Lifeworlds and Their Experience of Making EOLMDs.***Mrs. Purple*

Mrs. Purple, 75 years old at the time of the interview, was born in 1926 in a rural community in Alberta. She dropped out of school after grade nine, but it wasn't because she wanted to: that was the highest grade available in the local country school. She married at age 17 and has been married for 58 years to the same man. Although she worked part time for ten years at the food services department at a local university, she has primarily been a wife and a mother and if you ask, she will say her family has been her most important job. She and her husband have one son, six grandchildren and eight great grandchildren. A daughter, her oldest child, died of ovarian cancer approximately ten years prior to our first interview.

In terms of religion, Mrs. Purple declares herself an Anglican Protestant. However, she does not attend church regularly, and doesn't consider herself a "Christian church goer". She does say she tries to live by the Ten Commandments

Mrs. Purple lives with her husband in a senior's apartment on the ground floor of the complex. The entrance shows evidence of Mrs. Purple's gardening talent. It is surrounded by a small patio where flowers bloom in pots and there is a small, well kept patch of lawn. On the patio, beside the door, is a two-person garden bench, with a plaque inscribed in memory of the Purples' daughter. The apartment itself is small (approximately 700-800 square feet) with two bedrooms, a kitchen-dining area and a small living room. Mrs. Purple tells me that she and her husband bought the apartment outright with the proceeds from the sale of their house in Victoria six months prior to my first visit. Their home is immaculately clean and, with the exception of the sofa, which looks fairly new, the apartment is furnished with what Mrs. Purple calls "my antiques". Just to the right of the sofa, as one walks in the door, there is a china cabinet, filled with Hummel figurines.

During our initial interview, the first thing I noticed about Mrs. Purple was her hands. They are permanently clenched by rheumatoid arthritis and as she gestured me into the neat little living room of her condo, the marionette-like movement of her welcoming hand stopped in mid-sweep, halted by her disease. As I settled into an overstuffed "conversation pit" sofa, and took out pen, paper and tape recorder, Mrs. Purple struggled to arrange a padded board between herself and the sofa, to give her arthritic hips and spine more support. (ON, July 18, 2001).

She has had the arthritis for over twenty three years (PNs, July 18, 2001) and although she sometimes acknowledges the toll it takes on her ("I am 100 lbs, no energy, R/A flared pain everywhere, all the time.") she feels she has coped with determination and has "made friends" with her arthritis. She speaks of her body with affection, ("this little body, I don't know how it keeps going) as if she were talking about a friend whom she would be reluctant to cause any extra misery.

In making end of life decisions, Mrs. Purple's experience with chronic rheumatoid arthritis has made her "realize that enough is enough and just by hooking you up to tubes, you're just prolonging it, and the ones who are really in pain then are your family." In other words, Mrs. Purple experiences making EOLMDs as a way to spare both her family and her self the further pain of her chronic illness.

Despite her illness, at the time of our first interview, she described herself as coping well with the disease and said she had no other health complaints. By the time of the second interview, however, that had changed. She had been admitted to hospital with a flare up of her disease and had had a fall. Her biggest complaint about her health during the second interview stemmed from her perception that the doctors had made her worse during her hospital stay by treating her with narcotics which she viewed as the cause of her fall.

In fact, in her journaling and in the second interview, the sole subject of Mrs. Purple's offerings was her negative experiences with the medical profession. For example, in the second interview, she recounts an incident, years before, when a doctor had given her antibiotics which gave her an allergic reaction. At that time, she was sent to hospital

"because they thought they had ruined all of my platelets." After relating this, she concluded, "I've never been treated for anything ... that I haven't had worse happen to me than if I'd just crawled into bed and stayed there."

Given these experiences, it is not surprising that in her imagined EOL, Mrs. Purple's relationship with the medical profession is one fraught with danger and uncertainty. Will the doctors help her or make her worse? She seems sure they will not help. She makes comments like "I would sooner rust out than get pushed out [of life, by doctors]", and "After going through this kind of stuff, when there's nothing much wrong with you, who'd want to be hooked up?" and "I don't want to be hacked and sawed." All of these comments speak of a lack of trust so great that Mrs. Purple is unwilling to make EOLMDs that might result in putting herself in the care of "medical people" when she is unable to speak for herself.

This mistrust of physicians as a profession confronts Mrs. Purple with the possibility that she might be harmed at a time when she most needs help. When asked to describe heroics, she replied, "Heroics. I think if your heart stopped and they were pounding on you they would probably break every rib I've got and I would end up in more pain ... I figure if my little heart stopped - leave it alone." In her relationship to medical professionals, Mrs. Purple experiences making EOLMDs as a way of protecting herself from an uncertain EOL situation where she has to surrender control to the medical profession.

Mrs. Purple not only experiences making EOLMDs as a remembrance of her own past illnesses but also as a recall of the deaths of loved ones. During both the interviews,



in response to a question about how she made EOLMDs, Mrs. Purple recalled how her daughter, dying of ovarian cancer, was "like a porcelain doll, she had no flesh, just skin over her bones". Mrs. Purple also recalled her husband's desperation when he asked the attending nurses "if there was anything [he] could do for her, because [their daughter] was in so much pain". Mrs. Purple concluded, "So, I think when you've been through something like that, your own going is not so terribly traumatic". Mrs. Purple recalled the death of her daughter to see what can happen at life's end and used the memory to prepare for her own death.

Mrs. Purple not only recalled traumatic experiences of death and illness, but also projected these experiences into an uncertain future as she tried to imagine how her life might end (in prolonged illness? quickly?) and what kind of acts and circumstances might be desirable at that time. For example, she imagined that she might have Alzheimer's and declared that if she did, she would want to be treated with dignity. She then went on to suggest that this dignity is, at least in part, dependent on being able to live in a place that "will accommodate people's dignity, even if they haven't got huge amounts of money". According to Mrs. Purple, making EOLMDs is, in part, experienced as a hope for being treated with dignity, even if her life does not end quickly as she hopes it will.

In speaking about EOLMDs, again and again she demonstrated a concern for her family that would be left behind. For example, she spoke about her husband's lifetime of duty to her, how he has "paid his dues" and of how she sees her death as release for him: "If there's anything left of his life [after Mrs. Purple's death] I'd like to think that he could do some of the things that we haven't been able to do for twenty three years, because I've

been sick." Mrs. Purple does not want to prolong her own life, in part because she hopes her death will bring him some benefit.

Mrs. Purple's experience of making EOLMDs is also an occasion of hope for a life after death and views her relationship with God primarily as one of responsibility to have lived a good life. In response to questions about how religion affected her EOLMDs, she replied,

Lord Jesus gave us the opportunity to make choices. He didn't tell us to do things, He gave us the choice. So, all, anything I've done, I feel if it wasn't a good choice, I've always made a point of asking forgiveness for it, and then putting it aside.

In other words, if she has lived a good life according to what she believes God intended, she experiences being "satisfied that I've had my seasons ... [and] when it's time to go, I'm ready." Mrs. Purple's experience of making EOLMDs is partly an experience of preparing for EOL and hoping for an afterlife that is in keeping with her religious beliefs.

#### *Mrs. Purple's Experience of Making EOLMDs*

Mrs. Purple's experience of making EOLMDs is an experience of recalling past experiences with illness that have led to a lack of trust in the medical profession, and past experiences of loved ones dying. These latter experiences include memories of the pain of watching loved ones die. Her experience is also one of trying to imagine her own dying and what that will be like. She hopes to go quickly, to spare herself physical pain, and her family the agony she suffered in watching her daughter die. But will that happen? Perhaps not. She knows she could die slowly, as with Alzheimer's Disease or suffer at the hands

of a medical profession she doesn't trust. So her experience is also one of uncertainty of what circumstances the end of her life will bring.

*Mr. Purple*

Mr. Purple is a 79 year old man who resides in the senior's apartment described above with his wife of 58 years. He was born in Dorset, England and grew up on a farm, the younger of two brothers and finished high school just as W.W.II was beginning. In 1942, he joined the British Air Force and became a pilot, and eventually a flight instructor. During a posting to Canada, he met and married Mrs. Purple.

Over the course of his married life, he and his wife have lived in England, followed by a move to Drumheller, then to Calgary, where they raised two children. After their children were grown, Mr. Purple took early retirement at age 55, and he and his wife moved to Victoria and lived there until 1-2 years before the time of the first interview. They returned to Calgary in 2000 primarily because of Mrs. Purple's desire to be closer to children and grandchildren. Mr. Purple very much liked living in Victoria and was reluctant to return to Calgary and only did so at his wife's insistence.

Over the years, Mr. Purple has held various jobs as a miner, a distributor for a foreign car manufacturer, a parts manager in a car dealership and owner of his own auto parts business. His last job was with a local telephone company where he worked his way up from repairman to personnel manager by taking some university courses.

He has had some minor health problems which include "heart trouble" (CNs July 24, 2001) for which he takes medication. He also experiences some minor arthritis pain but overall, considers himself healthy.

Of all the participants, Mr. Purple was the most difficult to engage and tended to distance himself from the subject of EOLMDs. For instance, he frequently spoke in the third person when speaking of EOLMDs and often found some difficulty in responding to my questions. (ONs, July 26, 2001).

At least part of Mr. Purple's experience of making EOLMDs seems to be related to the "the fact [he is] always bodily in the world" (Van Manen, 1998, p.102). For example, when he discusses his EOLMDs, he says "I know I would not want to be kept around as a vegetable." and later, he says, "... if I was in a sort of terminal situation ... [and] if all you can do is prolong life for a few more weeks, I wouldn't want any heroics." According to Mr. Purple, making EOLMDs is an experience of trying to imagine what the state of his bodily health will be at EOL and making decisions based on that.

However, in imagining this kind of end of his life, Mr. Purple's primary concern is for his son. For example, Mr. Purple spoke with some pride about he and his wife having set down their wishes for EOL care in Personal Directives, and said "so things have been more or less planned out. It will make it [his death] less dramatic for [his son]." The meaning here for Mr. Purple is clear. By setting his decisions down on paper, he experiences making EOLMDs as an act of caring for his son.

In making EOLMDS, his thoughts about his relationship with the medical community also have meaning in terms of how it will impact his son, and others left behind. For example, communication with physicians also comes into play as when he mentions that a good relationship with one's doctor is a part of making decisions about "no heroics" for example, because one must feel free to ask questions. Communication

with nurses also comes into Mr. Purple's experience as he sees nurses as both a source of help for both himself and his family at EOL:

Well, perhaps the nurse could share with the person you wanted to deal with a situation like that. For example, in the case of our son, I suppose, the nurse could share her understanding of the patient's condition and help them in any decision he had to make. And, usually the nurse would be the one to know....and what's . . .and how the patient is coping with it and. . . and what the prognosis is, I guess.

From this, it would seem that in making EOLMDs, Mr. Purple experiences medical professionals, and in particular, nurses as sources of information and support.

As Mr. Purple thinks about making EOLMDs, he experiences an awareness of time pressing in, and an urgency to prepare for EOL. For example, he speaks of his age and how the "process of time" has sparked his desire to start to plan for EOL. He also says that he has been postponing making EOLMDs and implies that time in which to make them is running out. He comments:

one always has a tendency to keep postponing making these kinds of decisions, (laughs) and I, I'll be 79 this year and (wife) wants to make those decisions, so I've got to follow along and make mine, I guess, make mine now, so, I guess that's really what prompted the thing [making EOLMDs]. Age, and the process of time.

Mr. Purple's experience is not only one that brings an awareness of limited time, but one that sends him back to memories of past losses, which he experiences in a

cautionary way. For instance, he recalled both his wife's illness and the death of his daughter from cancer as a way of explaining why EOLMDs were urgent. "We know what cancer's all about" Mr. Purple declared. In other words, these memories of deaths of friends and family members and of his wife's illness are cautions to him that he needs to prepare for EOL because he is not invulnerable or immortal.

Yet, even with these memories and pressing age urging him to prepare, he hesitates in the face of his lack of knowledge about what his future will hold. "This [EOLMDs] is so hard to put into words ... without knowing exactly what the situation is. You don't know exactly what situations you ... will be personally in when the time comes." It's as if Mr. Purple experiences the anxiety of being squeezed between the urgency to make EOLMDs and his uncertainty about the specifics of his EOL situation.

Mr. Purple's relationship with God reduces his anxiety somewhat as he views religious belief as a help in passing on from this life to an afterlife. He also implies that this relationship affects his EOLMDs when he says that making such decisions "depend on your beliefs"; that is, on whether one believes in an afterlife or not. Although he never makes an explicit connection between his EOLMDs and his belief in an afterlife, the implication is that such a belief would make it easier for one to make EOLMDs that would direct health professionals to "let me go". In other words, his belief in God and an afterlife is seen as a way of reducing the anxiety of his EOL situation although the anxiety of not knowing the actual circumstances of death remains.

Despite this uncertainty, Mr. Purple experiences making EOLMDs as hoping for a quick peaceful end. He speaks of the tension between the uncertainty of his own EOL and

his hope to pass away peacefully or have a heart attack that will kill him quickly, but in the end he acknowledges that "none of us can really plan how that's going to end, so we just hope for the best." Mr. Purple lives with a hope for a good death, while knowing that he really has no control over the situation.

Even with this hope, Mr. Purple's experiences also include attempts to imagine the specifics of the kinds of deaths he wouldn't want to experience. For instance, he speaks of Alzheimer's Disease and other debilitating illnesses as things he "wouldn't want to happen" to him at EOL. However, here again, he acknowledges that he can not prevent that from happening.

This lack of control and uncertainty does not seem to prevent Mr. Purple from also experiencing making EOLMDs as an occasion to make concrete plans and prepare for EOL as best he can. Between the time of the first and second interview, both Mr. Purple and his wife had made personal directives and powers of attorney, made changes to their wills and had given away some of their possessions to their grandchildren. In the interview, he spoke of a Living Will as being "the way you plan your life's ending." Mr. Purple experiences EOLMDs as a need to set his decisions down on paper and make concrete plans for his inevitable EOL.

### *The Experience of Making EOLMDs for Mr. Purple*

His experience of these decisions is first and foremost one of concern and care for others. When he imagines his own EOL, his primary concern is for his son. Will his son have the information he needs from nurses and doctors to make the decisions he has to

make? Has he prepared for his EOL well enough so that it will not be "dramatic" for his son? These are concerns that Mr. Purple expressed.

This relationship with those left behind is also a part of his experience when he tries to imagine his EOL situation and prepare for this. He views communication with physicians as a possible obstacle to making and carrying out his EOLMDs, but as he imagines his EOL he predicts that nurses will be there for his family and hopes that someone will listen to his EOL wishes.

Another part of the experience of Mr. Purple's making EOLMDs is one of time pressing in. As he experiences the urgency to plan and prepare, because of his age and for the sake of his loved ones, he also experiences the uncertainty and the unpredictability of his EOL situation. His religious belief mitigates uncertainty about an afterlife, but the way he will die remains uncertain. And while he experiences hope for a quick death that is not too upsetting for his family, he also experiences the need to make concrete plans, in writing, and to take care of what details he can.

*Mr. Red*

Mr. Red is as tall as his wife is short, about six feet, and lanky. He has the loose walk of a cowboy although he has spent his entire career as an insurance adjuster. It's hard to imagine him at a desk. He has none of the owly look of a man used to meticulous attention to detail, yet his replies to my questions are careful and well thought out. He looks at home against the view from his living room window, which opens out onto a high-plains-drifter scene of bluffs and coulees. When he and his wife first moved there, twenty-some years ago, there was no one else living across the valley, he tells me. The



view is “spoiled” now by the clusters of houses visible from the window, that dot the opposite ridge (Compiled from CNs and ONs, Aug. 7, 2001; Jan. 29, 2002).

