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Knowledge and Attitudes of Older Adults regarding Personal Directives

by

Peggy Jean Sawchuk ©

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

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Knowledge and Attitudes of Older Adults regarding Personal Directives" submitted by Peggy Jean Sawchuk in partial fulfillment of the requirements for the degree of Master of Nursing.

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Abstract

Advance care documents have been available since the 1960s. However, only recently have these documents been legalized in three Canadian provinces. The documents allow people to express their preference for future medical treatment in the event they are unable to speak for themselves. With these advance planning documents, older adults' autonomy is maintained and greater control over decisions regarding their health care is reinforced. Considering Canada's aging population, older adults are considered a group that may find these documents useful. This exploratory/descriptive study was proposed when Alberta was drafting legislation relating to Personal Directives.

The study consisted of sixty interviews with seniors ranging from 65 years to 88 years of age. A purposive sampling technique was utilized to obtain the required participants. The results of the study suggest this group of seniors was aware of personal directives, though only in relation to the refusal of medical treatments. The seniors wanted to be involved in making decisions about their health care. Eighty percent of

participants wanted family members to speak for them in the event of their incapacity. Even though they may have not communicated their wishes to their substitute decision-makers, all participants indicated they believed their family would follow their wishes. If a physician was chosen to be involved in making decisions on their behalf, participants indicated it would be their family physician. Age was not considered to be a criterion for completion of a personal directive. Other questions relevant to personal directives and communicating wishes to substitute decision-makers are discussed.

The results of this study are relevant to older adults, their families, their physicians and other health care professionals. In addition, this study may assist health care professionals in introducing a discussion of personal directives to their patients. The information provided in this study adds to existing research literature and contributes further information regarding older adults' preferences for planning for their futures.

Acknowledgments

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To my husband Ray and sons Matthew and Samuel, a very heartfelt thank you for your love, support, encouragement and unwavering enthusiasm during this endeavour. To my sister Caroline, thank you for your love, support and the many hours of listening while I wrote this thesis.

Most of all, I am indebted to the older adults who took the time to share their opinions about personal directives. The sharing of your thoughts about this subject has been very valuable and made this thesis possible. I enjoyed each and every interview. Thank you! I hope the information you have provided me will assist other health care professionals in the future.

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CHAPTER 1: INTRODUCTION

Advance care documents were first introduced in 1967 at the Euthanasia Society of America (Anderson, Gladue, Laurie, Skotniski & Tramer, 1991; Emanuel & Emanuel, 1990; Ney, 1990; Crump, 1989; Matthews, 1986; Eisendrath & Jonsen, 1983). There are different types of advance care documents described in the literature, such as the Living Will, Medical Directive and Values History. Since the 1970s, these documents have become widely available and, by 1992, there were 47 states plus the District of Columbia that had some type of legislation regarding Living Wills (Downie, 1992; High, 1990). Despite this availability, only 4 - 25% of the population actually completed one of these documents (High, 1993; Stelter, Elliott & Bruno, 1992; Wanzer et al., 1989). By the end of 1994, three Canadian provinces, Manitoba, Ontario and Nova Scotia, had proclaimed some form of living will legislation. Quebec has legislation regarding proxy directives and Saskatchewan has supported the use of advance directives (Kohut & Singer, 1993). Alberta recently passed Bill 35 -- Personal Directives Act and is awaiting proclamation (Province of Alberta, 1996).

In the next 20 years there will be a dramatic shift in the population grid when the 'baby-boomers' reach the ages of 65 - 75 years. Older adults fear their lives may be either painfully prolonged or that they will be ignored if they need health care. An additional concern expressed by this current population of seniors is that they will not be involved in the decision-making process. In response to some of these concerns, draft legislation was introduced into the Alberta Legislature regarding Advance Directives and Substitute Decision-Making in Personal Health Care by the Alberta Law Reform Institute in 1991. In the Spring of 1996, Alberta passed Bill 35 - Personal Directives Act as the final step prior to legalizing the use of these documents in the province. To reflect the current Act, the terms Personal Directives and Advance Directives are used interchangeably throughout this document since it was written after the passage of the Personal Directives Act.

The research that will be undertaken is an exploratory/descriptive study design using quantitative and qualitative data collection and analysis. The purpose of the study is to explore and describe knowledge and attitudes about personal directives of older adults living in the community and receiving treatment in rehabilitation hospitals and community health centres. In addition, the study will explore who the elderly want to speak for them if they are no longer able to speak for themselves. The literature on the topic of personal directives is extensive, though research in the area of what older adults know or understand about these documents is not. The writer was only able to obtain one Canadian and two American research studies that considered older adults' knowledge and attitudes about this subject. Therefore, the writer believes this research is timely as older adults comprise one of the groups that may be encouraged to use these documents in planning for their incapacity.

Statement of Purpose

Level I

The study is designed to explore and describe the knowledge and attitudes about personal directives of older adults living in the community or receiving treatment in a rehabilitation hospital or community health centre.

Statement of the Research Problem

What are the knowledge and attitudes of older adults living in the community or receiving treatment in a rehabilitation hospital or community health centre regarding advance care documents?

1. Are older adults aware of and/or knowledgeable about the purpose of advance care documents and do they feel it is necessary to complete one before the onset of a serious illness?

2. Do older adults want others to be involved in the discussion and/or the completion of an advance care document? If so, who do they want involved?

3. Is there any difference in the knowledge and attitudes between older adults living in the community or those receiving treatment in a rehabilitation hospital or community health centre?

4. Do older adults describe the type of education and/or information necessary prior to completing an advance care document?

Definition of the Study Terms

Terms used in this research study are defined as follows:

1. Advance Care Documents - defined as a "generic term" used to classify all the different types of these documents (Emanuel & Emanuel, 1990). The different types of advanced care documents described in the literature are the Living Will, Medical Directive and the Values History. For this study the term "living will" will be utilized as this is used in the mass media. As noted previously, the Alberta legislation passed in 1996 has been named the Personal Directives Act and refers to these documents as personal directives for personal or health care.
2. Community Environment - defined as older adults living in their own home, relatives' home, apartment, seniors' apartment complex or lodge setting. The older adult may or may not be receiving homemaking or home care support.
3. Hospital Setting - defined as a facility that provides assessment and treatment post acute and for chronic illness or injury. The older adult may receive the services of any, or all, of these professionals: geriatrician, physician, registered nurse, physical therapist, occupational therapist, recreational therapist and/or social worker. One of the goals of this setting is the improvement of the older adult's functional status. The treatment took place in a rehabilitation hospital or a community health centre.
4. Knowledge - defined as an awareness or understanding of personal directives.

5. Attitudes - defined as having and expressing an opinion about personal directives.
6. Older Adults - for this study, the sample population will be those adults aged 65 years or over.

Significance of the Study

This study will add to the existing research information already available regarding the knowledge and attitudes of older adults about personal directives. The results identify gaps in older adults' knowledge about notifying their family members and/or physicians, in advance, about their wishes. The results describe whether older adults feel it is necessary to complete a written document or if they would rather make a more informal arrangement with their families and physicians. Comments cited in previous research studies regarding barriers to completing a personal directive are also applicable to this study population. This study may assist health care professionals in introducing this topic with their clients and families as our population ages. It has been clearly established that the participants in this study want to be involved in the decision-making process about their health care and do not feel the topic is too disturbing to discuss.

The findings also give some direction, though limited, to health care professionals regarding who older adults would like to have involved in decisions about their health care. The results suggest some of the educational methods that may be most beneficial.

This study was timely as it occurred when draft legislation was before the Alberta Provincial Legislature. The study may have raised the awareness level of older adults whether they took part in the study or no. It is hoped this increased awareness has promoted discussions between older adults and their spouses, families, physicians and other health care professionals to ensure the promotion of their autonomy well before the onset of a crisis situation.

Limitations

As this study used an exploratory/descriptive design with information collected through interviews with study participants, there were inherent limitations, outlined as follows:

1. As there was limited information in the literature about older adults' knowledge and awareness of personal directives, there was no theoretical framework in which to base this work or for the basis of a hypothesis. In addition, there was only one published study relating specifically to Canadian older adults' knowledge and attitudes when this research study was proposed.
2. As a result of limited empirical research studies available for review on this topic, a reliable and valid research instrument was unavailable for use. The questionnaire developed for this study was based on the literature and the draft Alberta legislation. Therefore the validity was limited to face and content validity.
3. Even though the questionnaire was evaluated by experts in the field of gerontology and ethics for objectivity and readability, there still may have been some concern for participants in

relation to question organization and language. The researcher asked the questions in the standardized format and only elaborated and/or clarified the question if participants did not understand. Participants were informed that there were no right or wrong answers to the questions. The researcher emphasized that it was their opinions that were important for the study. This was done to reduce any anxiety they may have felt and, hopefully to increase their comfort.

4. The study consisted of a purposive sample of 60 participants, 30 from each of two settings - the community and hospital settings (rehabilitation and community health centres). This number was derived by the availability of seniors for the study and resources to complete the data collection. As the sample size was limited to 60, the results need to be interpreted cautiously. In some instances there were limited cell sizes to run tests such as chi-square.

5. Study participants were selected on the basis of their knowledge and opinions about personal directives. They were already aware of personal directives, so they were comfortable in discussing this topic with the researcher. The sampling procedure was nonrandom. Therefore, generalization of any results should be cautious.

6. The findings of this study are limited to those older adults who are 65 years and over, mentally competent, English speaking and physically and emotionally stable. Generalizations to any population, other than those in a small urban centre and those

receiving treatment in either a rehabilitation hospital or community health centre, is cautioned.

7. Mental competence was screened using the Mini-Mental Status Examination (MMSE) screening tool developed by Folstein, Folstein and McHugh (1975). Even though the researcher is aware that there have been concerns raised regarding the reliability of the tool, it is in common use in geriatric assessment and rehabilitation facilities to screen older adults' mental status. Seven participants refused to complete the MMSE. Therefore, the researcher relied on the unit nurses and/or her own observations to determine the competence of the participant.

Assumptions

1. Participants had an opinion about personal directives and/or the type of health care they would want if they were no longer able to speak for themselves.
2. Personal directives have potential to benefit older adults by allowing them more control over care in circumstances where they may not be competent.

Organization of the Thesis

The thesis is organized in chapters dealing with a specific portion of the research study. The second chapter outlines the current theoretical and empirical literature on the topic of personal directives. Chapter three delineates the research methodology and data analysis undertaken. In chapter four, the results of the data analysis are described in relation to answering the four research questions and to the content analysis completed on 10 transcribed interviews. Chapter five discusses the findings and interprets those significant in this study population in relation to the current literature. Recommendations for older adults, health care professionals, educators, other professionals and for future research, are addressed in chapter six.

Summary

It is documented in the literature that older adults' awareness or understanding of personal directives is limited. The purpose of this study was to explore the knowledge and attitudes of older adults about personal directives in light of the draft and now current legislation passed in Alberta. To clearly identify the direction of this study, four research questions were outlined. The potential significance of this research to older adults and their families was to increase awareness about personal directives and their ability to indicate, in advance, what their health care wishes might be. It was determined the results of this study may assist other health care professionals in introducing this topic with older adults and their families. In addition, suggestions for the development of educational tools or programs to assist older adults in the completion of these documents prior to the onset of a serious illness are outlined. The limitations and the assumptions of this study were presented along with the organization of the remainder of the thesis.

CHAPTER 2: REVIEW OF THE LITERATURE: ADVANCE CARE DOCUMENTS

In the last 25 years, medical technology has advanced to the degree that individuals, who in the past would have died from their injuries or diseases, are now surviving well beyond previous expectations (Bailly & DePoy, 1995; Singleton, Dever, & Donner, 1992; Reigle, 1990; Bross, 1990; Houston, 1988; Bosmann, Kay & Conter, 1987). These advances in medicine mean there has been a change in the way society views health care and its expectations of medicine. According to Callahan (1987), medicine has changed from a caring model to a curing model. As a result, the expectation is that "[w]hat can be done medically ought to be done. What ought to be done ought to be available to all" (Callahan, 1987 p. 17). The concept of health has also changed over time so that it is now considered a medical goal and a social ideal (Callahan, 1987). Health is viewed as a fundamental requirement for everyone; that any injury or illness should be able to be altered with the use of drugs, surgery or other interventions. This societal attitude is reinforced by advances in medical technology which allows for resuscitation and supporting or extending life. Longevity undoubtedly has been achieved for many people, but the question now being asked is at what cost to the individual and society (Molloy & Mepham, 1992; Provincial Senior Citizens Advisory Council, 1985; Crump, 1989). Some individuals may not consider their life worth living as it is too much of a burden for either themselves or their families

(Bennahum, 1992; Fiesta, 1992; Downie, 1992; Orentlicher, 1990; Ney, 1990; Callahan, 1987; Crump, 1989; Houston, 1988; Kelly, 1985; & Provincial Senior Citizens Advisory Council, 1985).

There has been considerable concern expressed by certain individuals over the last 20 years about the possibility that they will be subjected to "inappropriate and overly-aggressive medical treatment" at the end of their lives which will only prolong their dying (Alberta Law Reform Institute, 1991, p. 16). Individuals now confront these fears about loss of control and try to develop strategies to better deal with situations before they result in either conflicts or ethical dilemmas in the clinical setting (Rodney & Starzomski, 1994; O'Neil, 1987). People express, and even perhaps insist, that they be involved in decisions related to their health care. In today's society, there is a movement that considers death a "natural end to a normal life span" and that all of us should stop trying to avoid the inevitable (Reigle, 1990, p. 201). The 'death with dignity', 'patient rights' and 'quality of life' movements have evolved partly so we can again 'become more comfortable with allowing... [patients] to die, [and] the compassion we show in life can be extended to death." (Crump, 1989 p. 92). These movements have evolved because the public is more aware and informed of its rights. Patients want to be involved in deciding their futures, more so perhaps than in previous generations. It has been noted that many people have the following two concerns: that they receive medical treatment in accordance with their beliefs and values and that health care decisions made for them, once they are incompetent, are made by the appropriate person (deBlois, McGrath, & O'Rourke, 1991).

The basis for the belief that individuals have the right to accept or refuse treatment is based on informed consent. Individuals must be informed by their physicians and understand the nature and consequences of their decision. Once it is clear that the person does understand the consequences of a decision, the individual's wishes should be respected, even if health care providers do not agree or want to be involved (Parker, 1994; Fiesta, 1992; Stephens & Grady, 1992; Anderson, Gladue, Laurie, Skotniski & Tramer, 1991; Ventres & Spencer, 1991; Brock, 1991, Fisher & Meslin, 1990; Markson & Steel, 1990; Appelbaum & Grisso, 1988; Cox, 1988; Abrams, 1985; Provincial Senior Citizens Advisory Council, 1985).

In 1990 and 1991, the right of competent adults to determine their health care acceptance and to use personal directives was upheld in common law. Two cases that occurred in Ontario challenged the assumption that personal directives were only morally binding and not legally binding. The cases were Malette versus Shulman and Fleming versus Reid (Ontario Reports, 1991; Plachta, 1994; Kleinman, 1994; Kohut & Singer, 1993).

In the first case, a woman of Jehovah Witness faith had signed a card stating she did not want blood or blood products, though the declaration was not dated or witnessed (Kleinman, 1994; Kohut & Singer, 1993). The physician was "found liable for battery" for administering a "life saving blood transfusion" to the woman after a motor vehicle accident (Plachta, 1994 p. 663). The Ontario Court of Appeal upheld the judge's original decision.

In Fleming versus Reid, the case outlined the ability of a patient to forego treatment even if the treatment was deemed to be beneficial to the patient's life or health (Plachta, 1994 p. 663). Specifically, a patient suffering from schizophrenia, who had received neuroleptic medications previously, indicated that he did not wish to have them administered again. The document was signed and witnessed prior to his becoming incompetent. The physician, after he determined that the patient was incompetent, proposed to administer the medication. The physician requested the review board, under the Mental Health Act, to review the situation. The review board "granted orders authorizing the administration of neuroleptic drugs....in the [patient's] best interests" (Ontario Reports, 1991 p.74). The court allowed the patient's appeal based on his prior expressed wishes when he was competent. The court documents indicated that the action by the physician and the Mental Health Act deprived the patient of his rights under the Canadian Charter of Rights and Freedoms (Ontario Reports, 1991).

The two common law cases outlined above upheld the concept that adults have the right to determine what shall or shall not be done to their bodies. This right is well grounded in the doctrine of informed consent and the patient, not the health care professional, has the freedom to decide whether or not to accept treatment (Ontario Reports, 1991).

It is a well documented fact that the North American population is aging. There will be a dramatic shift in the population grid when the 'baby-boomers' reach the age cohort of 65 - 75 years in the next 20 years. Health care professionals will be confronted with a growing number of acutely and chronically ill patients grappling with end-of-life issues. To this end, a factor to be considered in any discussion about rights and maintenance of personal autonomy is respect for people regardless of their age. A negative attitude or bias towards the elderly in North American society prevails to the extent that some believe the elderly should be treated as children instead of competent adults, as if individual autonomy somehow declines with advancing age (Bailly & DePoy, 1995; Buehler, 1990; Butler, 1990; Reigle, 1990; Bennett, 1990; Kapp, 1989; Callahan, 1987; Libow, 1981). Older adults have already confronted death through previous losses and, according to Callahan (1987), Bennett (1990) and Bross (1991), the elderly do not necessarily want excessive treatment. In fact, they generally have two fears: first, that they will be neglected once they are critically ill and, second, that they will be excessively treated and their lives and their dying will be prolonged. Older adults want and do have the right to be well informed and to choose what will or will not be done to them. Age should not be used as a criterion that life is "long enough" and treatment should not be expected. It is a very personal and individual decision, irrespective of age (Gadow, 1987).