At the first interview, Mr. Red, a 70 year old man, greeted me at the door and showed me up the stairs of his modern, bi-level home. The house is about 1800-2000 square feet and is furnished in a traditional fashion except for one detail: there are no curtains on either the kitchen or living room windows to obstruct the view. The furniture looks new and the house is immaculately kept. Even the corners of the 'mud room' in the entrance below are swept clean and the bookshelves are orderly and free of dust.

As we go up the stairs, Mrs. Red is already in the living area above and Mr. Red stops once, halfway up to rest. It is difficult for him to climb stairs and talk at the same time, but nonetheless, he speaks to me, between gulps of breath, of having his grandchildren out to the house for visits and of how they like to play below in the mud room.

Once I am settled, Mrs. Red offers me coffee and Mr. Red chats about his past work in the insurance field. I detect a slight trace of England in the way he rolls his 'R's and he confirms that he was born in Northern England, then came to Canada during the war. He spent some time in the service, although he did not specify which branch nor did he share any of his experiences.

As we chat, he mentions that both he and his wife are practicing Roman Catholics who are very involved in their church. In our conversation, we discover that I know their daughter and we chat about her and people we know in common from the Church community (CNs July, 2002).

A significant part of Mr. Red's experience of making EOLMDs seems to be one of making decisions based on an imagined state of physical well-being or a lack of it. For example, as he imagines being brain dead, he comments:

Apparently when the brain stem shows no sign of life there's not much point in keeping the body breathing or the blood circulating because there's nothing there. And I wouldn't want that.... Just to say that I don't want any heroic measures taken.

As he talks about his EOLMDs, his decisions are ones that center around not prolonging life after a certain point where he imagines being "brain dead". He imagines his body as separate from himself and these are decisions based on an imagined, theoretical physical state where his physical body "shows no signs of life".

Mr. Red's experience not only includes an imagined state of illness in the future, it also includes consideration of his present state of physical health. He discussed a recent unsuccessful surgery to remove blockages from his arteries and although he said he didn't consider it "serious", he also called it "a failed angioplasty" and commented:

At 70, you can't do what you could do at 20, obviously. But I look back, to say, when I was 68 and suddenly the strength level has dropped. The ability to walk has dropped. The ability to walk up the stairs is impaired. The ability even, to put my foot on a chair and lean over and tie my shoe is impaired. And that is quality of life I don't have, you see?

Mr. Red's experience of this phenomena is one of not only imagining his own EOL but also of recalling his own past and present state of health.

More deeply, Mr. Red experienced this decision making as trying to imagine his own end and how close that end might be to his ideal death. He experienced hope for an end that is "quick, clean and clever", one where death might come in his sleep, or quickly from a heart attack . He also experienced an uncertainty as to how his life will end. As he said, "Until you're in the situation, on the edge of the knife, it's difficult to say" exactly what his decisions will be. Therefore, he imagined his end in terms of situations that are both hopeful and hopeless, like the ones in which he imagined he "has no discernible brain activity" and is being "kept alive by being plugged into a heart machine." Mr. Red's experience is one of imagining himself in various possible futures where he is dying and experiencing the uncertainty of his EOL situation.

As Mr. Red makes concrete preparations for EOL, and tries on various EOL scenarios, he also experiences an urgency to make those decisions brought on by an awareness that his life is coming to an end. "You realize you have a limited number of years," he says when explaining the influence his recent surgery has had on his EOLMDs. "We all have a limited number of years but when you're closer, it's a more limited number of years, and you begin to realize that." Part of the experience of making EOLMDs or even simply talking about them, is an experience of time closing in and of having his comprehension sharpened by his increasing age.

#### *Mr. Red's Experience of Making EOLMDs*

The experience that Mr. Red has of making EOLMDs is first one of uncertainty. He imagines his EOL in an ideal way but also as worst-case scenarios, where his quality of life is so reduced he would not want to prolong an inevitable death. Mr. Red recalls his

experiences of his illness, in particular, his failed angioplasty, and the illnesses of others and feels the urgency to prepare for the inevitable end of life. In the process of going back and forth between hopeful and fearful scenarios, Mr. Red experiences the uncertainty of the end of life that he is trying to imagine.

*Mrs. Red*

Mrs. Red is a small woman, compact, one might say, with restrained energy that belies her 68 years. She was restless and during both interviews and spent much of the time, perched on the edge of the neutral-colored sofa. She is much like the decor of her house: with clean, straight lines, and no frilly knickknacks to interfere with the wide open view.

She and her husband have lived in this same house for over 20 years. It is where they raised five children, all still living, who made them grandparents to eight grandchildren. One of her children has a hearing handicap as a result of a childhood fever but, for Mrs. Red, that is not an occasion to complain. Her son has done well, she tells me by being independent and by requiring all of his girlfriends to learn sign language.

If there is one word that sums up Mrs. Red, it would be 'independent'. She went to Normal School for two years but then married and did not teach until her youngest child was in school. She then worked as a relief teacher on and off while her children were growing up. When her children were grown, she returned to teaching part time and went back to school to get her degree in Education. Despite this seemingly traditional life path, Mrs. Red's description of it was peppered with stories about her battles with the

school board, and her resistance to accept any authority, even that of the Catholic Church, without question.

This independence of mind was significant in Mrs. Red's experience of making EOLMDs which was, first of all, one of hoping for a particular kind of death. She recalled experiences that others had of illness and dying and used this to imagine the kind of death she would want, a kind of ideal death. For example, she spoke of the short time (four months) between her mother's first stroke and the time of her death. Then, she spoke of how her father just "made up his mind" to die and expressed the hope that "this is what the good Lord has in store for me" A significant part of Mrs. Red's experience of making EOLMDs seems to be recalling deaths of close family members and using those experiences as a basis for hope for death that is short, comfortable and one where she gets to make up her mind to die.

Mrs. Red's greatest fear, however, is that there might be a time in the future, when she would have no control over her own body. As she imagines this unpleasant prospect, she has decided that she would not want to live in this kind of future. For example, she mentions in both interviews that she has seen people who "have to have everything done for them" and says she wouldn't want to be like them. Being brain dead is of particular concern for her as when she says that she has told her daughter that "when we're (she and her husband) are dead, we're dead" This concern for bodily independence is such that it is the basis for deciding whether or not she would want life-prolonging measures at EOL. "If I'm incapable of doing things for myself and I will never, ever be able to do anything

for myself again, I do not want to be alive," she remarks. In making EOLMDs, Mrs. Red imagines being physically dependent and decides that she would not want to live like that.

The experience of making EOLMDs for Mrs. Red is also one of facing the certainty of physical death and the uncertainty of what kind of quality of life she would get in return for various EOL treatments. For example she comments:

If I'm incapable of doing things for myself, and I will never, ever be able to do anything for myself again, I do not want to be alive. Because that's all it is. It's the same as being brain dead.... It would mean that they were doing everything. You would be fed intravenously. You wouldn't have any control over any of your body functions. It would be being paralyzed. You wouldn't be able to turn. You wouldn't be able to move. You wouldn't be able to do anything. And I just cannot think of existing, because that's what it is, it's not a life – it's an existence. And I cannot visualize wanting to be like that.

Later, when Mrs. Red responded to a question about what treatments she might want, she said that she wouldn't want intravenous or even a blood transfusion if it was not going to "help me have a better life". She would accept painkillers, but nothing that would prolong her life if she were going to die anyway, or if living meant having to live being dependent on others to meet all her physical needs.

However independent Mrs. Red is, she struggles to be dependent on God as her religion directs her to be. She wants to "let go, so that He can do whatever He wants, what He knows is right." That will impact her end of life because she knows that "He will

be with us. When it's the right time He will be with us." In other words, her experience with making EOLMDs is, in part, a consideration of her eventual death and an experience of a struggle to be dependent on God to control the right timing of her death.

In making EOLMDs Mrs. Red has a need to protect her independence in preparing for EOL, while acknowledging that others will play a role in carrying out her decisions. When she speaks of the decisions that she has already made, for instance, she emphasizes that she had communicated these decisions to her daughter and would "put it in writing for her, if that's what she wants." Mrs. Red wants to maintain independence, but with the trust she puts in her daughter to be willing and able to carry out her EOLMDs, Mrs. Red tacitly acknowledges that others will be responsible for carrying out the decisions she is making. She is independent in her decision-making but also wants to help the people responsible carry out her EOL wishes.

#### *Mrs. Red's Experience of Making EOLMDs*

Mrs., Red's experience of making EOLMDs is one that includes hoping for a quick death where she can maintain control and fearing being physically dependent on others. Her experience also conjures up memories of past deaths that she has seen, ones that she would desire for herself and ones that she wouldn't. And while she maintains hope for an ideal death, she also is committed to avoiding the kinds of EOL she has seen if at all possible. In any case, though, she experiences making EOLMDs as a need to make all of the preparations for EOL that she can make, and trying to trust in God to choose the right time for her death.

*Mrs. Green*

Mrs. Green is a 75 year old woman of average height and weight who moves around her house slowly and has some difficulty getting up out of her favorite swivel rocker, perhaps as a result of arthritis, although she didn't complain of this during any of our meetings. Her home, a circa 1960's stucco bungalow, is furnished traditionally; there are both drapes and sheers on the living room window and the living room, which is connected to the dining room, is carpeted and has a sofa, two chairs, a coffee table and two end tables. Pictures of her children when they were in school and newer ones of grandchildren that she still baby sits are very much in evidence. She has lived in this house for over 40 years and the history of her years with friends and family here are everywhere.

Although she was born and grew up in a rural area outside the city, she has lived in Calgary all of her life except for a short stint in Victoria before she was married. She was married for 40 years to the same man, a city policeman, and except for a year when she worked as a bank teller, she looked after their home and their three sons. She finished Grade 13 and completed part of an X-ray technician course, but then quit because she wanted to get married. "In those days, they didn't allow you to continue if you were married," she explains. However, she never lost the intellectual curiosity that urged her to get more education as a young woman; she reads incessantly and widely and can speak with knowledge on authors like Elizabeth Kubler Ross.

One of the most indelible experiences of Mrs. Green's life was the loss of her husband. At the age of sixty one, her husband was diagnosed with pancreatic cancer and



died of it a year later. During that time, Mrs. Green “lived at the hospital”, watching her husband die and finally, she had to make the decision to withhold treatment. She returned to the subject of her husband's death again and again in the interviews, describing how hard it was on her to see him in such pain. As she put it, “I went through this [EOLMDs] with my husband. He died of cancer.... And it is the hardest decision you’ll ever make ... But, I made it and we let him go. Because the future was pain.”

With these images of death and illness in mind, her experience is also one of imagining her own end of life with hope and fear. For example, she hopes for a quick, relatively painless death like a heart attack. She imagines specific circumstances that might help her achieve her ideal death, like being in a hospice (a wish she expressed in both interviews) or being able to request euthanasia. However, she also imagined the specifics of an end of life that she would want to avoid based on her experience of others’ deaths. She speaks of

watching other people die. Slowly. My mom of heart and that was many years ago, so they didn’t have the technology that they have now. And a cousin of mine, who died of liver cancer and my mother-in-law, who died of cancer also. So, I’ve seen quite a bit of it. And I don’t want to end up stuck full of things and a vegetable.

For these worst-case scenarios, Mrs. Green has made some specific preparations which she has communicated to her son, verbally. She has decided she does not want a funeral based on her belief that there is no God and therefore no need for religious observance. She has also decided that in the event of one of her ‘worst case scenarios’

that she would want someone to "pull the plug" or not give her treatment to extend her life if the end "was inevitable". She asks, "What is the use of being alive if you're say, on a respirator and IVs and you can't move, you can't talk, you have no quality of life?"

In addition to recalling deaths and illnesses, imagining her own end, and making preparations for life's end, Mrs. Green's experience is also one of considering the role of others in her EOL. She considers that her sons will be the ones to carry out her EOLMDs: "Cause it's difficult for them too. It's very difficult watching [someone die]". She also has made her decisions based on what her family can cope with. She recounts:

I did decide once to give my body to medicine. And I told the boys that and my eldest couldn't live with it strangely enough [Because] we've always been very open about death. And he said that he couldn't, just couldn't cope with the idea with medical students cutting me up. And I said, "Well, it's not going to bother me." (Laugh) Well, it bothered him, so I stopped that ...

Mrs. Green also considers the role that the medical profession and health workers will play. During our interviews, she quizzed me as to my beliefs and debated my willingness as a health care professional to perform euthanasia.

You're a nurse so you probably don't agree with euthanasia at all.... But can you...What do you think when people are suffering, really suffering? You know, I mean the woman out in Vancouver....Sue Rodriguez. That's what I call lack of quality of life.

Throughout this exchange was an implicit acknowledgment that even if Mrs. Green would ideally like euthanasia to be available, that its availability along with other EOLM care rests on health care professionals.

Mrs. Green rejects any participation in a faith community and this absence of religious belief plays a role in her experience both in making EOLMDs and in funeral preparations. She was the only participant to specifically mention euthanasia and she attributed this, in part to the fact that she does not believe "there is a God looking out for us". She considers herself "agnostic", "cynical" and "realistic" about the existence of God. However, the main impact her absence of belief has is in her funeral planning. In explaining the difference between herself and people who have religious beliefs, she comments:

You have to have a funeral according to religion, but I don't agree with that. My husband didn't have one and I'm not going to have one. I don't think. . . It's a way of saying goodbye they say, but I think you've said goodbye before that.

From this, it would seem making EOLMDs for Mrs. Green means acknowledging both the impact the absence of religion in her life has on her EOLM wishes, and on her other EOL plans, such as funeral plans.

### *Mrs. Green's Experience of Making EOLMDs*

Mrs. Green's experience of making EOLMDs is one of recalling the death of her husband as well as friends and her own diagnosis of cancer. With these images of death

and illness in mind, she imagines her own end of life with hope and fear, knowing that the actual circumstances of her death are unknowable. Mrs. Green has discussed her EOL wishes with her son and made some specific preparations in case of the worst coming to pass, but also hopes for a quick death, or at least one where she will get care in a hospice. In making her EOLMDs, she considers both the role her sons will play in her EOL and experiences concern for their emotional well being. She also believes she would want euthanasia under certain circumstances, but understands that for this or any other EOL care, she will be dependent on medical professionals to execute her EOLMDs. Finally, in keeping with her rejection of faith in a God, Mrs. Green rejects participation in a faith community. Still, a significant part of her experience is a consideration of how this absence of faith should play out in her other EOL wishes and preparations, such as decisions about burial.

*Mrs. Orange*

Mrs. Orange, a 74 year old soft-spoken woman, is slight in build and before our first interview, she showed me into the apartment in a seniors' complex where she and her husband have lived for approximately two years. When I remarked on the number of chairs in the large, formal dining room she observed that she had room to have all of her family to dinner at once- children, grandchildren and friends- and often did. The apartment was large (I estimate 1500 square feet), well appointed with a dishwasher and other new appliances. With the exception of the dining suite, the furniture looked as if it was recently purchased. As I prepared for the first interview, I noticed both the spectacular mountain view from the third story window and the elaborate layering of

sheers, panels and valances that framed the view. For both the interviews, we sat in the dining area which was decorated with a woven wall hanging, in Danish, a reminder of Mr. Orange's Danish roots.

Mrs. Orange has a Grade 12 education and has been a housewife for the past 50 years. She is a practicing member of the United Church and does volunteer work for the church in a number of capacities. She attends services regularly and plans to have funeral services conducted through her church when the time comes. She has been married to the same man for 50 years and has raised three children-- two sons and a daughter and has five grandchildren who all live close enough to visit regularly.

Her daughter died in 1998 of cancer, and despite the passage of time, sadness and anger were never far from the surface when she discussed her daughter's death. On two different occasions, she became tearful during the interviews and verbally expressed feelings of anger and loss over her daughter's death.

Mrs. Orange's central experience of making EOLMDs is that of recalling the death and illness of herself, family members, friends, and acquaintances, particularly the death of her daughter. For example, she recalled her own surgery and near death, three years before the interviews, recalling it as a time "when I didn't have an opportunity to choose". She described in great detail how doctors didn't expect her to pull through.

She also described her daughter's death two and half years previously, again in great detail: how her daughter died in pain, how her daughter said good bye to her siblings before dying and how much her death affected Mrs. Orange:

...And her kidneys had stopped functioning for about . . . they had stopped functioning. You know, she could (inaudible) no longer sleep, she couldn't swallow and she could still see, she could still think. If I thought [fear of her own death] was bad, it was nothing, nothing compared to the way I felt then [when her daughter was dying]

For Mrs. Orange's, part of the experience of making EOLMDs was reliving the pain and loss of her daughter.

Mrs. Orange's experience was also one of imagining her end of life on a kind of continuum that ranged from an ideal death, to one where quality of life was acceptable, to one where she would say "pull the plug". According to Mrs. Orange, an ideal death is one where she would just have a heart attack and die. She also imagines situations of decreased physical capacity that she could live with, such as being in a wheelchair. For example, she said, "I mean just because you've had a stroke and can't speak or can't walk, that's no reason to pull the plug." In those cases, she said she would want treatment to prolong her life.

Finally, she imagines worst case situations and she imagines not wanting to be resuscitated: "...once you've reached that stage where they have to keep you alive, I think you have to (inaudible) you know.... When you're not thinking, you're not capable, you're beyond anything. You're brain dead more or less". All of this range represents Mrs. Orange's attempt to imagine her own end of life situation and determine when she might want measures taken to prolong her life.

Mrs. Orange's experience is also one of considering how others, ranging from family members to health care professionals will be involved in her EOL situation. In recounting her daughter's illness and death, for example, she recalled her rage at a doctor who had misdiagnosed a stroke as a migraine headache. She also spoke of the trust that she had for her own family doctors but spoke, too, of the physicians who "are only there because they are smart enough to pass the exams and get the title 'doctor'." She said that health care professionals were a vital source of information about when one was near to death and they were people "you should be able to rely on". That "should" however, is telling. Although Mrs. Orange experienced the health care professionals as playing a necessary role in her imagined EOL, she also experienced doubt as to whether she could actually trust them to carry out their roles.

The experience for Mrs. Orange of making EOLMDs was also one of care and concern for the family that would be charged with carrying out her decisions. In commenting on her wish to be 'let go' under certain circumstances, her focus was the need to make things easy for her sons:

....the two boys, they get along very, very well, all my family does. But if one said, "I want to do this" and the other says, "I don't think so. This is what Mum and Dad wanted." I think if it's down in black and white, there isn't anything of that, provided you're organized about it.

In preparing for EOL, Mrs. Orange voiced a desire to protect her children from the burden of making the decisions and acknowledged that her death would "be difficult for the boys". She experienced making these decisions both as an acknowledgment that her sons

would be called upon to play a role as her life ended and as a desire to lessen the burden of that role.

With these memories of death and illness and with considerations of her family in mind, Mrs. Orange's preparations included other EOL plans, such as selecting a headstone and making her will. She communicated her EOLMDs preferences to her children in informal ways, such as a note stuck to the refrigerator, and made plans to put these wishes into a more formal and permanent form of a Personal Directive. However, with all these EOL preparation, she procrastinated about making her EOLMDs formal and encountered uncertainty about her EOL situation. For instance she had decided what her EOLM preferences are, but then realized that "[how I die] is not up to me, is it?" and that both the manner of her end and what she might want done was in question.

#### *Mrs. Orange's Experience of Making EOLMDs*

Mrs. Orange's experience of making EOLMDs is one of recalling and reliving the pain and fear of her daughter's death and her own brush with death and an imaginative construction of EOL scenarios that would be ideal, those that would be acceptable and those that would not be acceptable in terms of her quality of life. She experiences care and concern for the role her family members will be called upon to play and experiences a desire to lighten their burden. She also experiences the need for health professionals to play a role in her EOL but also the uncertainty as to whether she can trust them to fulfill that role by being competent and giving life and death information to her family.

#### **Creative Non-Fiction Expression of Participants' Lifeworld in Making EOLMDs.**



In keeping with the comments made at the beginning of this chapter and the underlying philosophy of this study, the section presented here is an alternative form of data display. Just as the previous sections of this chapter were meant to give a thorough understanding of the lifeworld of each participant, including my role in those worlds, so this section is meant to give a more thorough understanding of the experience as a whole before proceeding to the findings chapter. This section can best be understood as van Maanen's (1988) "literary tale" (p. 133) who argues that "narrative and rhetorical conventions assumed by a writer... shape ethnography" (p. 5) and that "there is no sovereign (writing) method for establishing fieldwork truths" (p. 138). He goes on to demonstrate ethnography written in a variety of ways including a literary tale, which is characterized by an author's use of literary techniques such as characterization, plot development and metaphor and simile. It is this last form that best describes the following section.

The section of Creative Non-Fiction is offered for a number of reasons. First, since "[w]ays of personal expression, choice of metaphor, figurative allusions, semantics, decorative phrasing or plain speaking, textual organization and so on all work to structure a cultural portrait in particular ways" (Van Maanen (1988, p. 5), this section is presented as a rhetorically different presentation of the data intended to deepen both my understanding and the reader's of this phenomenon. In addition, as Sherman (1993) notes, "Writing is crucial to qualitative research because this kind of research rests on *descriptions* and *narrations*, rather than on the quantification of data. Its aim is to *present*, not *represent*, experience; its target is *complete (or holistic)* accounts ... "(all italics as

quoted) (p.235). For these reasons, this alternative form of data display is compiled from details from all of the transcripts and is intended to present the experience of the participants in a more immediate and holistic manner than can be achieved with the above descriptions.

Richardson (1994) lends credence to this kind of approach. In her discussion of experimental writing, she describes fiction and other "evocative forms" of data representation as "powerful tools in the 'writing as analysis ' tool chest," (p. 521) and " ...a good way for the writer to see the material from different points of view," (p. 521). These comments point to the legitimacy of creative non-fiction writing as a way to re-present data to uncover truths, such as emotional truths, that cannot be related in a "realist tale" .

### *"Filling Out the Forms"*

Edith stroked her cheek with the pen and studied the form in front of her. Finally, she'd gotten around to having one sent out to her. Now all she had to do was fill it out. She'd always thought wills were enough. But the lady at the guardian's office said it was best to have one of these too. What did she call them? Not living wills. Something else. Personal Directives. That was it.

She read from the brochure that came with the form. "Those who choose to make personal directives have thought carefully about what would happen if they were no longer able to make decisions for themselves." Well, she'd done some thinking about it.

I'd want Bill to decide for me, she thought. I know that.. After 50 years, who knows me better. But if something happens to him? Who'd do it then? She thought of Kathy. She couldn't handle seeing me sick, Edith thought. And if I got like Grandpa?

Edith remembered like it was yesterday. The way he clutched at his stomach. The way he got thinner and thinner, not able to eat or drink.

Kathy couldn't even bear to see an animal in pain when she was a kid. Would she be able to let me go, even if I was in that much pain? God knows I don't want that. Edith looked at the form. I'd better write that down, just in case. If I'm in pain, let me go...

She returned to the brochure. What else? *What kind of medical treatment would I want?* She thought of Mr. Phillips from church, on a respirator for two months after his heart attack-- two months!! All because his kids were fighting over whether or not to let him go. If he was a young man, I could see it, Edith thought. He'd have his whole life ahead of him. But at our age! I wouldn't want that. Kathy has to know that's what I'd want. No heroics. I don't want her to feel guilty if they have to let me go. She began to write, then stopped.

But what if it was a stroke or something like that ? She shook her head, trying to shake the image away. When Aunt Ada had her stroke, why, she lived for another fifteen years. Would I want to live like that, she wondered They had to help her up and down the stairs but she did chores right up until she died. Edith looked closely at the form. Is there a place to check off "quick death"? I'd like to go like Aunt Ada- not knowing it's coming- one minute doing the dishes, the next on the floor. But if a stroke made me so I didn't know what was going on? What then? Maybe then I'd say, just let me go. She suddenly realized it wasn't death she was afraid of. It was the dying. How it was going to happen.

Still, it isn't up to me. She touched the cross at her throat. The good Lord knows when it's my time. The blank page seemed to contradict the thought. Maybe it would be best to leave it with Bill and the doctors after all. She rubbed her stomach. He'd ask them to let me go if I was in pain. She shivered. Bill would never let them do that to me. He'd make sure they didn't prolong things.

Edith looked at her watch. Almost lunchtime. She folded the form carefully, laid the pen beside it and pushed her chair back. Enough for today, she thought. There were breakfast dishes to do and Bill's lunch to get. This death stuff will have to wait. Meanwhile, she thought, I'll have to hope for the best.

### **Conclusion**

In this chapter, I have given a description of the lifeworld of each participant and their experience of making EOLMDs to provide a rich description and to provide the context necessary to make judgments about the trustworthiness of this study. In addition, I have provided a non-traditional presentation of the data to provide the reader with an additional way of understanding both the participants' experience of this phenomenon, and my understanding of it. In the following chapter, I will describe the findings of this study with emphasis on the central meaning of the experience for these six participants and in the final chapter, I will discuss the significance of these findings for nursing education and research.

## **CHAPTER FIVE: FINDINGS REGARDING END OF LIFE MEDICAL DECISIONS**

In Chapter 4, an attempt was made to give a clear picture of the lifeworlds of the participants as well as a detailed description of their individual experiences of making End of Life Medical Decisions (EOLMDs). In Chapter Five, the commonalities of the experience will be presented in a thorough description of each of the five themes discovered in the data. These themes are: (1) experiencing uncertainty (2) recalling death and illnesses (3); imagining my end of life (EOL) and beyond; (4) considering the role of others in my EOL (5) preparing for EOL.

A descriptive overview of these five themes is presented first. Next, each of the themes will be described, including illustrative examples from the data, and a description of significant sub-themes or incidental themes. These are themes that are “incidentally related to the phenomenon under study.” (Van Manen, 1998, p.106) but are not *essential* themes. The final section of this chapter summarizes the experience of making EOLMDs for older adults living in the community.

### **The Five Essential Themes of the Experience of Older Adults Making EOLMDs:**

#### **Some General Observations**

Before beginning a detailed description of the phenomenon under study, it is fitting to make some general remarks about how the five themes are related to one another. First, it is important to note that the experience does not take place in a linear fashion; instead, the different essential themes are in tension with one another as the experience takes place “all at once” (Merleau Ponty, 1962). For example, there is a

tension between 'Imagining My EOL and Beyond' and 'Recalling Past Deaths and Illnesses', as participants recall these happenings, and use their memories to predict what might await them at their EOL. There is also tension between 'Preparing for EOL' and 'Considering the Roles of Others' as participants try to make concrete preparations and consider who they will have to rely on to carry out those preparations. Participants might move from recall, to imagining, to preparation, then back to recalling, and then considering others at EOL. Or, participants might start with various kinds of preparations, and then go to imagining their own EOL. In other words, there is no fixed order of the happenings implied in the themes; instead, participants may move between and among the different structures of this experience.

Although the lived experience is in participants' "here and now", as they reflect on the experience, the focus of these participants' mental processes shift from a recall of the past, to a projection or an imagination of the future. This is similar to Benner and Wrubel's (1989) concept of "temporality" which "means being anchored in a present made meaningful by past experiences and one's anticipated future" (p. 117). Simultaneously they might be considering the roles that others will play in their EOL and making preparations for EOL. In this respect, the experience of making EOLMDs projects the participants into the past and forward into the future, even though the experience takes place for them in the present moment.

Finally, the theme of 'Uncertainty', is central to the meaning of the experience. That is, uncertainty is a part of 'Considering the Role of Others in My EOL', 'Imagining My EOL and Beyond', and "Preparing for EOL". This uncertainty pervades all of the

other structures of the experience of making EOLMDs. For example, there is uncertainty about both the exact circumstances of dying and death as participants imagine their EOL, and about whether family members and health workers will fulfill their expected roles at the time of the EOL of the participants. Each of these five themes that make up the structure of EOLMDs for older people are described in detail below.

### **The Structure of the Experience of Making EOLMDs for Older People**

#### *Theme 1: Experiencing Uncertainty*

The first theme in the experience of making EOLMDs, Experiencing the Uncertainty of End of Life (EOL) was found to be the most central of the five themes. This is because, as indicated in Figure 5.1, this uncertainty pervades the entire experience of making EOLMDs. As participants imagined their EOL situation, they experienced tension as they attempted to make EOLMDs such as “when to pull the plug”. They did not know, and indeed, *could* not know the exact circumstances of their end of life. Would they be in pain? How much pain would they be willing to bear? They tried to imagine, but in the end, they simply did not know. This uncertainty was perhaps described best by Mr. Purple who said:

The [making of EOLMDs] is so hard ...to put into words, you know, without knowing exactly what the situation is ...one can't be very specific because you don't know exactly what situation you ...will be personally in when the time comes.

What Mr. Purple is describing is the difficulty in decision-making when information is missing about what his EOL will actually be like.

It is not only the uncertainty about the exact situation at EOL, but also an uncertainty about whether EOLMDs made in present day circumstances will be right or meaningful when faced with EOL. As Mrs. Green put it:

I'm sure a lot of us will say we want this and this and this until it comes down to it. Never having been there yourself, you are never sure how you would react to knowing you are terminal.

Or, as Mr. Red put it:

..if I was faced with ...a situation where a heart transplant was necessary ...probably wouldn't want that ...[but] until you're ...on the edge of the knife, it's sort of difficult to say.

Both of these participants are describing the uncertainty they experienced when trying to imagine the end of their lives and make EOLMDs without knowing how their wishes will change when they are actually in the situation. All of them know what they want now. In the future, however, when they are at EOL, what they will want is uncertain.

There was also uncertainty for these participants about the role that others would play in their EOL and if these family members and professionals could be trusted to carry out participants' EOLMDs. For example, Mrs. Orange spoke of her concern about whether her sons would remember and carry out her EOL wishes:

So, if we told them we wish to be cremated then that's fine, they'll remember that part. But are they going to remember in emotional times the other things, the little things that I've said. And will they let you go?



Mrs. Orange has entrusted her EOLMD to be “let go” to her sons. But she experiences uncertainty as to whether they will be able to carry out those wishes.

This uncertainty extends to the role that participants foresee health professionals playing at EOL. For example, Mrs. Purple described an encounter with a doctor as an illustration of how doctors can not be trusted at EOL

...I noticed I had a spot on the bottom of my foot and it was festering so I went to a young doctor I hadn't been to before. Well, he gave me antibiotics....Well within two days I had a rash from my ankles right up to my butt. And they were filled with raised pimples. So they sent me to the Foothills Hospital. I was there for 5 hours. They were doing testing because they thought they had ruined all of my platelets. Um, I got the results back and luckily they hadn't - the platelets were O.K. So they sent me upstairs to the infectious unit to see [another doctor]. She looked at my foot. She said, “Mrs. Purple, you go home. Stop taking those pills. Stick your foot in some Epsom Salts and soak the heck out of it” and that cured it but this just about killed me. So, you know, I feel that maybe the doctors don't look at people.