In a landmark decision in the American courts in 1914, Justice Cardozo stated that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body" (McCullough & Lipson 1989, p. 587). This statement has been adopted by various Canadian provinces since that time. More recently, the Manitoba Law Reform Commission emphasized in its report that "the law presently accepts that individuals can control their current medical treatment...they can now consent to treatment, refuse treatment or choose one treatment over another...the principle of self-determination guides the law... " (Alberta Law Reform Commission, 1991, p. 16). Though the principle of self-determination is the basis for informed consent in our society, it is not always adhered to in the clinical setting. The apparent failure to adhere to the person's wishes and actual or perceived paternalistic attitude of health care professionals may be explained in part by the fact that: 1) physicians have traditionally made the decisions in clinical situations and have been educated and encouraged to use all the available technologies when faced with either an uncertain diagnosis or prognosis (bias towards treatment); 2) families may request the physician 'to do all that is possible to save their loved one' which may put the physician in a quandary on how best to proceed (Bross, 1991; Bennett, 1990; Anderson et al, 1991; Fisher & Meslin, 1990; Callahan, 1987; Alberta Law Reform Institute, 1991; Schneiderman & Arras, 1985; Zweibel & Cassel, 1989). Regardless of the actual reasons for why patients' wishes are not respected, the end result is that their autonomy is not promoted. In response to individual and societal concerns regarding the prolongation of dying, a movement evolved in the 1960s which promoted advance health care planning. Individuals' thoughts regarding values, beliefs and what quality of life is, could be expressed in writing. If individuals could no longer speak for themselves, their families and/or their physicians could make decisions based on prior knowledge of their preferences. With this type of advance health planning, it was thought there would be some assurance that, as the individual's wishes would be known and respected, appropriate care would be provided. (Buehler, 1990; Crump, 1989; Schneiderman et al., 1985). These documents, commonly known as Living Wills, Advance Directives, are currently generating discussion and receiving support in Canada and in Alberta.

The focus of this research will be to determine if advance care documents are beneficial for older adults' use in planning for possible incapacity. The study will explore and describe the knowledge and attitudes of older adults related to the documents being proposed and whether older adults would utilize these documents as a method to ensure their autonomy. The literature review will outline the history of the inception of living wills and the research in the area of Proxy Decision Making and completion of Advance Care Documents.

Definition of Terms

In the literature, certain terms are commonly used when discussing Living Wills and/or Advance Care documents. These terms have been defined as follows to provide a common reference point.

1. Autonomy (self-determination) - autonomy is defined as the capacity for self-determination, which the person may or may not choose to exercise (Kapp, 1989). When individuals are provided with sufficient information they are able to make decision(s) based on their value system, therefore promoting their autonomy (Beauchamp & Childress, 1994; Downie, 1992; Brock, 1991; Riegle, 1990; Henderson, 1990).

2. Beneficence (well-being) - an important principle that governs medical decision, provides "that health care providers pursue only treatments that will contribute to the well-being or the good of their patients" (Scheiderman et al., 1985 p. 693).

3. Substituted Judgment - this principle requests that significant others or caregivers make the same decision (based on the person's previously expressed wishes) that the person would have made if able to do so. In order for substituted judgment to be a reliable guide, the person's wishes must be known by the proxy agent. There are rarely written declarations of an individual's wishes, so previous statements may be used to substantiate the proxy's decision. If there is no "clear and convincing" evidence regarding the person's wishes, the proxy uses the individual's life pattern (if they have lived long enough) to extrapolate what the person would have decided if capable. This standard is thought to promote the incompetent person's autonomy in the most appropriate manner (Bandman & Bandman, 1995; Fiesta, 1992; Downie, 1992; Reigle, 1990; High, 1989; Schneiderman et al., 1985).

4. Best Interests - this principle is used when information is unavailable regarding what the person would have wanted or in the event the person has never been competent (Downie, 1992; Brock, 1991). The ethical principle of beneficence dictates that the proxy should act to "promote the [person's] presumed interests" (Schneiderman et al., 1985 p. 695). The best interest standard requests the proxy to made choices according to "socially shared values", which may or may not reflect the person's preferences (High, 1989 p.8)

History of Living Wills

The terms Advance Care Documents, Advance Directives, and Living Wills (LW) are commonly used in the literature. The writer will begin by clarifying these terms. Emanuel and Emanuel (1990) stated that the term "advance care document" is actually the "generic term" used to classify types of documents (p. 9). Advance care documents are used to indicate the person's preferences regarding the acceptance or the refusal of certain types of treatments or interventions. An example of this type of document would be the Medical Directive or the Directives to Provide Maximum Care (Emanuel et al., 1989, 1990; Haber, 1986). Emanuel and Emanuel (1990) indicate that the advance care document may be used by anyone, not just those individuals who have been recently diagnosed as having a 'terminal illness', while the LW document can only be completed when the individual has actually been diagnosed as being terminally ill. A LW is restricted to the rejection of life-sustaining medical treatment and is, therefore, called a rejectionist advance care document.

Greaves (1989) indicates that the term LW is a name commonly used in relation to a document written by competent individuals to "request and direct that certain measures be taken if they become incompetent" (p. 172). This author does not indicate that LWs are only used to reject certain types of medical interventions. According to Greaves (1989), the term advance directive indicates the individual is referring to both a LW and durable power of attorney (DPOA). Downie (1992) defines the term in somewhat the same way, that an advance directive is the generic term that may be divided into two categories called instruction directives (living wills) or proxy directives (durable powers of attorney). She also states that LW do not need to be "limited to the withdrawal or withholding of life-sustaining procedures from terminally ill patients" (Downie, 1992, p. 73). Regardless of the differences in definitions, it remains that LWs were the first advance care documents to receive widespread public support (Anderson, et al., 1991; Markson, et al., 1990; Emanuel et al., 1990; Greaves, 1989; Crump, 1989; Province of British Columbia, 1989; Novak, 1988; Webster, 1988; Matthews, 1986; Raffin, 1986; Tobin, 1986; Haber, 1986; Abrams, 1985; Kelly, 1985; Provincial Senior Citizens Advisory, 1985; Cohn, 1983). For the purposes of this paper, the writer will utilize Emanuel and Emanuel's (1989, 1990) definitions of advance care documents and LWs.

The concept of Living Wills was first suggested by Luis Kutner in 1967 at the Euthanasia Society of America meeting and from there it proceeded to the educational council. The Euthanasia Society of America was the forerunner of the Society for the Right to Die and the Concern for the Dying (Anderson et al., 1991; Emanuel et al., 1990; Ney, 1990; Crump 1989; Matthews, 1986; Eisendrath & Jonsen, 1983). The document was to be used by individuals, while they were still competent, to outline their wishes regarding the type of treatment they did or did not want (Matthews, 1986; Henderson, 1990; Sachs, Stocking & Miles, 1992; Crump, 1989; Bellocq, 1988). It was also hoped the document would safeguard individuals from overly aggressive medical procedures that might prolong "unnecessary suffering or,...produce meaningless existence" (Grundstein-Amado, 1992, p. 32). Another benefit would be that both families and physicians would be better able to make difficult decisions when they arose in the clinical setting. The definition provided by the educational council for a LW is: "a document which enables individuals, while competent, to inform family members and health care providers of their wishes regarding the use of life-sustaining treatment when death is imminent" (Matthews, 1986 p. 26). The original concept of LW was that they were to be filled out by a competent adult, who was currently suffering from a terminal and irreversible illness (confirmed by two physicians), from which there was no reasonable hope of recovery (Ney, 1990; Areen, 1987; Matthews, 1986; Provincial Senior Citizens Advisory, 1985). The prevailing thought was that LWs would protect terminally ill patients from unwanted or prolonged life-sustaining treatments that would only prolong the dying process (Ney, 1990; Greaves, 1989). Incompetent persons' autonomy would be maintained or enhanced by respecting their choice of treatment initiated or continued and their families and physicians would be relieved from making difficult decisions in isolation (Greaves, 1989; Webster, 1988; Matthews, 1986).