Later, in the same interview, Mrs. Purple sums up her experiences this way: “After going through this kind of stuff, when there's nothing much wrong with you, who'd want to hooked up? I have no desire to be handled, manipulated.” Although participants understand the important role that health professionals will play at their EOL, they

experience uncertainty about whether these professionals can be trusted with their well-being at EOL.

In summary, this uncertainty about what the EOL will actually involve was experienced by the participants as central to the meaning of making EOLMDs . As they recalled past deaths and illnesses to get a sense of what hopeful or fearful fate might await them, and as they considered the roles that others might play in their EOL and prepared as best they could, they remained faced with an impenetrable mystery. The most important information that they needed to make EOLMD-- what their EOL situation will be, how much they will be called upon to bear and whether others will prove trustworthy-- is part of an unknowable future.

*Theme 2: Recalling deaths and illnesses (the things that can happen)*

This second theme focused on recalling past experiences with death and illnesses of people close to the participants, as well as their own illness experiences. It included recall of good deaths, ones that were quick and easy, and ones that were preceded by long periods of suffering or illness. This theme also included recall of illnesses or chronic conditions that the participants themselves had experienced, and sometimes included health care professionals as significant actors in that experience.

Part of this theme was recall of examples of an ideal death situation. For example, when asked about how she had come to her EOLMDs, Mrs. Red talked about the deaths of her mother and grandfather as a way of imagining her own ideal EOL:

I'd like to go the way my grandfather went and the way my mother went.

She was partially paralyzed and she couldn't remember who she was....In

January she began to shake. She had tremors....February she had the stroke and the end of March she was dead....My grandfather on my mother's side when he was in his seventies....he went into hospital and they performed an operation and they said that they didn't think it would be much help to him. Well, [they said] he needs help to do all these physical errands [so he should be in a nursing home] and he said, "If you send me there, I will die. They said....You may not be able to do all of the things that you were doing before, but there's time for you to do some more things." "No," says he. He'd made up his mind [to die]....So, I'm hoping that this is what the Good Lord has in store for me.

Like all of the other participants, Mrs. Red had an ideal death in mind, one that was quick and one that left her in control until the very end.

However, more often, what participants remembered were long, drawn out deaths of loved ones which served as examples of how they did NOT want "to go". For example, the first thing Mrs. Green talked about in the first interview was her husband's death. She emphasized that "I went through this [making EOLMDs] with my husband ...and he didn't want to be kept alive either ... So I feel the same way ..." When I asked about EOLMDS, recall of the death and suffering of her husband became a way to inform Mrs. Green's decisions about what she wanted at EOL.

In response to a question about how she came to her EOLMDs, Mrs. Purple, too, recalled the death of her daughter from cancer as one of the factors that "brought me to these decisions". She put it this way:

....she [Mrs. Purple's daughter] was in so much pain. And she went from a beautiful, beautiful girl down to....she was like a porcelain doll, she had no flesh, just skin over her bones and the minute I walked in the door, you could see she was looking for reaction, and she said... "Aren't you shocked?" I said, "Honey, I love you so much," I said, "to me, you look like a porcelain doll."....I think when people are dying, I felt that if I, if I fell apart, I'd be admitting I was going to lose her.

Here, Mrs. Purple recalls not only her daughter's pain and suffering but also her own and that of her family as an indication of what can happen at life's end and uses this background knowledge to inform her EOLMDs.

Sometimes, the witnessing of illness and suffering of others was recalled as a way to determine when participants would want to be kept alive, as in Mrs. Orange's recounting of her experience of a woman she encountered in her volunteer work:

But you could still be a living person even though you're paralyzed, after a stroke and in bed. At [a local] hospital every four to six weeks we used to take people to the chapel. This one lady I used to bring out, she made these weird sounds, really loud sometimes and as soon as we started the singing, she would stop. As soon as we stopped singing, she would start, so. . . that showed. . . And there was another lady who as long as you stroked her arm, stroked her hand, she was quiet. But when I stopped stroking it, she'd start "Uh, uh, uh. . .", like that. So something in those people, that's telling us, they had contact . . . to me they're functioning.

Their mind is not functioning, but they're functioning....There's always hope until you draw your last breath. And, and when hope is gone, everything's gone.

Here, Mrs. Orange recalls the illness and suffering she has seen and uses it to make decisions about when she might still hope for more life, even at a reduced capacity, and therefore make a decision to accept treatment to prolong her life.

This second theme included more than just experiences of death and illness of loved ones. A significant part of this recall involved experiences of the participants' own illnesses and past suffering. For example, Mrs. Purple recalled one of a number of incidents where she had suffered at the hands of medical professionals who "didn't listen". She had been admitted for treatment of a back injury and was given narcotics to control the pain, despite telling physicians that she was sensitive to them. "I did mention I didn't do well with narcotics," she remarked dryly in her diary, "I got them anyway". She called the incident "a sad tale of woe" that she attributes directly to her (mis)treatment in the hospital. Mrs. Purple had seen some of the things that could happen during illness and recalled instances of suffering at the hands of the medical profession as a way to determine what she might want at her own EOL.

Recalling some of the negative things that had happened, and that could happen at the EOL for the participants themselves, was thus a significant structure of their experience of making EOLMDs. Participants recalled past deaths and suffering of significant others and their own illness experiences as positive and negative examples of the things that can happen at life's end. These participants understand that death can come

swiftly and with relatively little pain, or it can be a long, drawn out affair with much suffering. They have seen both, and part of the structure of this experience for these participants is recalling “the good, the bad and the ugly” of what they have seen.

*Theme 3: Imagining my EOL and beyond*

The third significant structure of this experience is that of participants trying to imagine their own EOL situation. Participants experience this imagining in a number of ways. They imagine an ideal death for themselves and hope for that kind of death. However, they also imagine the worst; that is, a situation where they would decide to “pull the plug” or would not want to be kept alive by “heroics”. Imagining EOL also means imagining the kind of quality of life that would be ‘minimally acceptable’. If they envisioned the latter outcome, their decision would have to include acceptance of medical intervention to prolong their lives. Finally, participants experienced imagining what, if anything, lay beyond EOL, sometimes with hope, and sometimes with resignation.

One part of this structure for the participants was an imaginative construction of an ideal death. Several participants, such as Mr. Red and Mr. Purple, were very specific in their imaginings of what this kind of death would be like. For example, Mr. Red described it like this:

Well, I have a pain in my chest. I hope that I would die suddenly, quickly, bang – gone. My friend’s brother had a heart condition and when at the Post Office one day, walking, he fell down dead. I’d like to go like that. Not. . . probably won’t, but that would be nice. It would be quick, clean, and clever. Here one minute and gone the next, you know?

Here, Mr. Red imagines a heart attack as an ideal way to go because it is a way to die quickly, with a minimum of pain and suffering.

Other participants described other ways of ending. For example, part of Mrs. Green's ideal end was euthanasia.

And [making EOLMDs means] being able to go. I'm a great believer in euthanasia, you know. With parameters, like the Netherlands. And why shouldn't you be able to, if you know it's inevitable and you don't wish to live any longer?

Even though Mrs. Green knew euthanasia was not legal and therefore not possible, she considered it a dignified and humane way of ending her life and a part of an ideal death if she was in severe pain.

A second part of this third theme was participants imagining scenarios wherein they would decide to forego medical intervention to prolong their lives. These imagined scenarios ranged from "being unable to do anything for myself [physically]" (Mrs. Red) to "losing my ability to think and relate to my family" (Mrs. Purple). All participants included the prospect of "being a vegetable" and "being kept alive on a machine" as in this example where Mr. Red tries to explain the difference between the circumstances where he would want medical intervention and the circumstances when he would not:

If I have a heart attack, I think the medics are obliged to do what they can to keep me alive, providing that I have my faculties. Now, if I have a heart attack and the heart attack does something, which causes my brain to be obliterated, then I'm not alive anymore. I might be breathing but I might

have to be hooked to a machine to make me breathe. I might have to be hooked to a machine to make my blood flow and that is unnatural, in my view. That's, I think, in my understanding, is prevention of a death, which would occur naturally. Now, in some cases, I think, medical science has reached the point where even though we would die naturally without medical intervention, that medical intervention is justified because we still have our faculties. But if the faculty is gone then there's no point in a lump of material.

Here, Mr. Red imagines a scenario where he is "a lump of material" and expresses his opinion that, in those circumstances, "there's no point." He is imagining a worst case scenario and trying to explain his decisions about when he would and would not want medical intervention.

When participants imagined such an undesirable end, they all chose in their imagined EOL to "let me go" or "pull the plug", common phrases that participants used to describe saying "no" to life-saving or life-prolonging measures as in this example, where Mrs. Red considers when she would want a "no code" order:

And if my heart stops, just let it stop (laugh) (Researcher: Okay, so you would understand that to mean that they wouldn't come with the paddles and. . . ) Yep. If I were younger – I'm 72. And I realize I could live to be as old as my grandfather was – 93...but do I want to? Not if I'm in any kind of situation where I'm not capable of doing things – no thank you. I'm just as happy to let go.



As Mrs. Red imagines her worst case scenario--not being able to do things for herself--she considers medical intervention and decides to "let go" rather than extend her life if she is "not capable of doing things".

A third aspect of this structure was found in the middle of these two imagined extremes (i.e., that of an ideal death and a worse case scenario), whereby participants also imagined to what degree they could bear a decreased quality of life at EOL. For instance, Mrs. Orange made a distinction between those situations when "you're beyond hope" (when someone is brain dead) and situations where there is hope: "I mean, just because you've had a stroke and can't speak or can't walk, that's no reason to pull the plug". During the second interview, she stated "I wouldn't care if I was frail, had to be in a wheelchair. I'd hire somebody to push me around". As with other participants who recounted their stories in individual ways, according to what they valued most, here, Mrs. Orange makes a judgment about what level of quality of life would be acceptable in an imagined EOL scenario. By implication, she suggests that she has "drawn a line in the sand" of her imagined future, as if to say "beyond this level, I have no wish to go on with life".

In addition to this imagining of the EOL period (i.e., the period of illness just before death), a fourth aspect of the structure was an attempt by all participants to try to imagine what lay beyond death. For example, in his diary, Mr. Red was very explicit about how he imagined that "in Heaven we will all have work to do: Hopefully, I'll be able to do some soldiering" Others were less detailed and more practical in their construction of what lay beyond. Mr. Purple simply stated his belief in something

“beyond this life” and a recognition that this belief would help him “in the process of passing on from this life”. Even Mrs. Green, who stated she did not believe in God or an afterlife, did consider what might lie beyond. In one interview, she commented: “I don’t know. I have no idea what comes after. You want to hope it’s something better, but who knows”. In their experience of making EOLMDs, these participants not only imagined possible EOL scenarios, and the worst case circumstances when they would not want to live, but they also imagined what might lie beyond this life.

One might summarize the aspects of this third theme as follows. In trying to imagine their own EOL situation, the participants imagined extremes of desirable and undesirable ends to their lives, while also considering , according to their individual values (Mrs. Red’s valuing of independence, for example) what quality of life would be minimally acceptable for them to accept treatment to save or prolong their lives. Thus, part of the experience of making EOLMDs for these participants is a “trying on” of various, imaginative EOL situations and trying to predict what they might or might not have to bear by way of pain, suffering, and decreased quality of life. A final aspect involved trying to imagine what might lie beyond that suffering, if indeed something does. Taken together, these various aspects indicate that their experience is one that involves making informal, tentative choices about whether or not to have EOL medical treatment.

#### *Theme 4: Considering the Roles of Others at EOL*

A fourth structure of the experience of making EOLMDs for these participants is that of considering the roles of others at their EOL. 'Other', in this context, is understood as anyone whom the participants see as having a role to play in their death and dying. It includes both people who are close to them, such as children, spouses, as well as health professionals that might have a role in the participants' EOL decisions, and in their care at the time of death. The term also extends to include Van Manen's (1989) notion of 'other'; that is, it encompasses a relationship with God or a higher power at EOL for those participants who have such a belief.

The most prominent expression of this fourth theme was found in the care and concern shown by the participants for those they would leave behind. This care was expressed in their desire to make things as easy as possible for their loved ones who would be charged with carrying out all of their EOL decisions, medical and legal ones alike. One of the most explicit examples of this concern was Mr. Purple's expression of care for his son's well-being as he discussed his plans to follow his wife's suit and make a personal directive:

...it [his wife's completed Personal Directive] will go into our safety deposit box which we now have here ...so our son will have access to that , so things have been more or less planned out ...it will make things less dramatic for him.... it's just, you want to do, you want to make things easy for those you leave behind and, because of that too, you, you tend to think, you know, how should I approach this?

In a discussion of thinking about and writing down his EOLMDs in a Personal Directive, Mr. Purple's motivation was to make things as easy as possible for his son, who might be charged with carrying out these decisions.

Mrs. Orange is another example of how participants were concerned with loved ones who would be left behind:

I think the boys rely on me. Very much so....to make those kinds of [EOLM] decisions. I'm not so sure if something happened to me first, I think they would feel more, that they would need help more. I don't know why they feel that way, but they do. At one point, I had to have some major surgery and I had a five percent chance of survival of this surgery, but had no chance without it. That was seven years ago last Friday. At the time, my daughter said, "I just can't believe that Dad will get along without you." I mean, I know he's quite capable I mean, he had a good position but they do rely on me to make a lot of these kinds of decisions.

Here, Mrs. Orange expresses the responsibility that she feels to make EOLMDs because her children rely on her "to make those kinds of decisions". In making both medical EOL decisions and other EOL preparations, the majority of participants experienced a concern for those family members who would shoulder the burden of "carrying on" and carrying out the EOL decisions made by the participants.

At first glance, one exception to this expression of care and concern for significant others would seem to be Mrs. Red. When asked if others influenced her EOLMDs, she said "No, I tend to be a little selfish." In addition, she spoke at length about her

independence, and how she is a “loner” with few friends who had any influence on her. In this context, her desire not “to be a burden to anybody” and not to have anyone “give up anything to accommodate me” might be interpreted as simply another expression of her independence, as opposed to a concern for others.

However, in spite of Mrs. Red’s expressed independence, there is evidence that she actually did experience care and concern for those that she will leave behind. For example, although Mrs. Red states that she does not want to be a burden, she subsequently elaborates that “I just don’t want them [her family] to feel that ‘could we have done more? ...That’s not right, They’ve got their lives to live. I’ve lived mine. And I just don’t want them to be feeling that I am a burden to them” Hence, despite statements that she does not consider others in her EOL decisions, and that she is independent in such decisions, Mrs. Red obviously experiences both concern about the impact her end of life might have on her family, and her care about them, as indicated by her statements that they not be burdened by her dying.

A second expression of this theme of ‘Considering the Roles of Others’ in My EOL is a consideration of the role of health professionals at EOL. When these participants experienced making EOLMDs, part of that experience was thinking about the role health professionals might play. The participants considered professionals as information-givers about medical conditions, as experts in identifying when end of life was at hand or had taken place, and as sources of support for family members at end of life.

Mr. Red's account provides one illustrative example of the way some participants weighed the role of health professionals as information-providers and experts about when death was imminent. When he discussed his decision to have "no heroics" if he was "brain dead" he also acknowledged that "I'm not up on medical science so I didn't know when they would consider me to be dead or not dead". Mr. Red was conceding that "brain dead" was a medical definition that he did not understand. The logical implication of this statement is that he would need a medical professional to say when he was in effect, dead, even if he was still breathing.

Similarly, Mrs. Orange experienced both the role of medical personnel as information givers, and her need to trust them in this role. She put it this way: "If you can't trust the medical staff who are making medical decisions for you, who can you trust?" And later she conveyed her hope: "You can't always make informed decisions, 'cause you don't know medical things. You hope you can rely on them". Part of Mrs. Orange's experience of making EOLMDs was consideration of the expert role of medical personnel who will inform family members how the patient is, how close the patient may be to death, or conversely, what the chances might be for recovery. As with the other participants, Mrs. Orange experienced the medical profession as having a powerful role to play in the quality of one's EOL.

Even when the role of some of the medical profession is perceived in a negative light, as was the case with Mrs. Orange, Mrs. Purple and Mr. Purple, the relationship between the participants and their doctors carried considerable weight in their experience of making EOLMDs. For example, despite Mrs. Oranges' dislike and distrust of one of

the doctors who treated her daughter, she expressed trust in her family doctor. Also Mr. Red, who in spite of his perception that “I sometimes find doctors very hard to communicate with” , acknowledged that he has “a pretty good relationship” with his doctor in Victoria . Part of the experience of making EOLMDs for these participants is weighing the relationship they have with health care professionals and considering the role that the latter might be called upon to play in their EOL.

In summary, the theme of ‘Considering the Roles of Others at My EOL’ describes participants’ experience of being concerned about, and caring for, those left behind. This concern can have a strong thread of self-interest (e.g. Mrs. Red’s “selfishness”; Mrs. Orange’s fear that her children won’t let her go). However, it is an experience of concern of how the loved ones chosen to be present at EOL will be able to cope with the participant’s death. This theme also captures the expectations participants have of health care professionals at EOL. Despite concerns about how those professionals will care for them, participants hope that these same members of the health care community can be relied upon to decree when they have finished their lives and, even though breathing, have become the dead.

#### *Theme 5: Preparing for EOL*

A fifth and final theme in participants’ experience of making EOLMDs was that of making specific preparations for EOL. This theme captures personal preparations such as trying to overcome the procrastination of formalizing these decisions in ways discussed below, despite experiencing the press of time and the urgency to complete EOL preparations. It also captures the way that participants experienced making EOLMDs as a

part of broader preparations for EOL, which, in addition to medical decisions, included personal, religious and legal preparations that will be discussed in the latter part of this subsection.

One salient aspect of this fourth theme involved the participants' experience of formalizing EOLMDs, a process that included communicating these decisions to others, gathering information about Personal Directives (PDs), and talking to the researcher about the need for completing their PDs. In the region where this study was conducted, Personal Directives are legal, advance planning documents that communicate personal decisions about "health care, accommodation, with whom a person may live and associate, participation in social, educational and employment activities, [and] any non-financial legal matters such as providing consent for the release of medical records" (Government of Alberta, 2001). These decisions can be communicated in writing or by appointing an agent, "a person designated in a personal directive to make personal decisions on behalf of the maker" (Government of Alberta, 1998). Such advance decisions come into effect when the maker's agent consults with a physician or psychologist and the maker has been declared "not competent to make decisions" (Government of Alberta, 1998) in specified areas of personal decision making.

In thinking and talking about making EOLMDs, all the participants asked the researcher questions about making PDs, or they informed her that they were getting information from government agencies about how to set their EOLMDs down in writing. For example, Mrs. Green, at the time of the first interview, did not know that PDs (what she called "living wills") were legal:



(Researcher: Have you written a formal personal directive or a living will or. . .) No, I didn't think they were legal in Alberta. Actually, I think I'm positive that my children would acquiesce to what I have told them but it wouldn't hurt to have a will just in case there's a problem. You never know. I didn't know you could get them. As I say, I did not think they were legal in Alberta.

Here, Mrs. Green attempts to fill in knowledge gaps by discussing Personal Directives with the researcher and expresses her intent to complete one. Mrs. Orange, too, sought information from this researcher and from the Office of the Guardian. In all cases, participants' experience was of a need to begin to formalize these decisions by writing them down as part of their overall preparation for EOL.

Another significant aspect of this fifth theme is the apparent tension for these participants between coming to a personal decision about 'when to pull the plug' on the one hand, and making that decision formal on the other hand. First, there is the experience of the press of time that comes from the inevitable end that draws near for all of them. As Mr. Red remarked,

...we all have a limited number [of years] ...but when you're closer [to death], it's a more limited number of years, and you begin to realize that.... My last angioplast was unsuccessful. So, that really focuses things. I think sharpens the lines of comprehension a bit. It brings you closer to the fact that. . . a wake up and the fact that I'm close to 71.

Here, Mr. Red conveys that he knows the time he has to make *all* of his end of life decisions is limited by his age and an end that could come at any time.

Despite this knowledge, there is a hesitation, or “procrastination” (Mr. Red’s and Mr. Purple’s word) in formalizing these decisions. For example, Mrs. Orange admonished herself in two separate entries in her diary for postponing getting information about Personal Directives:

**April 30, 2002** Had lunch with S. today and we talked a little about our future or lack thereof and I told her I still hadn’t done the paperwork and she told me to get the lead out!

**May 5, 2002** Public Guardian 297-3364

9<sup>th</sup> floor 855 - 8 Ave. S.W. 297-4628 DO IT!

Similarly, at the time of the second interview, Mr. Red had not made a PD, although he had acknowledged the need and his intention to make one in the first interview. He put his hesitation down to being a “natural procrastinator”. Indeed, although all the participants had made EOLMDs, none of them had made Personal Directives at the time of the first interview. And at the time of the subsequent interviews, although participants had previously expressed their intentions to do so, all of them confessed that they had “put off” formalizing their EOLMDs. Some of them did complete PDs by the end of the study period (Mr. And Mrs. Purple) but during the period of the interviews, the hesitation that the participants experienced is clear.

Part of the experience of this phenomenon might thus be understood as a kind of internal “push-pull” between pressure to make such preparations, and a hesitation to do

so. Although knowledge of their increasingly limited time presses these participants onward to prepare for EOL by formalizing EOLMDs, there is something that seems to pull them back. None of them were able to identify just what caused this hesitation, yet all of them experienced it in one form or another. Put another way, one aspect of the experience of making EOLMDs for these participants was a tension between deciding in their own minds when they might want to pull the plug, and formalizing those decisions by putting them on paper in the form of a PD.

Let us turn now to a discussion of the findings pertaining to how the participants experienced making EOLMDs as a part of broader preparations for EOL. In addition to their medical decisions, these other preparations pertained to topics of a personal, religious and legal nature. For Mrs. Orange, these non-medical EOL preparations included formalizing funeral arrangements, including the selection of songs that were to be sung at her funeral, and deciding what kind of service she would have. Legal preparations for EOL were an important concern for Mrs. Green, who had prepared her will, and appointed an executor for her estate (CNs, June 22, 2002).

Indeed, all the participants referred directly or indirectly to the various non-medical EOL decisions and preparations that they had made. They all spoke of making EOL preparations based on their personal and/or religious values such as Mrs. Purple's comments about "making peace with the people" in her life and feeling satisfied that "when it's time to go, I'm ready". Another example of these other EOL decisions was Mrs. Green's preparations to dispose of her body without any religious ceremony. As she put it, "You have to have a funeral according to religion, but I don't agree with that. My

husband didn't have one and I'm not going to have one". And as noted above, legal EOL preparations were made such as making a will (Mrs. Orange; Mr. and Mrs. Purple;; Mr. and Mrs. Red) and naming an executor (Mrs. Orange; Mrs. Red;; Mr. and Mrs. Purple). Hence, it appears that making medical decisions at the EOL were related to broader EOL preparations which included personal, religious and legal preparations.

This aspect of this fifth theme raises the question: In what way were the non-medical and medical EOL decisions related? The answer is suggested by the observation that in making these *other* EOL preparations, participants did not distinguish between them and EOLMDs. For instance, in all of the interviews, participants spoke spontaneously about their legal and personal EOL preparations, despite not being asked about them and, in many cases, they included such responses when asked specifically about their end of life *medical* decisions. For these participants, the experience of making EOLMDs is part of the experience of making *all* of their EOL preparations. In other words, making EOLMDs is experienced as only one aspect of making broader EOL preparations that include legal, personal and religious preparations based on personal beliefs and values.

In summary, in making EOLMDs, the participants experience making these decisions as one aspect of overall EOL preparations that include personal, legal and religious preparations. As part of these preparations, making EOLMDs is experienced as a tension between urgency, brought on by an awareness of the end of life and hesitancy to formalize decisions in PDs. However, despite this hesitancy, participants move in the direction of formalizing their EOLMDs by gathering information about Personal

Directives and, in some cases (e.g., Mr. and Mrs. Purple; Mrs. Green) by eventually writing an actual Directive.

### **Summary of the Experience of Making EOLMDs**

The experience of making EOLMDs for these participants is one of tension between recalling death, illness and suffering, yet trying to predict what kind of EOL might be in store for them. As they try to imagine their own end, they hope for a good death; that is, one that is quick and painless. However, experience tells them that suffering is more likely going to be a part of their own death, so they try to imagine when they would want to “pull the plug”, based on their construction of the quality of life that is minimally acceptable.

They also imagine the role that others might play in their EOL. They plan as best they can to make things easier for those who will be left behind, while wondering if they can rely on medical professionals to have their best interest at heart when EOL comes. In spite of this doubt, they also trust health professionals to help their family members decide when they are ‘beyond hope’, ‘just being kept alive by machines’, or ‘just a vegetable’.

The participants also convey a sense of urgency to prepare for EOL, to formalize all of their EOLMD decisions, but they nonetheless experience a hesitancy to do so. In spite of this hesitancy to formalize decisions by completing a Personal Directive, they do make other EOL preparations of a non-medical nature such as personal, religious and legal arrangements.

However, through all of this recalling, imagining, considering and preparing, there is an uncertainty about their EOL that is insurmountable. There is uncertainty about how they will cope with suffering at EOL, what their actual EOL circumstance will be, and whether the EOL decisions they make will be appropriate and meaningful at their EOL. There is also uncertainty about the ability of their loved ones to carry out their EOL wishes and about how trustworthy health care professionals will be to help and not harm.

Golda Meir once said, "Old age is like a plane flying through a storm. Once you're aboard, there is nothing you can do about it" (Pipher, 1999. p 121). Like people aboard such a plane, these participants can only see vague shapes of what is ahead. The exact circumstances of their end must remain unknown and they know that. As they think about and formalize their EOLMDs, the best they can do is hope for the best and prepare for the worst.

## **Chapter Six: Discussion and Implications**

A critical clinical incident in my practice as a psychogeriatric nurse, described in Chapter One, and my concerns about the increasing pressure on older adults to complete Personal Directives (PDs) led to this research. In this qualitative study, the experience of older adults making end of life medical decisions (EOLMDs) was examined and the results suggest that there is an important difference between the way older adults interpret making EOLMDs and how health professionals might interpret those decisions. Following a summary of the research process, these findings and their implications will be discussed in the context of recent literature on the concepts of uncertainty, spirituality, ethics, and end of life (EOL) care. Throughout this chapter, limitations of this research will be discussed under the appropriate headings.

### **Summary of the Research Process**

In Chapter One, the purpose of this study and the initial questions that guided the research were defined. In addition, I described my personal and professional background that gave rise to this research and identified knowledge about the subject that had to be bracketed. The world view that underpins this study was also addressed as were the philosophical assumptions that were taken for granted throughout the research process.

The experience of older people making end of life medical decisions (EOLMDs) was chosen for study in order to gain an understanding of this phenomenon from an older person's viewpoint, particularly an understanding of the role family ties, and spirituality and religion play. Using participants' own words from two in-depth interviews and diary

entries, the experience of these six older people in making EOLMDs was explored and described. Five major themes were identified as essential to the experience. In this exploration and description, uncertainty was found to be central to the meaning of the experience. In addition, the role that relationships, and religion and spirituality played for these participants was found to be a significant part of the essential experience. By describing all of these structures, I gained an understanding of the meaning of this experience for these older people as well as a better understanding of what I and other nurses need to know to support these elder clients in making EOLMDs.

In Chapter Two, the focus of the current literature was described, which was quantitative in approach for the most part, and focused on medical and legal perspectives of EOLMDs. In addition, I examined two competing theoretical perspectives of the human person and offered a critique of the mechanistic view that underlies quantitative research, using the works of Francis Bacon as an example.

After examining the current literature, I described the need for a study that would explore the qualitative nature of making EOLMDs from an older person's perspective. This study is most timely given the lack of information and research available that articulates older adults' points of view. There was also an identified need to provide nurses with more knowledge about the experience of these clients in order to better educate and support them in their decision-making regarding EOLMD. In other words, the major limitation of the literature reviewed was that it did not give a voice to older people to express the meanings for them, of making EOLMDs.



Chapter Three described the hermeneutic phenomenological design of this study which used purposive sampling methods to gather a sample of two married couples, one widowed female and one married female for a total of six participants. The rationale for the selection of this particular qualitative method was also provided as well as a description of the purposive and snowball techniques used to find participants who met the inclusion criteria.

Chapter Three also included a discussion of the methods of data collection, which included two open-ended, focused interviews with each participant. I made use of an interview guide but new questions were added as the research progressed to explore emerging themes. Data collection methods described in Chapter Three also included diaries completed by the participants and five types of field notes based on the format used by LeNavenec (1993).

Also described in Chapter Three were the methods of data analysis, which included the use of Van Manen's (1998) approach as a guide to analyze verbatim transcripts of tapes and participants' diaries. A summary of the steps of data analysis were provided and issues of ethics were addressed. Issues of rigor were also discussed in this chapter, in part, through a description of the use of Parse's (1990) and Burnard's (1991) methods of data analysis to provide a triangulation of methods. A description of Lincoln and Guba's (1985) criteria for credibility, transferability, dependability/auditability and confirmability was provided as was the means by which these criteria were met (see also LeNavenec, 1993).

The findings are presented in Chapters Four and Five. In Chapter Four a description is given of the lifeworld and pertinent history of each participant in order to provide context, as well as a summary of the meaning for each participant of the phenomenon under study. Chapter Five provided the findings of the five themes that comprise the essence of the experience of making EOLMDs for elders and an explanation of the experience as well as a visual presentation in Figure 5.1.

### **Summary of the Principal Findings and Implications of the Study**

In terms of the value for nursing and education, these findings have significance because they provide insight into the difference between the way the older people in this study conceived of making EOLMDs and Personal Directives (PDs) compared to the way health care professionals conceive this phenomenon. They also provide a better understanding of the uncertainty experienced by older adults and suggest areas for further research. In the remainder of this Chapter, the findings for uncertainty and each of the guiding questions will be discussed; that is, the answers to the following questions: (1) what role does spirituality and religion play; (2) what role do strong family ties play; (3) how do past illnesses impact EOLMDs; and (4) how do older people conceive EOL planning tools like Personal Directives? The findings are examined in light of these questions and in terms of the differences in the way participants view PDs. In the final section, the implication of these findings for learning needs of both nurses and older clients will be discussed with a focus on the need for further research.

*Findings Regarding Uncertainty in Older Adults' Experience of Making EOLMDs.*

A major finding of this study was that participants experienced uncertainty in several forms when attempting to make EOLMDs. In an effort to understand the nature of that uncertainty, the findings will be discussed in view of recent literature on uncertainty.

Uncertainty has been found to be a significant theme in a variety of nursing-related phenomena including illness (Mishel, 1990) high-risk perinatal situations (Stainton, Harvey, & McNeil) and in nurses' and physicians' perceptions of ethical problems (Oberle & Hughes, 2001). One definition of the concept of uncertainty from a nursing perspective is "the inability to determine the meaning of illness-related events, assign definite values to objects and events, and/or accurately predict outcomes" (Neville, 2003, p. 206). Uncertainty has also been described as:

a dynamic state in which there is a perception of being unable to assign probabilities for outcomes, that prompts a discomfiting, uneasy sensation that may be affected (reduced or escalated) through cognitive, emotive, or behavioral reactions, or by the passage of time and changes in the perception of circumstances. The experience of uncertainty is pervasive in human existence and is mediated by feelings of confidence and control that may be highly specific (event-focused) or more global (a world view) (Penrod, 2000, p.238).