In the United States (U.S.) legal recognition was first given to LW through 'Natural Death Acts' or 'Right to Die' laws. The first state in the U.S. to legally pass a law recognizing LWs was California in 1976 under the 'Natural Death' or 'Right-to-Die' laws (Anderson, et al., 1991; Markson, et al., 1990; Emanuel et al., 1990; Henderson, 1990; Ney, 1990; Greaves, 1989; Crump, 1989; Province of British Columbia, 1989; Bellocq, 1988; Novak, 1988; Haber, 1986; Matthews, 1986; Tobin, 1986; Raffin, 1986; Abrams, 1985; Kelly, 1985; Provincial Senior Citizens Advisory, 1985; Eisendrath et al., 1983; Cohn, 1983). Following California's passing of the natural death statutes, other American states followed suit, and by 1992, there were 47 states plus the District of Columbia that had some type of legislation regarding LWs (Downie, 1992; High, 1990). The legislation varies greatly from state to state and the document is not transferable from one state to another (Emanuel et al., 1990; Orentlichler, 1990; Ney, 1990; Bellocq, 1988). In the U.S. Living Will legislation has two primary functions: to protect health care professionals from malpractice suits based on wrongful death, and to document valid refusal of care as if the incompetent patient was still mentally capable of refusing the care (Ney, 1990; Rozovsky & Rozovsky, 1989; Matthews, 1986). Therefore, a vehicle is in place to ensure promotion of the person's right to self-determination and guide and/or potentially protect health care professionals from liability suits (Fisher et al., 1990; Greaves, 1989; Cox, 1988; Matthews, 1986; Novak, 1988).

The Patient Self-Determination Act (PSDA) has been in effect since 1991 in the United States for institutions receiving government insurance payments (Emanuel, et al., 1993; Hague & Moody, 1993; Gerety, et al., 1993; Robinson, DeHaven & Koch, 1993). This Act requires patients to be informed of their rights, upon admission, regarding the acceptance or refusal of treatment if they become incompetent (Robinson, DeHaven & Koch, 1993; Hague & Moody, 1993). In conjunction with informing patients of their rights, the legislation indicates that education must be provided for all staff regarding advance directives and designation of substitute decision makers. With the implementation of the PSDA, an objective was to "bridge the gap" between interest in advance directives and the actual completion of the form (Emanuel et al., 1993 p. 620). Many physicians and health care and advocacy groups have expressed reservations about the ability to effectively enforce the Act. Reservations include the timing of the introduction of the topic of advance directives, hospital admission may not be the "optimal time"; the PSDA does not specifically include the involvement of the patient's physician in the discussion or completion of advance directives and there is no funding provided for public education on the planning in advance (Emanuel et al., 1993 p. 620). To date the completion rate of advance care documents remains low even with the PSDA. In Canada, as advance directives are introduced into provincial legislatures, other issues are being addressed.

The concept of Living Wills has evolved differently in Canada, due in part to our differing medical and legal system. In 1977 a private member's bill regarding Natural Death Acts was introduced in the Ontario Legislature. However, it did not get past second reading (Alberta Law Reform Institute, 1991). In Alberta in 1977, 1978, and again in 1979, a private member's bill regarding Living Wills was introduced in the legislature by Dr. Walter Buck, an independent member of the legislature (M.L.A.), but the bill was not passed into law. (Alberta Law Reform Institute, 1991; Provincial Senior Citizens Advisory, 1985). In the 1989 Rainbow Report (Premier's Commission on Future Health Care for Albertans), the sixth recommendation was that the Alberta Government "introduce legislation in 1990 which will enable Albertans to provide 1) enduring power of attorney regarding financial and other matters; and 2) advanced directives, also referred to as 'living wills', regarding personal matters" (p. 34). In 1991, Ontario introduced legislation regarding consent to treatment entitled the "Consent to Treatment Act, the Substitute Decisions Act, and the Advocacy Act" (Singer, Choudhry & Armstrong, 1993). This legislation includes the recognition of advance directives and, if enacted, would make Ontario the fourth Canadian province to introduce legislation dealing with proxy directives or instruction directives. Nova Scotia and Quebec recognize proxy decision makers and Manitoba has legislation related to both proxy and instruction directives (Kohut & Singer, 1993; Singer et al., 1993; Downie, 1992). Alberta passed legislation in June 1991, allowing enduring power of attorney (EPA) for property and financial matters. In 1991 the Alberta Law Reform Institute drafted a report for discussion relating to advance directives and health care. Recently passed through the Alberta Legislature is Bill 35 - Personal Directives Act, that will legalize the use of advance directives, now called personal directives in Alberta (Province of Alberta, 1996).

According to Rozovsky and Rozovsky (1989), there is uncertainty in Canadian law about whether an individual can refuse treatment or care in advance of such care being offered or required. Usually, an individual is given specific information related to the risks and benefits of the treatment and any alternatives to the treatment. A LW may negate this as it only comes into effect once patients can no longer speak for themselves, when they may be unaware or uninformed of the current treatment choices or alternatives (1989). Therefore, depending on when the living will was completed and when it was actually required, treatment choices may have changed and as a result there is some question whether patients would have changed their minds if they were aware of current alternatives. This factor may negate the basis of the LW concept as it may not really promote individual autonomy because the individual would no longer be considered to be 'informed' (Greaves, 1989). There is, therefore, some question about the benefit of either Living Wills or advance directives (Brock, 1991; Fisher et al., 1990; Rozovsky et al., 1989).

In Canada, the Dying with Dignity group based in Toronto has made copies of LWs available to its members since 1981. Although the completed documents are not legally binding, they are thought to be morally binding (Anderson et al., 1991; Fisher et al., 1990; Goddard, 1988). This organization has also indicated that the signed, witnessed and dated living will is to direct "a physician [to] allow a patient to die should there be 'no reasonable expectations of recovery from extreme physical or mental disability'" (Goddard, 1988, p. 246). The LW distributed by this group is not only to be completed by those people currently suffering from a 'terminal' illness, but may be filled out by anyone well in advance of any illness, injury or disability. This definition may potentially expand the use of the document to the general public, and not just those suffering from a 'terminal illness'.

There has been a suggestion that specific interventions that a patient does or does not want be listed in the LW (e.g., cardiopulmonary resuscitation, intubation, artificial hydration and nutrition). This was to assist in specifying which intervention(s) individuals may not want, therefore reducing vagueness. However, concerns have been expressed about this solution as there is no space for individuals to indicate what intervention(s) they want on a trial basis. Even with these additions to the basic LW form, it remains an incomplete and rejectionist document. A concern expressed by Emanuel and Emanuel (1990) was what should happen if an individual does not list an intervention they do not want? Does this omission indicate to health care professionals that the patient wants the intervention? Again, how do others interpret the patient's wishes?

To aid in clarifying the issues surrounding LW documents, the writer will summarize the main advantages and disadvantages outlined in the literature:

<u>Advantages of Living Wills:</u>

- instructions can be very specific in the document;
- promotes or maintains autonomous decision-making or self-determination of individuals as it provides a vehicle for a person to outline or to clarify their preferences;
- allows ease of completion because of the standardized format;
- relieves the family and the physician from making difficult decisions in a vacuum as there is some notation regarding preferences;
- promotes communication and respect between patients and their physicians and families;
- has the potential to save health care dollars because costly treatments or interventions would not be initiated.

Disadvantages of Living Wills:

- standardized format and specific language only allows restricted interpretation. Therefore, its limited and provides no flexibility in the clinical setting;
- imprecise language which may have vague and conflicting meanings depending on the person's beliefs and value system (for example: confusion over the definitions of terminal versus hopelessly ill and/or heroic, ordinary or extraordinary measures);
- applies only to the terminally ill or, at least, is vague in outlining specifically what condition(s) the person must have before they may complete one;
- in some U.S. states, persons must be certified as 'qualified' (diagnosis of terminal illness at least fourteen days before executing a living will) and the diagnosis confirmed by a second physician;
- concern expressed by some people regarding those who do not have a living will (does it mean they want all types of treatment?);
- may cause conflict because the person's wishes may be in direct opposition to those of the family and/or health care providers' beliefs and value systems;
- concern expressed about possible changes to the physician-patient relationship with legislation, possibly more adversarial as potentially a third party may be involved (lawyers);
- limited flexibility, as it is impossible for people to convey all their wishes in advance as they are unable to foresee what may actually occur to them or how a specific illness may

progress. Therefore, there may not be enough information to guide physicians in a clinical situation;

- advances in technology mean there are ever changing methods of treatment and prognoses so patients may no longer be completely informed of the choices;
- in some American states, artificial hydration and nutrition is mandatory and may be in conflict with the person's expressed wishes;
- not a substitute for ongoing empathetic communication between health care professionals, patients and their families;
- perception that living wills are not needed, as physicians already have the ethical/legal duty to forego medical treatment (therapeutically useless treatment) if the burdens outweigh the benefits. This falls under the best interests standard.

(Complied from: Grundstein-Amado, 1992; Downie, 1992; Fiesta, 1992; Watts, 1992; Brock, 1991; Fenna, Friesen & Maxston, 1991; Roberston, 1991; Alberta Law Reform Institute 1991; Doukas & McCullough, 1991; Orentlicher, 1990; Ney, 1990; Henderson, 1990; Greaves, 1989; Province of British Columbia, 1989; Johnson, 1988; Areen, 1987; Matthews, 1986; Novak, 1988; Provincial Senior Citizens Advisory Council, 1985).