In addition to these broad definitions, Neville (2003) identifies a number of subtypes of uncertainty such as temporal uncertainty which is "not knowing when an inevitable harm would occur" (p. 207) and event uncertainty which refers to "a situation

where the time of occurrence was known, but where the probability of occurrence may vary” (p. 207).

In view of these definitions, it would seem that the uncertainty experienced by the participants in this study can be understood as a dilemma brought on by their inability to predict the outcome of EOL treatments and yet believing they must because of feelings of responsibility to prepare for EOL. In the case of these participants, the “inevitable harm” that they anticipate is that of suffering and pain at EOL, but they know neither when that will occur, or if, indeed, it will occur at all. This understanding of the uncertainty surrounding EOLMDs suggests that uncertainty exists not only during an illness as suggested by Neville (2003) and Mishel (1990), but also in cases of imagined or anticipated illness.

The literature describing uncertainty also suggests the procrastination experienced by many of the participants might be rooted in this uncertainty. If, as suggested by Penrod (2001), uncertainty “prompts a discomforting, uneasy sensation” (p. 241), then it might well be this sensation that propelled some participants to seek out information on PDs on the one hand (an attempt to reduce the sensation through cognitive and behavioral means) and arrested their attempts to do so on the other (an attempt to avoid feelings of reduced confidence and control). This procrastination has been documented in past studies of PDs (Glick, Mackay, Balasingam, Ryan Dolan, & Casper-Isaac, 1998; Winland-Brown, 1998). Although more research is needed to explore the connection between uncertainty in EOLMDs and the procrastination in completing Personal Directives, the findings of this study suggest that such a link might exist.

*Findings Regarding the Role of Spirituality and Religion*

One question asked at the beginning of this study was “what role does spirituality and religion play in making EOLMDs?” At the beginning of the study, I expected that religion and spirituality would, in some way, impact the kind of decisions that would be made, such as wanting certain life-prolonging measures and refusing others on the basis of religious belief (PNs, September, 2001). For example, after thinking about the Catholic censure of euthanasia, I expected people who practiced Catholicism to be more apt to have thought about all the treatments that might be offered and to make decisions that favored extending life, even in a state where the quality of that life might be decreased.

However, that may be true for some older people who make EOLMDs, but it was not the case for these participants. Their decisions about when to “pull the plug” were remarkably similar regardless of whether they were practicing Catholics (Mr. and Mrs. Red), practicing Protestants (Mrs. Orange), non-practicing Protestant believers (Mr. and Mrs. Purple) or agnostics (Mrs. Green). More specifically, regardless of religious affiliation, all of them had considered various treatments in ‘Imagining their EOL and Beyond’ and in ‘Preparing for EOL’. Furthermore, they seemed to make decisions based more on the specifics of the imagined EOL situation (such as not wanting to “live as a vegetable”) than on their religious convictions.

Where spiritual and religious beliefs and practices came into play were in decisions about funeral arrangements rather than specific treatment decisions; that is, in EOL decisions rather than EOLMDs. For example, participants suggested that choices of funeral services and burial arrangements were influenced by their religious practices

(Mrs. Orange, and Mrs. Red). In addition, the presence or absence of specific spiritual beliefs, even the non-believing afterlife speculation of Mrs. Green, were more focused on trying to imagine what might lie beyond death, rather than on any particular EOLMD. In other words, religion and spirituality were part of the *experience* of Imagining My EOL and Beyond and Preparing for EOL, but did not seem to have any impact on the actual decisions for treatment that participants thought about accepting or refusing at their imagined EOL.

This finding is supported by research into holistic nursing, and spirituality and aging which suggests that spiritual needs are not necessarily met by religious means. For example, Heriot (1992) suggests

it is not sufficient [for nurses] to know the church, synagogue or fellowship group a person attended. Although these may be indicators of religious involvement ...they are not necessarily the only manifestations of the spiritual orientation to life (p.26).

While some researchers believe that spirituality cannot be separated from religion, many others, like Atchley (2000) indicate a distinct difference between spirituality as a knowledge of the transcendent and religion as its social expression. (See also Health Canada, 2000; Heriot, 1992; Keegan, 1991).

Given these understandings of spirituality and religion, it is not surprising that participants' experienced this aspect of making EOLMDs as brief imaginings of what might lie beyond this life and as part of the practical EOL planning, (e.g., making funeral arrangements), rather than as a part of their actual EOLMDs. If spirituality is a supra-

intellectual knowledge of the transcendent, and religious practice its social expression, then the role of spiritual knowledge, is (at least in part) to give people an understanding of what lies beyond the physical world. It is an understanding that sends the mind on a quest to know if there is an afterlife, and if so, what the nature of that life might be. And if religion is the social expression of those beliefs about the transcendent, ( i.e., the material-world expression of them) then religion is expressed by rites and ceremonies within a community. Preparation for the afterlife and preparation for the rites after death would likely be the focus of spiritual and religious thoughts, not the kind of medical treatments one would want to keep the body alive (or not). In this study, participants seemed to separate spiritual and religious concerns from treatment decisions such as those necessary to make a PD.

Perhaps one reason for this separation is that EOLMDs are decisions that have consequences for these participants, not in the afterlife, but in their imagined worlds of hospitals, illness, and pain. The decisions these participants were making about treatment at end of life did not have to do with the transcendent, or an afterlife, except perhaps, in the sense of deciding what religious rites they needed to “cross the divide”, if they believed such a divide exists. As participants reflected on decisions about treatment, their focus was very much on the ‘here on earth’ dimension of their decisions. Therefore, although the experience of making EOLMDs included thoughts of the transcendent and the practical preparations of more general EOL preparations, decisions about treatment did not. From this perspective, participants’ experience of spirituality and religion in

making EOLMDs can be best understood, not as a part of decisions for treatment that participants made but rather, a part of a broader experience of making EOL decisions.

### *Findings Regarding the Role of Family Ties*

At the beginning of this study, one of the guiding questions was “what role do strong family ties play in making EOLMDs?” where the term “strong family ties was understood to mean that the participants had frequent and positive contacts with family members and received social and physical support from them. This guiding question implied a hypothesis that strong family roles do, in fact have some role in older people’s EOLMDs, and although, it was not clear to me at the beginning of the study, I had an idea of what that role might be. One of the concerns behind this study, which was outlined in Chapter One, was that older people might not know what their decisions meant and that they might be pressured into making choices that they either were not ready for or did not want to make. In view of this concern, my initial idea, which was bracketed, was that strong family ties might prevent older people from being pressured by well-meaning members of the health care system into making decisions that might shorten or extend their lives in ways that they did not want. (TN, October 18, 2001) In other words, my hunch was that strong family ties in some way protected older people from making EOLMDs that they might otherwise feel pressured into making, thus casting family members in the role of protector.

The findings from this study suggest otherwise. In discussing their EOLMDs, all of the participants mentioned family members as a significant part of their experience and related that they had strong relationships with their family members. However, they did



not view family members as protectors, nor was there an expectation that family members would act in such a role. Rather, the findings suggest that older people view *themselves* in the role of protector and their family members in the role of the protected. For example, when they spoke of preparing for EOL, whether it was naming executors of wills or appointing someone to make medical decisions for them, participants spoke of making things easier for those left behind. As Mrs. Orange put it, “They’re the ones who will have deal with things. By that time, I won’t care” (CNs, July 12, 2003). The findings suggest that strong family ties are part of the experience of making EOLMDs insofar as the family member who is responsible for carrying out the EOLMDs raises a concern for the older person that his death will be a burden for the loved one. In imagining his or her EOL, not only do the participants imagine what *they* might have to suffer, they also imagine what their loved one might have to endure. The older people in this study saw themselves as part of a web of relationships, making decisions to protect the welfare of their loved ones.

Some of the recent literature supports this finding. For instance, the *Guide to End of Life Care for Seniors* (Health Canada, 2000) asserts that becoming a burden is one typical fear of seniors at end of life (p. 18). This fear was echoed by all of the participants in this study under the theme ‘Considering the Role of Others at EOL’. In addition, a study by Carling (1991) on palliative care for the elderly, identified the loss of the role as head of the family as one of the key elements of loss experienced by elders in long term care settings. If one is fearful of becoming a burden and losing a senior role in family

relationships, one might well focus on the welfare of loved ones as did the participants in this study.

However, the literature suggests that this view of older adults as relational decision-makers is a view different from that held by health care workers. For example, Frank (1991) points out that:

Medicine assumes that the person who has the disease is the only one who is ill. This assumption is shared by other institutions and even by family and friends who should realize that illness is an experience that a couple has together - each differently, but one no less than the other (p. 105).

In addition, both the *Guide to End of Life Care in Seniors* (Health Canada, 2000) and the Alberta Association of Registered Nurses (AARN, 1996) suggest that autonomy is a key principle for nursing professionals to consider in EOL decision-making. This autonomy is expressed variously as “an individual’s right to make choices about one’s own course of action” (AARN, 1996); and self determination (Emanuel & Emanuel, 1989). In addition, much of the literature (Canadian Nurses Association, 1998; Kleinman, 1991; McLaughlin & Braun, 1998) is centered on discussions that assume self-determination of the patient as a central nursing goal for EOL planning.

This literature on EOL issues for seniors seems to assume what Pellegrino (1995) concludes is a conceptualization of the human person as a “bearer of legal rights” that dates back to the Roman Empire. It is primarily a legal view, whereby people are seen as autonomous individuals acting out of self-interest. It also assumes what Benner (1988) calls the modern view about people:

....that persons are atomistic, utilitarian individuals related to one another at best, by an enlightened self-interest. In this view each autonomous, “self-possessed” individual freely chooses to care in order to fulfill some psychological need, or in order to further his or her own self-interest, (views of the person espoused by Locke and Hobbes ...). (p.3)

However, this is not the view of personhood to which Benner subscribes. Rather, she critiques this view, indicating that it leaves nurses with an impoverished language with which to describe and affirm “a need-based psychological understanding of the person” (p. 3).

The literature described above suggests an ethical stance that emphasizes autonomy and views older people as ideal, isolated decision makers. However, the participants’ focus in considering others at EOL, in particular the role they imagine family members will play, suggests that they, like Benner (1998) might suggest that they were not isolated decision-makers, but rather, “participant[s] who [are] constituted or defined by membership and who share a common world of meanings...” (p.3) In other words, for the purpose of EOLMD-making at least, rather than viewing themselves as autonomous individuals, these participant seemed to view themselves in relationship with others, where their EOLMDs have repercussions that will be felt by their loved ones during and after their deaths.

In this discussion, I do not mean to suggest that nurses do not consider family relationships in their assessments of older adults in the community. Some nurse researchers acknowledge that “end of life care...must address the relationships and

transitional needs which impacts both elders and family members” (Trueman, 2001). However, participants did seem to view themselves in a more communal way than was indicated by the majority of the research (including most nursing research) on EOLMD-making. They considered the effect of their decisions not only on themselves but on the people who will have to carry out their decisions, while the literature suggests that health care professionals might view older adult clients in a more circumscribed way. This difference suggests the current interpretation of autonomy as shown in the literature, might overvalue autonomous decision-making in comparison to older people’s values.

#### *Findings Regarding Recalling Deaths and Illnesses*

Another of the initial guiding questions for this study was “do past illnesses impact EOLMDs?”. The findings suggest that past illnesses do, in fact, impact EOLMDs as do the deaths of family members. In particular, it is the *recall* of deaths and illnesses that was found to be an essential part of the experience under study. Throughout the interviews, participants consistently recalled both positive and negative examples of deaths they had witnessed which served as examples of what kind of deaths were possible. This understanding, then served as a basis for imagining their own EOL. In other words, their past experiences with death and illnesses suggested what they, themselves might face at EOL.

This finding has implications for the instruction of older people preparing EOLMDs, including the completion of documents such as Personal Directives. First it suggests that such elder clients should be asked about their experiences with death and illness, because such experience is likely to affect the kind of EOLMDs that participants

make. Since “unexpressed and unvoiced thoughts often arise as individuals remember unpleasant incidents in the past” (O’Leary & Nieuwstraten, 2001, p.166), it is possible that there is a trauma that remains from the memory of losses, whether those losses are of their own health and ability or the loss of a loved one. This kind of trauma might well keep older people from facing their own mortality, a task that is necessary to make EOLMDs or to prepare in any way for EOL.

*Findings Regarding Participants’ Conceptualization of Personal Directives*

In the beginning of this study, I asked how older people might conceive of the existence of PDs and hypothesized that they might see these tools as methods to maintain their autonomy in EOL situations, because this is how they are presented in the informational brochures issued by the Alberta government (e.g., Government of Alberta, 2001). However, the findings suggest otherwise. First, it appears that older people living in the community conceive of PDs as a vehicle for communicating relatively simple decisions. For example, the phrases used by the participants in ‘Imagining My EOL and Beyond’ were simple, somewhat vague ones such as “not being kept alive” and “not being a vegetable”. They also spoke of letting loved ones know “when to pull the plug”, which suggests that these were the kinds of decisions that they could imagine their loved one having to make.

In contrast, the health care literature on EOL care speaks of persistent vegetative states (Kleinman, 1991), withholding food and fluids at EOL (Lee, 2000) and definitions of brain death (Emmanuel, 1991). The research on EOL decision-making focuses on issues like whether or not to provide antibiotics, CPR or a naso-gastric tube at EOL. This

difference between the participants in this study and the health care research community, in both focus and language, suggests a difference in the basic level of complexity at which EOLMDs are conceived. Participants conceive of their EOL as being a straightforward situation where they are already brain dead and the only decision that remains to be made is whether or not to “pull the plug”. In contrast, health care professionals conceive of elders’ EOL in all the complexity that chronic illness and extended dying can bring. This difference suggests that there could easily be a breakdown in communication between older adults and health professionals who are attempting to help them to complete PDs.

There is another way the findings suggest a contrast between the EOL situation of elders that health professionals deal with everyday and the way older people might envision it. One of the findings of this study was that participants imagined their EOL situation ranging from an idealized “good death” to a worst case scenario where loved ones would have to “pull the plug”. However, only one participant out of the six (Mrs. Orange) suggested that her EOLMDs might have to face an EOL situation where she required nursing home care in the period before her death. All the other participants imagined either good deaths or a straightforward situation where their surrogate decision-maker would have to make a decision to take them off life support.

Although it is a myth that the majority of Canadians die in long-term care institutions, thirty-nine percent of Canadians do and only a minority of older people die suddenly or after an acute illness (Health Canada, 2000). These figures suggest a high probability that a significant portion of older people will end their days after a long period

of illness and in some type of long term care institution. In other words, the participants in this study imagined their EOL in a fairly limited way as compared to the kind of EOL they are likely to experience. Thus, the kind of situations that these participants would conceive of Personal Directives dealing with is limited compared to the likely EOL situations that health care professionals expect PDs to deal with.

The findings also suggest that participants see PDs as a vehicle to *avoid* certain EOL situations. The language participants used to describe ending treatment was “pulling the plug” and the state that they wished most to avoid as “being kept alive as a vegetable.” This use of language suggests that these participants envision mental incompetence as equivalent to being “Frankenstein-like zombies”, lacking both control and humanity, with the medical community playing the part of “the Mad Scientist”. In this kind of scenario, the only decision that must be made is whether or not “the monster” should die or be kept alive. In this sense, EOLMDs are viewed by the participants as a way to avoid being the victim of modern technology. They appear to consider PDs primarily as a vehicle for communicating such limited decisions to health care personnel. In the mind of an older adult, it might be simply a matter of saying, as many of the participants did, “I don’t want to be kept alive”.