While there is widespread acceptance of living wills in principle, completion rates range from four to 25 percent for the general population and for older adults (High, 1993). Therefore, it appears there is a definite gap between the acceptance of the directive and its actual implementation (Stelter, Elliott & Bruno, 1992; Wanzer et al., 1989). The lack of completion of the document may be due in part to the form itself, as it is too complex or difficult to complete, or due in part to patients waiting for the topic to be raised by their physicians (Ventres et al., 1991; Orentlichler, 1990). Despite the identified concerns with the document, the historical review does demonstrate the amount of thought that has gone into the formulation of the LW document. There have been alternatives suggested to the standardized, 'stand alone' LW document, which are: the Enduring/Durable Powers of Attorney; the Medical Directive, the Values History and the Narrative Inquiry.

Current Alternatives to the Identified Deficiencies of Living Will Documents

Enduring/Durable Powers of Attorney

To rectify some of the concerns with Living Wills (LW) the concept of Enduring Power of Attorney (EPA) for health care has evolved in Canada and Durable Power of Attorney (DPOA) for health care in the U.S. The term 'enduring' or 'durable' indicates that the designated individual is able to continue in the role after the designator has become incompetent. This previously has not been common practice. Therefore, the main thrust of EPA or DPOA legislation is to promote individual "self-determination and autonomy" and to ultimately "enhance personal dignity" by allowing individuals to plan for their incapacity by designating someone to make decisions on their behalf (Alberta Law Reform Institute, 1990, p. 2). By 1992, all 50 states and the District of

Columbia had enacted legislation allowing durable powers of attorney (Downie, 1992; High, 1992). The EPA legislation passed into law in Alberta in June of 1991 referred only to property or financial matters. This legislation provides an alternative to the Trustee section of the Dependent Adults Act (1985) in Alberta. The Dependent Adults Act is recognized as a necessary and beneficial act, though there have been concerns that the process is quite time-consuming and expensive. The Act has also been criticized because it does not promote self-determination since patients are not involved in choosing or appointing their guardian because they are already incompetent. As a result, patients become passive participants in this process (Alberta Law Reform Institute, 1990; Orentlicher, 1990). With the passage of EPA, individuals have the ability to direct their affairs and according to some proponents, this results in a reduction in the anxiety and feelings of loss of control in their lives.

The identified health care or proxy agents are to supplement LWs by being available to assist with the interpretation of the "abstract, rigid and imprecise documents" (Emanuel et al., 1990 p.12).

Benefits of health care or proxy agents are:

- patients are able to designate who they want to act as their proxy. Therefore, their autonomy is maintained;
- someone is available to communicate and to interpret either the LW or the patient's past behavior to the health care team and, therefore, is able to assist with substituted judgments necessary;

- promotes discussion between patients, families and physicians;

Some authors have indicated that the use of proxies to supplement LWs does not solve all the concerns identified and in fact may add to them.

Disadvantages of health care or proxy agents are:

- patients may not have discussed their wishes with their proxy and as a result the proxy will be unable to make informed decisions on the patient's behalf;
- if discussions did occur, they were in general terms or in the same vague and imprecise language that is in the LW document;
- proxies may state what they would prefer in the specific situation, not what the patient would prefer;
- proxies may disregard patients' wishes because of grieving, guilt or loyalty;
- other family members may disagree with the designated proxy which may lead to patients' wishes not being honoured;
- proxies may be unwilling to accept the responsibility for "withdraw[ing], withhold[ing] or continu[ing] life sustaining medical interventions if the patient is incompetent" (Emanuel et al., 1990 p. 12);
- patients may have no one they feel comfortable with or trust to designate as a proxy.

(Compiled from: Lynne, 1992; Watts, 1992; Orentlicher, 1990; Emanuel et al., 1990; Greaves, 1990).

The question raised by these authors is: does the addition of proxies actually clarify the confusion with LWs or add to it? In response to obvious differing viewpoints regarding the value of enduring/durable powers of attorney, an alternative has been proposed, to combine both LWs and DPOAs into an advance care document called the Medical Directive.

The Medical Directive

In response to the previously listed deficiencies of Living Wills (LW), other advanced care documents developed to address the limitations of LW documents include the Medical Directive and the Directive to Provide Maximum Care (Grundstein-Amado, 1992; Emanuel et al., 1989, 1990; Haber, 1986). The Medical Directive, developed by Emanuel and Emanuel (1989, 1990) will be discussed in this paper as it has been described more thoroughly in the literature.

The medical directive is comprised of five different sections: a section on specific treatment choices, durable power of attorney, patients' statement regarding their treatment preferences, organ donation and, finally a section available for a statement regarding personal values and beliefs. This type of document allows some "latitude or flexibility" in decision-making, for example what patients "want, do not want, want a trial or undecided" (Emanuel et al., 1990, p. 13).

To eliminate the vagueness that plagues the standard LW, 12 different types of possible medical interventions are listed. Patients indicate which type of intervention they would want, depending on the given situation. These specific types of interventions replace the terminology in the LW such as 'artificial means' or 'heroic measures'. The interventions include a brief explanation so that patients have some understanding of the clinical situation. Specific language is used to describe various types of mental incompetence (persistent vegetative state, comatose, terminally ill, demented) to lessen the ambiguity for patients. Emanuel and Emanuel (1990) concede that the medical directive is still not "absolutely clear", but because of the "uncertainty inherent in the practice of medicine", physicians cannot eliminate "medical vagueness". However, the medical directive does "clarify linguistic vagueness" of the LW (p. 3292).

The main advantages and disadvantages of the medical directive will be outlined:

Advantages of the Medical Directive:

- clarifies vague terminology;
- patients are able to respond to various medical scenarios. This may be potentially more useful in the clinical setting;
- promotes communication between patients, families and physicians;
- able to designate proxy within the same document and indicate who has the 'last say' if conflict occurs;
- ease of completion because of the format.

Disadvantages of the Medical Directive:

- use of scenarios is 'artificial' and may not be what actually occurs in the clinical setting. Therefore, information is not relevant;

- discussion may be limited between patients and their physicians as the situations are 'preset'. This may not allow for expansion or flexibility;
- document is too lengthy. Therefore, may not be completed by either patients or physicians.

(Compiled from: Emanuel, et al., 1990; Grundstein-Amado, 1992).

In conclusion, medical directives are an improvement over LWs whether they are used alone or in conjunction with durable powers of attorney. Emanuel and Emanuel (1990) caution however that the medical directive is "not the ultimate or final advance care document" (p. 14). The whole area of advance care documents requires further study, especially empirical research. One area requiring further investigation is the assessment of patient values. If the patient's values are known, this may potentially be a better guide in the clinical setting when unforeseen circumstances occur.

The Values History

When assessing any patient suffering from acute and/or chronic illness, especially elderly people, the health care professional is confronted with a multitude of complex and interrelated health problems and, perhaps, accompanying ethical dilemmas. As a result, more emphasis is placed on identifying and considering the patient's value system. The values history is a vehicle that may assist in the identification of the patient's values and beliefs (Doukas & McCullough, 1988, 1989, 1991; Gibson, 1990). As mentioned earlier, it is extremely rare that families or physicians are aware of patients' expressed wishes regarding end-of-life issues. Therefore, it may be very difficult for families or physicians to make accurate decisions on behalf of the patient in a time of crisis. Even if patients have discussed personal wishes or have written them down, their families or physicians would still be involved in interpreting their statements as different situations may arise than the ones documented. Therefore, a values history can be introduced to begin a discussion about what a patient would want in an end-of-life situation (Grundstein-Amado, 1992; Justin, 1987). Critical issues and decisions are discussed and made in a proactive manner which ultimately respects the patient's autonomous decision-making or self-determination. The values history that will be addressed will be the one originally developed by Doukas & McCullough in 1987.

A values history is divided into two categories: the first section deals with values and beliefs regarding terminal care. The second section is concerned with the explicit care decisions given the values and beliefs of the individual. These decisions again are made in advance of any critical condition. It is important that the values history is not interpreted as being what others believe, but as what the individual believes. Doukas and McCullough (1991) stated that to assess or even attempt to assess the values history according to another's belief system is a "gross... form of medical paternalism" (p. 146).

The goals of a values history are two-fold. The first is to assist patients to become clear about their wants and why they hold those views, for example the length versus quality of life. The second is for health care professionals to understand, respect and implement the patient's value-based decisions. Patients rank their values regarding acute care decisions such as consent for, or refusal of, cardiopulmonary resuscitation, respirators and endotracheal tubes. They also have the opportunity to rank the type of chronic care they would want such as intravenous fluids, enteral feeding tubes, dialysis and others. Included in the values history is a section for patients to identify their choice of a proxy decision maker (Doukas et al., 1989, 1991).

As stated previously, the main advantages and barriers to completing the values history will be summarized to assist with identifying the issues:

<u>Advantages of the Values History:</u>

- promotes thought on the part of patients, for example what do they value: length or quality of life?;
- promotes communication between patients, families and physicians;
- ease of completion;
- history may be helpful in the clinical setting when a situation arises that had not been previously discussed or documented.

<u>Barriers to completing the Values History:</u>

- value statements are very general, do not consider specific clinical situations and may lead to ambiguity in a crisis situation;

- language in the document is vague, overly simplistic and open to interpretation, (e.g., what is unnecessary pain and suffering?);
- too time consuming to complete;
- patients' values may change over time, especially if faced with an unexpected conflict. Therefore, depending when the document is completed, it may not be useful;
- physicians may be reluctant to introduce the topic as it may be perceived as harmful and contrary to their "beneficence-based role". They would be acknowledging their patients' mortality (Doukas, 1991 p. 149);
- patients may lack the comprehension or decision-making capabilities from the outset;
- patients may refuse to complete the document.
- families may disagree with the document. This may lead to conflict in the clinical setting;
- sections of the values history may not be adhered to because of state laws.

(Compiled from: Doukas, et al., 1989, 1991; Emanuel et al., 1990; Grundstein-Amando, 1992)

Emanuel and Emanuel (1990) and Grundstein-Amado (1992) state there may be a place for value assessments as an adjunct to other advance care documents. To link patients' general values with specific preferences may "illuminate" patients' specific choices (Emanuel et al., 1990, p. 15). This may be especially helpful if a patient is unsure of a particular intervention or if the clinical situation is not quite what was outlined in the document. Ideally, values elicited from patients should be both more specific and relevant to actual clinical situations. For example: the physician really needs to know patients' values regarding functional abilities (independently walking) or living at home. Also patients need to identify situations they want to avoid. Therefore, the values should be both rated and ranked. If this document is to become a valuable advance care document, it needs to be tested for its usefulness and reliability.

According to Doukas and McCullough (1991), the values history is a useful adjunct to both the living will and the durable powers of attorney documents. It allows patients to identify what is important to them prospectively. Another possible remedy designed to address some limitations with this document is the Narrative Inquiry.

The Narrative Inquiry

Grundstein-Amado (1992) proposes the method of narrative inquiry as a vehicle to "explore how human beings experience the world" (p. 36). This method is based on the premise that the past shapes the future. Only through discussing 'what life means' to them can patients move from fear about an illness experience to one of more control. The author proposes that individuals keep a personal journal of their thoughts and experiences. With this journal, the person will go through a process of "self-discovery" by exploring values of importance and deciding what this means for the future (p. 37). Once significant values are identified, the next step is to classify them according to: "basic or fundamental values; moral values; social and political values; spiritual values; and specific values" (p. 37). After this is completed, individuals discuss their important values with their physician. During the discussion, the type of future medical care desired is determined. This concept is based on self examination and informed consent. Patients should base their acceptance or rejection of the medical interventions on their current knowledge, their values and what 'quality of life' means to them.

According to this author, narrative inquiry has several benefits, which are:

- assists individuals in identifying who they are and what place they have in the world;
- explores the individuals' "values, preferences, feelings and thoughts and examines, evaluates and justifies them" (p. 36). Part of the evaluation phase is to assess if the values are coherent with individuals' life patterns;
- individuals have the chance to assess their basic values and whether they are congruent with their expressed preferences;
- allows individuals to examine events in their lives for interrelations between or among their value systems. This examination will ultimately benefit patients if they become incompetent because their designated proxies or physicians will be able to make inferences based on their previous life review;
- enhances patient-physician communication;

- assists in clarifying what is important and perhaps better ensures individual autonomy.

The narrative inquiry, as with every other suggested advance care document, has certain limitations. Grundstein-Amado (1992) identified these as:

- individuals and/or their physicians may be reluctant to be involved in this process because of the perceived amount of time this type of discussion would involve;
- individuals may be concerned that by examining their value system there may be disagreement or judgment on the part of others;
- individuals may already have cognitive changes that affect their memory. Therefore, the process is negated.

The author suggests the narrative inquiry process be taught in medical school as part of patient interviewing because communication is the basis of all relationships. However, he also acknowledges the use of narrative inquiry requires empirical research.

As mentioned earlier, there is a definite gap between the acceptance of living wills in principle and the actual completion of the document. Questions raised are: Why is there such a gap? What is stopping people from completing one? Do patients believe that their families will be able to speak for them or is there another barrier to completing these documents? The writer will now turn to the research literature to ascertain if the research completed to date will answer any of the above questions.

Research Studies on Proxy Decision-Making and Completion of Advance Care Documents

Emanuel and Emanuel (1990) have suggested that the area of advance care documents requires further research as there have been few "empirical evaluations". By 1991 there were fewer than a dozen studies in the literature on advance care documents, most related to physicians' attitudes. Four areas requiring further study are: 1) "patient attitudes and understanding of advance care documents, [especially the elderly]; 2) the most appropriate format and setting for discussing advance care documents; 3) effect of advance care documents on the physician-patient relationship; 4) effect of advance care documents on clinical care" (Emanuel et al., 1990 p. 14).

Though all the above are important, current research into all the identified areas is limited. Therefore, the writer will concentrate on the following categories: physician attitude to advance directives; whether predictions by physicians, spouses and/or other family members reflect actual patient preferences; who the elderly want as proxies; and the attitude of the public, especially the elderly, regarding completing living wills.

Two recent studies completed by Davidson, Hackler, Caradine & McCord (1989) and by the Dying with Dignity Organization (1987), reported by Goddard (1988), found that overall, the majority of physicians hold positive attitudes toward advance care documents (79.2% and 64% respectively). Physicians indicated it was important that patients' autonomy be supported. Physicians experienced with advance care documents indicated the documents do accomplish their intended purpose. Physicians participating in the Davidson et al (1989) study indicated that there was "improved communication and trust", and clinical treatments were easier and made with more confidence and less stress and guilt (p. 2417). Concerns expressed during the Davidson et al (1989) study were of potential problems such as; less aggressive treatment or treatment withheld for all patients, even if they have not expressed this wish. Also, as the advance directive is made in advance of any serious illness, the question arises whether this would be what patients would actually want in this particular event. The last concern noted by this research team was that approximately one third of physicians believed "their training and experience gave them greater authority...to make decisions about withholding heroic treatment" (p. 2419). The authors indicated this statement appeared to be very paternalistic. However, they questioned whether this statement was more reflective of physicians' knowledge about the success of specific interventions and not their right to make choices on behalf of their patients (Davidson et al., 1989). Both of these research studies tend to reflect a supportive attitude on the part of physicians regarding advance care documents.

Researchers have also investigated whether physicians, spouses or other family members can predict elderly patients' preferences regarding end-of-life issues (Uhlmann, Pearlman & Cain, 1988; Zweibel & Cassel, 1989; Seckler, Meier, Mulvihill &

Cammer 1991; Libbus & Russell, 1995). The Uhlmann, et al (1988) study examined the ability of patients' physicians and spouses to predict their preferences regarding cardiopulmonary resuscitation. They found that physicians underestimated their patients' resuscitation preferences if they suffered from either chronic obstructive lung disease or a cerebrovascular accident. On the other hand, if the physician only considered patients' current health status, they overestimated patients' resuscitation preferences. The findings for patients' spouses were consistent as they overestimated their loved ones' preference for resuscitation in all situations. These findings definitely bring into question the support for, or the validity of, substituted judgment. These authors recommended values be discussed openly between patients and spouses. As well, dialogue between these patients and their attending physicians is recommended so physicians actually understand, not just think they understand what patients want (Uhlmann et al., 1988).

In the Zweibel and Cassel (1989) study, the ability of "middle-generation family members" to be proxies for an "older decisionally incapacitated" adult was explored by using hypothetical situations (p. 616). Again, the proxies underestimated older adults' preferences for resuscitation. The proxies tended to withhold the intervention in circumstances where patients would want it. The researchers questioned if this underestimation was due to the fact that both physicians and older adult children tend to rate the older adults' quality of life as lower than the older adults. It is important to understand why there is such a marked difference in how others perceive an older adult's wishes, but this study suggests the preferences of older adults were not well understood by either their spouses or their physicians.

Secler, et al (1991) found that patients who participated in their study "predicted" that both their family members (90%) and their physicians (87%) would be able to speak for them if they became incapacitated. However, neither group was able to predict the patients' preferences accurately. Again, part of the problem was that only a few patients had communicated their preferences to either their surrogate family members (16%) or to their physicians (7%). Therefore, the accuracy or the usefulness of substituted judgment was called into question. Some of the research teams indicated that these findings may support the use of advance care documents to ensure an older adult's autonomy is promoted when the individual becomes decisionally incapacitated (Uhlmann et al., 1988; Zweibel et al., 1989). The one consistent finding was that there needs to be more discussion about these issues prior to onset of serious illness or incapacity.