However, as both the EOL literature and the experience of nurses like myself suggest, issues of competence and control at EOL are seldom that black and white. As documented in the literature, (Health Canada, 2000, Kleinman, 1991) and supported by my professional experience, patients who are incompetent (e.g., patients with Alzheimer’s Dementia) often have periods where they are legally competent to make their

own EOLMDs. In addition, older people who are incompetent to make their own EOLMDs are often admitted to hospital with an exacerbation of a chronic illness, one that does not necessarily put them beyond hope of recovery. Often, it is only later in a hospital admission that a doctor makes a judgment that the patient's condition is irreversible. This complexity in determining competence and decision-making control suggests that Personal Directives are conceptualized by health professionals in more complex ways than conceived of by the participants.

An additional difference between the way that older people view PDs as compared to health care workers is in the place of importance that these documents hold. For example, one significant finding regarding 'Preparing for EOL' was that participants experienced making EOLMDs as a small part of their overall EOL preparations, rather than as a distinct experience. As was pointed out in the literature review in Chapter Two, health care workers tend to write about the issue of EOLMDs from a medico-legal perspective. Researchers and most health care practitioners view PDs as a guide to treatment, while older people view a PD as part of the obligation of preparing oneself for EOL. It is interesting to note, for example that although all of the participants spoke of an intent to complete a Personal Directive, only two of them had done so by the time the second round of interviews was complete. It would seem that a PD is valued more by health care professionals than by the older adults who are making them.

The findings also suggest that there might be a discrepancy between the expectations older adults have of the role they expect physicians to play at EOL and physicians' ability to play that role. According to the literature, the physicians' ability to



accurately predict when life is ending or carry out EOL instructions of their patients is in doubt. For example, in a review of several studies Fincune (1999) found that the accuracy of doctors prognosticating their patients' life end was low. Another researcher (Orenlicher, 1992) suggests that "while theory may emphasize the patient's values, empirical data suggest that....physician values may be a more decisive factor than patient values in [end of life decisions]" (p.2101). Other researchers (Emanuel & Emanuel, 1992) concluded that "proxy decision-making fails to realize its objective of promoting the patient's medical care preferences." (p.2071).

Despite the conclusions of research such as this, many participants suggested that it was up to physicians to identify for them or for family members when life was over, when their condition was irreversible, or when the quality of their lives would be reduced and to what degree. They also expected that their proxy decision maker, in consultation with the physician, would carry out their end of life wishes. This discrepancy between the physicians' predictions and participants' reliance on those predictions suggests that older adults making EOLMDs might have expectations of physicians that even doctors themselves would find unrealistic. In other words, the findings show that participants rely heavily on physicians to supply information to family members, despite that the literature suggests that physicians may not realistically be able to supply the kind of information that the participants expect.

The most significant difference between the views of participants and health care professionals on PDs is in the degree of certainty that each group seeks from this advance planning tool. The finding of the 'Experience of Uncertainty' showed that participants

recognized that their EOLMDs were contingent on knowing more of the specifics of their EOL situation than they could know. They could recall how others close to them had died; they could try to assess how much pain and suffering they might be able to bear; and they could plan as best they could to make things easy for the ones left behind. However, participants recognized the inherent uncertainty in making EOLMDs and in recording them in a document such as a PD.

This acceptance of uncertainty among older adults is confirmed by at least one other phenomenological study. In a study of older patients and PDs, Winland-Brown (1998) found that when asked about preparing Personal Directives, participants made statements like "How can I make well informed decisions about treatment before an illness or injury occurs?" (p.38). Although Windland-Brown interprets this statement and others like it as evidence of denial of death, it might also be seen as an acceptance of a realistic limitation in this kind of decision-making. If decisions require reliable information and knowledge of which disease is to be treated, then how, indeed, are participants to make life and death decisions if they know neither the disease that will afflict them at EOL or the treatments that might be offered. This uncertainty suggests that PDs are viewed by participants as a vehicle to merely provide guidelines for EOLMDs being made by loved ones when the details will finally be known.

However, the purpose of PDs in the world of health care is to "support individuals in making decisions on their own behalf, thereby promoting the principle of self-determination" (Canadian Nurses' Association, 1998; see also Kjervik, 1997; Kleinman, 1991). If older adults view the PDs simply as a way to provide guidelines for loved ones

and physicians, then it would seem that their definition of “self determination” is a much more relational one than the definition by health care professionals.

### **Discussion: Implications of the Study**

In summary, the findings of this study suggest a number of conclusions of interest to nurses and other service workers teaching older clients about making EOLMDs: (1) that procrastination in completing Personal Directives might be linked to the uncertainty inherent in making EOLMDs; (2) that at least some older people find religion and spirituality a significant part of preparing for their EOL, but not a significant part of treatment decisions; (3) that one of the main goals of these participants’ EOL preparations in general and EOLMDs in particular is to protect their loved ones from pain; (4) that at least some older adults conceive PDs as part of their overall EOL planning, valued primarily as a method to communicate guidelines, but not as important in EOLMD making as the ability to rely on physicians and their loved ones at EOL.

### *Implications for Educational Needs of Older Adults*

In writing about educational theory, Van Manen (1998) proposes that ...what we need more of is theory not consisting of generalizations, which we then have difficulty applying to concrete and ever-changing circumstances, but *theory of the unique*; that is, theory eminently suitable to deal with this particular pedagogic situation, this school, this child, ...We can move toward theory of the unique by strengthening the intimacy of the relationship between research and life. (p.155)

By these standards, this study has contributed to knowledge about the educational needs of older adults in a number of ways. First, it has demonstrated a number of insights into the experience of older adults living in the community who are making EOLMDs. It has highlighted the role of past illnesses and death and the power of trying to imagine an end of life that is impossible to know. It has also underlined the central role uncertainty plays in these older adults' experience, characterized by hesitancy in completing EOLMDs. All of these insights "strengthen the intimacy between research and life" in that they (1) describe the nature and qualitative aspects (Le Navenec, 1993) of making EOLMDs from the point of view of older adults; (2) illuminate the importance in this phenomenon of recalling death and illness, imagining an EOL, considering others at EOL, preparing for EOL and experiencing uncertainty; and (3) demonstrate the centrality of uncertainty in the experience of making EOLMDs.

Therefore, this phenomenological research has contributed to knowledge of the educational needs of older adults by deepening the understanding of the lives of this group of people. Particularly important is the understanding of the way uncertainty and trying to know the unknowable permeates this experience. This holistic understanding goes toward meeting Van Manen's (1998) criticism that "much of educational research tends to pulverize life into minute abstracted fragments and particles that are of little use to practitioners." (p.7) Thus, another way that this study contributes to a "theory of the unique" is by a more holistic understanding of this group of older adults.

This study, with its findings of the inherent uncertainty in the experience of this phenomenon has thus suggested a direction for further research. Given the procrastination

identified in older adults making EOLMDs by a number of researchers (Health Canada, 2000; Sawchuck & Ross-Kerr, 2000; Winland-Brown, (1998)) further research is needed on the nature of this part of the experience. Is the uncertainty in this experience connected to the procrastination? If so, how? Or is it another part of the experience of EOL, such as fear of death, that stimulates the procrastination? Further phenomenological research will increase the understanding how older people experience making EOLMDs.

### *Implications for the Practice of Nurse Educators*

In addition to implications for the learning needs of some older adults, the findings of this study hold implications for the practice of nurse educators, and any other service workers who are responsible for meeting the knowledge needs of older adults on the subject of making EOLMDs and preparing PDs. One of the findings of this study was that the participants imagine their EOL in a relatively simplistic way compared to the way health care workers view EOL situations for older clients. This finding implies that meeting the learning needs of older clients should include information on some of the likely scenarios that might be the context for his/her EOL. If, as this finding suggests, some older people in the community, are making EOLMDs based on highly simplified EOL, then any educational programs should include content for the elders about a variety of EOL scenarios to encourage more realistic decision-making. If older adults have a more precise understanding of the scenarios that their EOLMDs might have to deal with, then they will be better able to write Personal Directives that will communicate their EOLMDs meaningfully to health care professionals.

This finding also implies a need for nurses to have a part in teaching about PDs.

At present, the Alberta Office of the Guardian has an educational program on Personal Directives for older adults. However, the focus of this program is primarily on the legal aspects of preparing a PD and does not include medical EOL scenarios that older adults might encounter. A co-operative program that included an RN to provide such information would prepare older adults more thoroughly for EOL than does the present program. It appears to me that such a program would provide older people with a broader basis to make EOLMDs that take into account the range of realities that they could encounter at EOL.

*Suggestions for Supporting Older Adults in the Community Making EOLMDs.*

The findings also have implications for community nurses who are called upon to give support to their older clients who are making EOLMDs. This study demonstrated that the participants conceived of making EOLMDs with a communal focus, with health care professionals and their family members playing a significant part in the experience. This research has also demonstrated that in preparing for EOL in general and in making EOLMDs in particular, participants experienced a tension between the need to make those decisions and the uncertainty inherent in the EOL situation. This suggests that nurses supporting such clients in the community should include family members who will play a key part in the elder's EOL.

Another of the major findings of this study was that a significant part of the experience of the phenomenon under study was that the participants recalled often painful memories of the deaths of loved ones and of their own illnesses. If the context of this

study is transferable (Lincoln & Guba, 1985), that is, for older adults who have similar cultural histories, and live with similar family obligations, then the findings suggest that some older adults may need emotional and psychological support in the process of making these kinds of decisions. Since “unexpressed and unvoiced thoughts often arise as individuals remember unpleasant incidents in the past” (O’Leary & Nieuwstraten, 2001, p.166) it is possible that there is a trauma that remains from the memory of losses, whether those losses are of health and ability or the loss of a loved one, a trauma that might well interfere with decision-making. An assessment for such trauma and provision by community nurses assisting older adults in making might make those decisions less painful for some older adults.

The findings also suggest that nurses need to show sensitivity to the older person’s dilemma by teaching about the purpose and limitations of PDs, and also by supporting those elders whose decision is NOT to complete one. A thorough assessment should be made of the older clients’ and family members’ level of knowledge about medical treatments, and possible EOL scenarios. In addition, the elder may need assistance to come to EOLMDs, (over time if necessary) that are both useful to health professionals and that realistically reflect their EOL wishes.

Finally, the findings that these older adults conceive PDs in a more simplistic way compared to health care professionals indicate a need for community nurses and nurse educators to devise a comprehensive plan to help older adults participating to make a plan of care for EOL. With education about realistic EOL scenarios and compassionate support which included clients’ families in decision-making, older adults could plan EOL

hospital care that would truly reflect their wishes and would communicate those wishes in a meaningful way to health care professionals.

### *Some Reflections on the Ethical Stance of Autonomy*

As noted above, some of the language used by participants in this study reflects a view of modern medicine as attempting to wrest control from patients at EOL. The participants' imagine themselves as "at the mercy" of a medical system which creates "zombie-like creatures". The popularity of movies like "Whose Life Is It, Anyway" seems to express a similar cultural belief that the medical system should not have power over people's EOLMDs. Instead, it is INDIVIDUALS who should be responsible for making these decisions. However, nurses working with older clients making these crucial decisions might be encouraged to reexamine this ethical stance in view of the findings to ask if the need for beneficence, an ethical principle rooted in a more paternalistic view (Health Canada, 2000) might outweigh or at least balance considerations of autonomy. In asking this question, nurses supporting older clients might be more sensitive to the need some clients have to be relieved of some of the more onerous aspects of making these decisions and rely on family members and health care workers.

### *Suggestions for Future Research*

This study has demonstrated the usefulness of a phenomenological approach by giving a thorough description of the experience of six older adults making EOLMDs. In addition to the suggestions for research already made, it is suggested that future studies continue to explore other aspects of this topic. Other areas that might be explored include the social processes that are at work in this phenomenon and if and how the culture of the



health care system and/or its professionals privilege certain discourses about EOLMDs (ones based on a scientific world view) and give less value to others that take a more ecological/relational view of the world. All of these endeavors would likely increase caregivers' understanding of this phenomena and thereby would assist nurses to develop effective support for these clients who are faced with making EOLMDs.

One limitation of this study is that it does not address cultural or ethnic influences on making EOLMDs, an influence that has been well documented (Braun, Onaka, & Horiuchi, 2001; Kiely, Mitchell, Marlow, Murphy & Morris, 2001; Mitty, 2001; Vaughn, Kiyasu, & McCormick, 2000). The philosophy underlying a phenomenological approach (discussed in Chapter 2) assumes that there are enduring structures in any experience. This stance suggests that there are many aspects of this phenomenon which would be experienced by members of different cultures and ethnic groups in a way similar to that of these participant. However, further research is needed to confirm or refute that hypothesis.

### **Conclusion**

In this qualitative study, I discovered that older people experience a concern for others who will play a role in their EOL, that part of this experience means reliving the pain and loss of the past and trying to imagine their own EOL and what lies beyond. I have gained a greater respect for these older people who face an uncertain EOL situation, yet accept the inevitability of death as it looms, with more equanimity than many could muster. They have endured many joys and trials in their lives, but still, as Mrs. Orange put it "seniors are more interested in planning for life than planning for death" (CNs, July

13, 2003). This hope is cause for optimism as health care professionals enter an era of debate about euthanasia, health care at life's end, and eventually, reach the end of their own lives.

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## APPENDIX A: Sample Letter to Colleagues to Suggest Participants

Dear Colleague,

In follow-up to our conversation, I am writing to give you more information about the study that I spoke of. I am enrolled in the Graduate Division of Educational Research and am conducting a study entitled End of Life Medical Decisions in Elders. This study aims to uncover some of the experiences of elders (age 65 and older) who are planning for a time when they might not be able to participate in their own end of life decision-making due to physical or mental infirmity. As they make the kind of end of life decisions necessary to write an Advance Medical Directive (sometimes called a Living Will) or to appoint an agent to make these decisions for them, what do they experience? What personal and societal values come into play? What do they experience emotionally? What meaning do they ascribe Advance Directives and the process of end of life decision making? These are questions that, when answered, will assist Registered Nurses in Community settings to support their older adult clients in making end of life decisions that truly reflect the elders' wishes.

In asking for your assistance in selecting participants, I would ask you to keep in mind the following criteria:

1. The participants must be age 65 and over, and may be either male or female.
2. They must have made at least one end of life medical decision within the last year such as completing an advance directive or appointing an agent.

3. They must be physically and mentally capable of participating in interviews and small group discussions and be able to speak and write English.
4. They must be legally able to give informed consent.
5. They must be living in a community setting.
6. And finally, they must be willing to disclose their affiliation, if any, with a faith community. Although participants might or might not be part of a faith community they must be willing to disclose any affiliation so that the number of participants from any one major religious group (e.g., Catholic, Anglican, etc.) can be restricted.

If you know of anyone who would be suitable and would be willing to participate, please give them my telephone number and ask them to phone. Your cooperation in this study is greatly appreciated and a copy of the final results will be made available to your agency when the study is completed.

Sincerely,

Linda Bondoc

## APPENDIX B: Sample Information Letter to Participants

Dear Prospective Participant,

Thank you for considering taking part in the study End of Life Medical Decisions in Elders. This letter will give you further information about the study so you may give informed consent should you decide to participate. Please read the following information carefully and if you have any questions, please direct them to me at (403) 238-8181.

In this study I hope to find out how elders (over 65) who are still in their own homes or in lodges make end of life medical decisions. Examples of such decisions might include the kind of medical treatments you might want or want withheld if you were ever seriously ill. Other examples of end of life medical decisions might be focused on who you would want to make medical decisions for you in the event that you became mentally incapacitated. Although much research has focused on *health professionals'* "need to know" very little has focused on older adults' **experience** of making such decisions. These are important and personal issues and I hope, with the insight gained through this study, that Registered Nurses like myself will be better able to guide and support elders in their making these kinds of decisions.