Libbus and Russell (1995) studied a convenience sample of 30 patients with at least one chronic disease and their surrogates. The purpose of the study was to examine decisions made by both patients and their surrogates regarding "life-sustaining treatments" and if there was agreement or disagreement between the two groups (Libbus & Russell, 1995 p. 136). The researchers used the interview instrument developed by Zweibel and Cassel (1989) that consisted of five hypothetical situations in which the individual was incompetent to make decisions. Patients and their surrogates were to independently choose between life-sustaining or life-ending treatment. At the end of each situation participants indicated how "certain" they felt about their choices and this was rated on a Likert scale (Libbus & Russell, 1995 p. 137). The results of this study indicated that the "predominant life-ending choice" was the refusal of cardiopulmonary resuscitation (CPR) and ventilation (p. 138). For all the hypothetical situations, the patients chose the life-sustaining option 45% of the time and their surrogates 54% of the time. The one discrepancy noted by the researchers was the choice of chemotherapy. The surrogates chose this option more often then the patient. In this study group it is important to note that 73% of patients reported having discussed their preferences and 60% of surrogates confirmed this discussion. In addition, 20% of patients in this study stated they had completed advance directive documents. Choices selected by the two groups were related to "quality of life" and a "good death" rather than "sustaining life" and a "sustained disease existence" (p. 139). The researchers suggested that health care professionals assist in the clarification of the cognitive functioning and the degree of pain that may be involved in specific conditions as this appeared to be an important consideration in the decision-making of both patients and surrogates.

Exploratory research and case studies completed by High (1988, 1989, 1990) and High & Turner (1987) regarding surrogate decision making found the elderly wanted their families to be the surrogates. If older adults did not have any family available, they turned to close friends or their physicians to make the decisions. The older adults involved in these studies actually preferred informal arrangements, "to keep it all in the family" and would rather not complete a formal document (High, 1988, p. 50). If older adults did not have immediate family to turn to, they were more likely to have completed either advance care documents or durable power of attorney forms. High (1990) states that older adults' autonomy is interdependent and interwoven with family autonomy. Patients may decide to 'delegate' their autonomy to their family members, which still promotes autonomy. High (1990) states that no advance care documents could take the place of families who have the best interests of older adults in mind. In the studies completed by High (1988, 1989, 1990) and High and Turner (1987), it is suggested that instead of recommending the standardized living will form to patients, completed by few, it would be more beneficial to promote better communication and discussions between patients, their family members and their physicians. The findings in these studies are interesting given the findings of Secler, et al (1991), Uhlmann et al. (1988) and Zweibel and Cassel (1989). Older adults in the latter studies request their families as the most able to speak for them, yet this is not found in the former research studies.

Studies investigating the knowledge and attitudes of older adults regarding living wills are not abundant in the literature. Gamble, McDonald & Lichstein (1991) undertook a study with 75 ambulatory elderly ranging in age from 60-80 years. The purpose of this study was to investigate the knowledge and attitudes of older adults related to the topics of living wills, end-of-life issues and whether a living will had been completed by this group of elders. More than half indicated they knew about Natural Death Acts and what the definition of living wills was according to North Carolina law (52% & 64% respectively). It is interesting to note that, of the 52% that indicated they knew about the Natural Death Act, 36% were unable to recognize the document and actually stated they were unaware of its existence. It was also noted in the course of the study that many elderly did not understand the "language used in the living will" such as "extraordinary means" and "terminal and incurable" (p. 278). Also, the majority (73%) indicated that they would want only basic medical care, defined as antibiotics and intravenous fluids, in the event of terminal illness, while 11% requested that all possible means of treatment be administered to them. Of the older adults that participated, only 45% had discussed their wishes with a family member or specified person. Asked if their physicians were aware of their wishes about terminal care, 69% indicated they were uncertain and only 24% indicated they were certain their physicians were aware of their wishes. The barriers cited by this group of elders as to why they had not signed a LW document are as follows: lack of knowledge (misconceptions, unfamiliar with the Act or did not understand the language), lack of communication between physicians and patients (81% were waiting for their physicians to initiate discussions) or preference for family members to make the decisions when they become incapacitated. The elders also expressed a reluctance to sign a legal document because of concerns about the latitude this could potentially give their physicians, particularly if they did not know or trust the attending physician at the time of serious illness? Could they be certain their wishes would be respected? Gamble et al (1991) concluded that the expression of patient autonomy is generally left to chance given the findings in this study. They also found that older adults do want to be involved in planning for their incapacity. Therefore, the researchers suggest educational efforts directed towards physicians (to take an active role in initiating discussions), patients and their families (to encourage sharing of their wishes) to ensure patient autonomy is promoted and not left to chance.

Similar findings were found by Emanuel et al (1991) in a study that involved both outpatients and the general public. Ninety-three percent of the outpatients under the care of primary care physicians and 89% of the general public expressed an interest in having an advance directive, regardless of age or current state of health. This group of participants indicated a perceived barrier to completion of advance directives was their physicians as they had not initiated a discussion with them. Contrary to popular belief, the least cited barrier was the sensitive nature of the topic or an unwillingness of participants to discuss end-of-life issues. The study also found that the younger participants did not want any more interventions than the elderly. This research team recommended discussions take place between patients and their physicians in advance of any serious illness. Also, advance directives should be available and supported for all patients, not just those currently suffering from terminal illness.

A Canadian study completed by Sam and Singer (1993) examined the knowledge, previous experience, attitudes and perceived barriers to completing advance directives. The study population ranged in age from 21 to 91 years, with a mean of 67 years. The researchers found that "patients' knowledge about life-sustaining treatments and advance directives was limited" (Sam & Singer, 1993 p. 1500). Only 16% of participants were aware of living wills, 11% indicated an awareness of enduring (durable) power of attorney for health care and 4% indicated they knew about advance directives. Patients who had more knowledge about life-sustaining treatments had more positive attitudes towards advance directives. Participants with higher levels of education demonstrated more knowledge about life-sustaining treatments, advance directives, enduring powers of attorney and were likely to want to document their treatment preferences and surrogate decision-makers. The participants in this study wanted to discuss their treatment preferences with their physicians, their spouses and their children, in that order. Also more than half of them indicated that their physicians should initiate the discussion during a routine physical assessment. The barriers to completing an advance directive were: inability to write; belief it was not necessary; fatalistic attitude; wanting to leave decisions to their physicians; uncertain about what they would want done; would rather discuss their wishes, not document them; wanted to wait until something actually happened; and finally, would rather not think about their preferences or about advance directives (Sam & Singer, 1993). Even though study participants had limited knowledge about the topic, they did have positive attitudes about advance directives. The researchers emphasized that physicians and patients needed to communicate better with each other regarding medical technology and language and about advance directives.

Studies completed by Sachs, Stocking & Miles (1992) and Stelter, Elliott & Bruno (1992) focused on the completion of living wills by older adults (65 years or older). In both studies older adults agreed with the concept of LWs though few had actually completed one. The characteristics of the elders who had completed a LW, according to Stelter et al (1992), were that they were highly educated and did not consider the LW form too long. The barriers cited as reasons why a living will was not completed were: procrastination; some expected their families to be involved or they needed their families' assistance with the completion of the document; and waiting for their physicians to initiate discussions. Stelter et al (1992) reported the following: physicians thought it was the patients' responsibility to bring up the topic; the topic was not discussed as physicians were not comfortable with the topic; physicians believed the discussion should take place when patients were older or finally, they did not want to engage in this type of discussion because they could not charge for it (U.S. study). Both research teams again concluded that patients wanted to be involved in end-of-life decisions. Therefore, they recommended further education for patients, families and physicians about this topic and suggested that education should be ongoing and supplemented with print information.

High (1993) conducted a comparative study that investigated whether lack of information was the main reason for the low completion rate of advance directives among adults more than 65 years of age. This researcher was attempting to gain insight into reasons why older adults either complete or decide not to complete advance directives. The results of this study suggest the reasons older adults do not complete advance directives are more complex than previously suggested by other authors. Lack of information or procrastination were not found to be major barriers to the completion of advance directives. Rather, the study suggested the reasons may be more multi-faceted and complex. Older adults may be refusing to become involved in the completion of these documents and indicated that they "trust" their children to make "better decisions" on their behalf when it is needed (p. 513). High concludes there may not be widespread use of advance directives in certain segments of the older population based on the results of this study.

Summary

Advance care documentation definitely has a place in today's health care system. These documents may become especially valuable for individuals who have very specific concerns or preferences regarding their health care (e.g., no cardiopulmonary resuscitation under any circumstances). To date, no 'perfect' form has been developed to meet every person's needs. The limitations to the various types of advance care documents are well documented in the literature. The salient fact that appears as an advantage, with every type of advance care document proposed, is that the document may promote discussions between patients, families and physicians. In fact, for any one of the suggested advanced planning methods to be of any value, there needs to be dialogue between the interested parties. The writer suggests that communication between all parties concerned should be a priority and may perhaps be more important than the completion of a form. These discussions are the first step in clarifying the person's thoughts and feelings. The next step may be the actual documentation of what patients want, and this may be completed through filling out a standardized form or patients may outline their wishes in letter format.