Through interviews and notes kept by both of us, I hope to develop a detailed description of what you experienced when you made your end of life medical decisions. I understand that speaking about death or recalling times of illness can be painful experiences. If you feel that it would be too difficult for you to discuss these issues,

please do not feel obligated to participate. There is the risk that discussing your experiences may make you feel very distressed.

However, if you do take part there may be some benefit in sharing your thoughts and feelings about end of life issues with someone outside your family or usual circle of friends. It is also possible that your contribution will improve health care professionals' understanding of older adults' experience of making end of life medical decisions.

If you do take part, you will be asked to meet with me at least twice at a time and place that is convenient to you. I expect our conversations to last approximately 1-2 hours each and I will tape them with your permission. At a later date, we will meet again, and I will ask you to talk more about some of the topics we covered in our first conversation. I might also ask you to read and comment on a story I will write, based on my conversations with all the people in the study. In addition, I will also ask you to keep a diary for approximately 6 months and record your thoughts and feelings about our conversations. At some point I will ask you to share this information with me. In total, the time you would have to commit is approximately 8-16 hours, which would include the time spent journaling.

If you become distressed as a result of your participation, a no-cost counseling service will be available. You would be free to withdraw from the research at any time with no penalty to your health care. Please also be aware that I may ask you to withdraw if, in my professional opinion, you are not able to continue because of emotional or physical distress.

There will be no money paid for your participation; however, you will be able to see a summary of the results at the end of the study.

All data (tapes, transcripts, journals, and research notes) will be kept in a locked filing cabinet in my home will be shared only with my thesis advisor, and my nursing colleagues. To maintain confidentiality, I will ask you to select an alias which will be used throughout the study. All of your personal information, such as addresses, etc. will be edited from the final report. The data will not be used for any other purpose other than in partial fulfillment of a Master's Thesis at the University of Calgary without your consent. All data will be kept secured for five years and then destroyed.

Throughout the study, you will receive updates as to the progress of the study every six months until it is completed.

I hope you will consider being a part of this research. If you have any further questions or if you have decided to participate, please contact me at (403) 238-8181.

Sincerely,

Linda Bondoc



## APPENDIX C: Sample Consent Form

**Title:** End of Life Decision making in Elders

**Investigator:** Linda Bondoc

**Thesis Supervisor:** Dr. Carole-Lynne Le Navenec

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

This research attempts to shed light on how elders (over 65) in community settings experience making end of life medical decisions. Although much research has focused on *health professionals'* "need to know" about Personal Directives, and DNR (Do Not Resuscitate) orders, very little has focused on older adults' experience of making such decisions. These are important and personal issues and it is hoped, with the insight gained through this study, that Registered Nurses in community care settings will be better able to guide and support elders in their end of life medical decision making.

Over the next six-month period, you will be asked to do at least two in-depth interviews that will be arranged at a time and place that is convenient to both of us. The interviews will be taped and will last approximately 1-2 hours each. At a later date, you will be asked to read and reflect on a written transcript from one of the original interviews. You might also be asked to read a fictionalized presentation of the data and to give comments on it. In addition, you will be asked to keep a journal of your thoughts and feelings about end of life decision making over a

period of approximately 6 months and share this information with me. The total estimated time commitment for participants is between 8-16 hours including time spent journaling.

Your signature on this form indicates that you have understood to your satisfaction the information about taking part in the research project and agree to participate. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact:

Linda McCloud Bondoc (403) 238-8181 or

Dr. Carole-Lynne LeNavence (403) 220-6269

If you have any question concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, at (403) 220-7990.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Investigator and/or Delegate's Signature

\_\_\_\_\_  
Witness' Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

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

## APPENDIX D: Sample Interview Guide

1. What were the concerns that led you to make end of life medical decisions?
2. What decisions did you come to?
3. Describe how you reached those decisions?
4. Who (if anyone) influenced those decisions?
5. What factors influenced those decisions?
6. What does making end of life medical decisions mean to you? To your family?
7. What impact (if any) has making end of life medical decisions had on you and your family?
8. How did your personal values influence your decisions?
9. What religious or spiritual beliefs (if any) affected your decisions?
10. Please describe the kind of scenario you envision that might require your end of life decisions to be implemented?
11. According to your end of life wishes, what kind of treatment do you envision being given? being withheld?
12. Who do you think is responsible for making medical decisions for you if you are no longer able to make them for yourself?
13. When is the last time you or a family member were seriously ill?
14. What impact (if any) did this illness have on your end of life decisions?

## APPENDIX E: Sample Interview Transcript

**CODE: R=RESEARCHER P=PARTICIPANT**

R: What, what would the 'right decisions' be?

P: If you're not able to get well, there is not point in resuscitating you.

R: Umm.

P: Leave you be and let you die. I think it would be difficult, very difficult for the boys to do that. Or my daughter-in-law.

R: Um, yeah.

P: (pause) But, but, I would think they would do it, with peace of mind in the long run

R: Uh huh.

P: because it would be anguish.

R: Uh huh. You mentioned they, that they might need some guidelines. What, what kind of guidelines. . .?

P: Well, well, I have a piece of paper on the fridge, that – I had to write new one, because the old one got kind of ratty but, under a magnet on the fridge and it tells the kids where all our legal documents are, where our wills are, where our RSPs are, where bank accounts are, where insurance is, where are the keys to the safe deposit boxes. It tells them all of that sort of thing. But those are details.

R: Yeah.

P: They know we have all these things, but they're not always going to remain there.

R: Right.

P: So, if we told them we wish to be cremated then that's fine, they'll remember that part.

## APPENDIX F: Sample of Participant Journal

**August 13, 2001**

Question: What would you expect the nurses, etc. to do to help you?

I think I would like them to make me as comfortable as possible without using extraordinary means i.e.: painkillers, comfortable bed, etc.

**September 7, 2001**

Read in the paper that those who need to give home care may begin to do so with the use of computers. The patient would be seen on a viewer connected to a computer and would be able to see and talk to the person who is "attending" them. Whatever happened to the human touch? Quite often all the patient wants is the touch of a hand, a nod of the head of the person sitting near them. Oh well, let's see as many patients as possible at the least cost.

I'm not sure how I would react to this.

Might just pack it all in, or get mad and do whatever it takes to get better?

Beginning to seriously think about funeral arrangements.

Hymns

Readings – who, which ones

Closed casket

Cremation

Pall bearers

Plot

Really feel for the nurses. They have too much to do. Can't give as much time as to those who are not too sick. Busy checking on all the mechanical devises to be sure they are all working properly. They are need I know. They help to keep track better.

## APPENDIX G: Samples of Field Notes

**Methodological Notes (MN)****August 7, 2001**

At Mr. & Mrs. Red's house: Mrs. Red sat in on interview, though she didn't say too much. Will this/should this affect my results? It turns out that I know this couple's daughter. Is this okay? I go back to interview Mrs. Red.?

It seems that many of my people don't have defined experience with end of life decisions so they are having to speculate a lot. Is this what I NEED? If not how do I find these people. A decision is a very nebulous think to talk about.

**June 14, 2002**

Going through the scripts on-screen. I'm picking out things that are related but different. If I go back and get the same themes (phrases) again, is that a sign of reliability. I'm not sure I agree with the article that says just because you are systematic you achieve reliability and validity. It depends on the system. Does it acknowledge the role of the researcher?

**August 1, 2002**

I wonder if "trusting others" to carry out end of life wishes might be a larger category than encompasses communicating end of life decisions to others. Is it part of communicating to others? Can you communicate without trusting that people will carry it out? They are connected, but how? Trusting comes first, then the communicating.

**Observational Notes (ON)****October 18, 2001**



I keep running into Mr. & Mrs. Red's daughter at the university yesterday, at Church last month. Last month we spoke of her parents and the fact that I was doing a study.

### **January 9, 2002**

I've observed how much more emotional Mr. Red is today when talking about his decreased physical capacity due to his heart condition. Is this because he trusts me more? My sense is that it is, at least in part due to our interview. How much these interviews stimulate people to action? Would he have felt/acted the same way if I hadn't interviewed him? I'm aware I've done my best to form a relationship with these people. We are all going along in the flow of time and we're in the same arena for awhile. It makes me realize how much everything is in flux and how "unavailable" the world is. That is, we are unable to nail something and say "this is how it is now, always has been and will be forever." Maybe there are some things like that in the world like the Law of Gravity, but most things that we REALLY want to know about are like my interviews – a mixing of currents for a very small moment in time.

### **Contact Notes (CN)**

#### **June 7, 2002**

Feedback obtained from 3 people – 2 given Mr. Purple's interview to read and asked to complete this sentence: Making end of life medical decisions means. . . They were asked to complete this from their perception of the participant's point of view. In other words: How do they think this participant would complete that sentence?

#### **July 14, 2003**

Contact with Mrs. Green. Able to recognize. Nothing to add. Especially recognized “hoping for the best; planning for the worst”.

### **Personal Notes (PN)**

**July 5, 2001**

First contact with G.L. by telephone. Maybe I was too circumspect when talking to her because she said, “You don’t have to beat around the bush when you talk about it (end of life decisions) because I’m 83 years old and I know I’m facing the end of my life and I’m not afraid of that.”

**July 24, 2001**

Perhaps one of the things I didn’t anticipate is that these situations are so nebulous that it is difficult to pin down. Many of the questions I ask, ask for speculation. Does this. . .

**August 7, 2001**

It seems I’m leading people or maybe it’s just that people don’t have as much to say as I thought. I’m worried that my question (questions) approach is too superficial.

### **Theoretical Notes (TN)**

**November 9, 2001**

Read Age Studies as Cultural Studies (Handbook of Humanities and Aging) and this suggests that I should look at films to see what else might be telling me about aging and end of life decisions in elderly.

**December 7, 2001**

Have been collecting fiction titles for possible use. "Wit" seems to be promising, especially one scene, that talks about the need for heroics (the main character doesn't want it). Also interesting is the way the young fellow in the play represents Science and the way medicine seen as science is often "enacted upon" people, making them into objects, while the nurse treats the main character as a whole, although dying human. Maybe THIS is what is frightening people the most? Maybe this is much of what decisions are based on – pre-empting this kind of situation where someone is objectified. Maybe the fear of loss of control is, at least in part, of this and not necessarily a fear of death.

## APPENDIX H: Glossary

1. **Category** - while Van Manen doesn't use a concept like categories, and even implies that experience cannot be captured in categories, ("It would be simplistic, however, to think of themes as conceptual formulations or categorical statements" (p.79)) the use of "categories" in this study most closely aligns with that of Dye et al ( 2000) when they state "To categorize is to render discriminable different things equivalent, to group objects and events and people around us into classes, and to respond to them in terms of their class membership rather than their uniqueness. Dye et al ( 2000) state, "Categories, created when a researcher groups or clusters the data, become the basis for the organization and conceptualization of that data (Dey, 1993)." (p. 2).

2 **Data** - that which is given. A construction of the experience under examination, in this case, the experience of elders making EOLMDs. (Lincoln & Guba, 1985, p.332)

3. **End of Life (EOL)** -The time that life ends AND the immediate period of illness that lead up to it. Encompasses the time of dying but may also include some period of time prior to that because the period of dying can only be defined by doctors, medically, or after the fact of death, as in, "we didn't realize it at the time, but she was dying." Or, alternatively, "the doctors told us she was dying."

4. **End of life medical decisions (EOLMDs)** - are understood to mean decisions such as choosing which medical treatments to accept or decline and under what circumstance, and choosing who is to be responsible for making such medical decisions if the one is incompetent. Although none of the older adults in the study made an explicit choice not

to make end of life medical decisions, these choices by default were included in the definition of *end of life medical decisions* at the beginning.

5. **Essence**-The study uses the views the essence that Van Manen (1998) articulates:

“that which makes a thing what it is (and without which it would not be what it is); that what makes a thing what it is rather than its being or becoming something else.” ( Van Manen, 1998, p. 177) This definition assumes (as does phenomenology) that there are universal essences. An essence, according to Van Manen, (1998) “ may be understood as a linguistic construction, a description of a phenomenon.” (p.39).

6. **Experience**- This study was guided by Van Manen’s (1998) understanding of experience as “lived experience”, that is, “our immediate, pre-reflective consciousness of life: a reflexive or self-given awareness which is, as awareness, unaware of itself.”(1994, p. 35).-Van Manen (1998) also cites Merleau-Ponty (1968) as having “given a more ontological expression to the notion of lived experience as immediate awareness which he (Merleau-Ponty) calls “sensibility”: “The sensible is precisely that medium in which there can be being without it having to be posited; the sensible appearance of the sensible, the silent persuasion of the sensible is Being’s unique way of manifesting itself without becoming positivist, without ceasing to be ambiguous and transcendent ....The sensible is that: this possibility to be evident in silence, to be understood implicitly. (p. 214)” (p. 36).

7. **Hypothesis**- an explanation of the data arrived at by induction, which identifies patterns in the data. (Janesick, 1994).

8. **Negative case-** defined in Lincoln and Guba (1985) as “‘a process of revising hypotheses with hindsight.’ The object of the game is continuously to refine a hypothesis until it accounts for all known cases without exception. (pg. 309).

9. **Participants** - The participants in this study are conceptualized as co-researchers (Cresswell, 1998).

10. **Phenomenology** - “is the study of the lifeworld - the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it. ( Van Manen, 1998, p. 90 )

11. **Religion** - was defined as a formal expression of spirituality through the belief system of some faith community (Health Canada, 2000; Heriot, 1992).

12. **Spirituality-** was defined as a sense of the transcendent and/or any conceptualization of a higher power, however participants might conceive of that power (Health Canada, 2000. p. 135-6).

13. **Theme-** phenomenological themes may be understood as the *structures of experience* (Van Manen, 1998). So, when a phenomenon, is analyzed one is trying to determine what the themes are, the experiential structures. In this study, theme is understood to be the conceptual abstraction that describes the essential elements of the experience.

**APPENDIX I: Copy of Letter of Ethics Approval**



UNIVERSITY OF  
CALGARY

## FACULTY OF MEDICINE

Office of Medical Bioethics  
Heritage Medical Research Building/Rm 93  
Telephone: (403) 220-7990  
Fax: (403) 283-8524

2001-06-12

Dr. C-L. LeNavenec  
Faculty of Nursing  
University of Calgary  
PF 2260  
Calgary, Alberta.

Dear Dr. LeNavenec:

Re: Medical End-of-Life Decision Making in Elders  
Student: Ms. Linda L. Bondoc Degree: MSc

The above-noted thesis proposal has been submitted for Committee review and found to be ethically acceptable. Please note that this approval is subject to the following conditions:

- (1) a copy of the informed consent form must have been given to each research subject, if required for this study;
- (2) a Progress Report must be submitted by 2002-06-12, containing the following information:
  - (i) the number of subjects recruited;
  - (ii) a description of any protocol modification;
  - (iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
  - (iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
  - (v) a copy of the current informed consent form;
  - (vi) the expected date of termination of this project;
- (3) a Final Report must be submitted at the termination of the project.

Please note that you have been named as a principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.

Yours sincerely,

Christopher J. Doig, MD, MSc, FRCPC  
Chair, Conjoint Health Research Ethics Board

cc: Dr. M. Reimer (information)  
Ms. Linda L. Bondoc, Graduate Division Educational Research  
Professor C. Levy, Chair, Conjoint Faculties Research Ethics Committee  
Dr. Michael Pyryt, Chair, Faculty of Education Ethics Committee