Another important factor to note after reviewing the literature, is that older adults are not completing these documents in advance of serious illnesses. The reasons for non-completion are as diverse as the population that may benefit from the completion of the forms. The reasons most commonly cited in the limited research completed regarding older adults' completion of LWs are: procrastination; reliance on families; waiting for their physicians to raise the issue or fear of giving their physicians too much latitude in the decision-making process. Again, a consistent theme appears in the literature, the elderly want to be involved in decisions about their care and they appear more comfortable with an informal arrangement involving their families.

On the basis of the research completed to date, the limitation the writer views as a concern is the ability to generalize the findings. To the writer's knowledge, none of these studies have been replicated. Therefore, the writer proposes further research in relation to what older adults' knowledge and attitudes are regarding advance care documents. It would also be useful to investigate if older adults in Canada prefer a more formal or informal arrangement of communicating their wishes.

CHAPTER 3: RESEARCH DESIGN AND METHODS

An exploratory/descriptive design was chosen to investigate the extent of older adults' knowledge and awareness about personal directives. This level of design allows flexibility in asking standardized questions and allowing participants to respond to open-ended questions to elaborate on their perspectives (Appendix J & K). This design is used when there is limited information in a topic area in an attempt to add to the current body of knowledge (Brink & Wood, 1989).

The researcher selected participants who met the "needs of the study", in this case those who have a knowledge of personal directives (Morse, 1991). Therefore, a purposive sampling method was chosen.

Settings and Sample Selection

The population participating in this study consisted of individuals 65 years and older who were aware of personal directives or living wills and/or had opinions about the type of health care they would want if they could no longer speak for themselves, who spoke, read and understood English, who were physically stable and cognitively intact scoring 24/30 or higher on the Mini-Mental State Examination. The participants were selected from both community and hospital settings, including two rehabilitation hospitals and two community health centres. A purposive sampling technique was utilized to obtain the required 60 participants for the study.

Community Setting

A letter of introduction was delivered to the executive director of the senior citizens' club and a meeting held to discuss the research (Appendix D). The researcher requested a list of seniors who currently frequented the facility and who met study criteria from the executive director. A letter of introduction and information sheet were sent to 30 potential participants in the community (Appendix B & C). The study and the seniors' possible involvement was described. The researcher contacted the seniors by telephone if she had not heard from them within one week. Alternatively, the senior could call the researcher directly or leave the bottom portion of the information sheet to indicate refusal to participate in the study with the executive director. A total of 55 letters were sent out from May 1995 to November 1995 to obtain the community sample size. (For personal reasons the researcher was unable to interview in July and August). The 30 community participants who agreed to be included in the study either resided in their own homes, in a relative's home, an apartment, a seniors apartment complex or a lodge with or without informal or formal support arrangements.

A general question was asked during the telephone contact to ascertain the senior's awareness of personal directives or living wills. When participants indicated their awareness and interest in participating in the study, an appropriate time and location for the interview was established. At the first meeting the purpose of the study was reviewed, the consent was signed and any further questions were answered. Participants received a copy of the signed consent (Appendix A).

In four situations, couples agreed to be interviewed. Three couples were interviewed independently and in only one situation did the spouse request to stay in the room. As the participant preferred the spouse present, the request was granted with the condition that the spouse did not add any comments during the interview session. The spouse abided by this direction and actually left the interview session approximately half way through so as not to interfere with the interview by adding comments.

Hospital Setting

Initially, the researcher obtained approval to approach potential participants from one rehabilitation hospital. Due to patient physical and/or cognitive instability, the researcher had difficulty obtaining enough participants for the study. As a result, in September 1995, another rehabilitation institute was approached for approval to access its population. By October 1995 it was again apparent the researcher would have difficulty obtaining the required sample size because of the cognitive status of the population. In November 1995 and again in January 1996, two community health centres were approached for their approval to access their adult populations.

The researcher identified potential participants in consultation with the nurse manager and the nursing staff by considering the age and cognitive status of patients (score of

24/30 on the Mini-Mental State Examination or based on the patients' ability to give informed consent). The nurses distributed the letter of introduction and information sheet to identified patients. If patients did not want to participate, they either told the nurse or completed the bottom portion of the information sheet. The researcher was introduced to potential participants the next day. At that point, the study was further described and questions were answered. If patients were agreeable, appointments for interviews were made that did not conflict with the patients' rehabilitation schedule. Prior to the beginning of the interview, further questions were answered and the consent was signed, and as in the community sample, participants received signed copies (Appendix A). All the interviews took place in private. To avoid any interruptions, staff were notified that the researcher was interviewing a patient. In one situation, a patient was in traction and unable to move. The interview was still conducted privately as the roommate was involved in an activity outside the room. On two occasions, family members were present for the interviews at the request of the participant.

Obtaining the required 30 participants in a hospital setting took from June 1995 to April 1996 (excluding July and August 1995). To complete the data collection for this study, a total of 88 patients were approached during the nine months. Of this total, 38 patients who met study criteria and approached by nursing staff refused to take part. The reasons varied from: too tired from the rehabilitation schedule to contemplate being in a study

(22); had a personal directive and did not want to discuss the topic (8); and were being discharged the next day and did not have the time (8). The researcher established whether each patient met the study criteria and found a further 20 patients, approached by nursing staff who were not eligible. Thirteen did not have any idea of the purpose of personal directives or living wills and did not have an opinion about the type of health care they would or would not want. Seven were found to be too young.

In order to provide additional elaboration of the participants' responses to the questionnaire on personal directives, they were also invited to respond to open-ended questions. The researcher selected 10 interviews for detailed content analysis of responses to the open-ended questions. It was expected that 10 interviews would provide adequate and sufficient information and could be analyzed within the available resources. Participants living in the community (five) as well as in the rehabilitation facilities (five) were included to incorporate variations in the participants' circumstances in their life situations. The participants who met the study criteria and provided the most detailed and articulate responses were selected. The study criteria included:

- living independently in the community (living alone or with a spouse, not receiving home care support such as: bath assist, medication management). Participants described their health status as "good" or above.

- receiving treatment in a hospital setting and had experienced changes in their health status within the last year and who described their health status as "fair" or "poor."
- articulate and expanded in detail on the five open-ended questions.

The researcher listened to the tape-recorded responses of each participant in order to select the 10 participants providing the most detailed and articulate responses. For these participants, responses to open-ended questions were transcribed verbatim and analyzed using a thematic form of content analysis.

To collect the data for this exploratory/descriptive study, a semi-structured questionnaire with closed-ended and open-ended questions was used (Appendix I & J). This approach was utilized to allow for flexibility. Participants were given the opportunity to expand on their thoughts about informing others of their health care wishes and about personal directives. Because this topic relates to potential incapacity for individuals, face-to-face interviews were preferred. This method allowed the researcher to observe participants' non-verbal behavior, affording the researcher the opportunity to seek clarification of statements and to do perception checks of body language if it was noted that participants were becoming distressed. In one situation, the participant's spouse had recently died and, during the interview, the participant became tearful when talking about the past. The researcher turned off the audiotape and asked if the participant wanted to stop the interview. The participant stated that the interview was very important and wanted to continue.

The interviews took place in either a private room on the unit or in the senior citizens' club or in the senior's home if it was more convenient. The allotted time for the interview was one hour. During the course of the 60 interviews, the sessions ranged from 20 to 70 minutes. The time varied depending on how much participants expanded on their thoughts during the standardized portion of the interview and at the end with the open-ended questions. (At the completion of the interview, the researcher handed out a resource sheet listing further information and resources available about personal directives (Appendix M). Books that were available in the local libraries and bookstores were also listed on the handout. The Discussion Paper - Decisions about Tomorrow: Directives for your Health Care was also made available to those participants and only two did not request this paper. It should be noted that approximately half way through the community interviews, participants began asking for samples of personal directive documents. With the permission of the BioEthics Centre, the researcher provided a copy of the document 'Advance Directives - Put Your Future in Your Hands'. The Living Will samples from the Jack Bell Foundation, the American Protestant Hospital Association and The Catholic Health Association of the United States were also in the handout. The purpose was to provide interested participants with different styles of personal directives and to discuss the pros and cons of each.

Instrument

Instruments identified in the literature did not include all areas the researcher considered important. Therefore, a questionnaire was developed for this study (Appendix I & J). During the development of the questionnaire the researcher reviewed current literature, draft legislation and consulted with other health care professionals. Once the questionnaire content was established, a senior meeting the study criteria was approached to critique the questionnaire. The senior was currently living in the community but had recently been discharged from a rehabilitation hospital. The interview with the senior was completed within the one hour allotted for the questionnaire. The response was favourable to the content, format and to the type of questions being asked. The questionnaire was also sent for review to four individuals currently working in the field of gerontology and research who had expertise in gerontology and ethics. Revisions were completed following suggestions regarding the clarity, content and the placement of some of the questions.

The interview setting was organized so participants could follow the questionnaire along with the researcher. It was important to demonstrate openness to the participants and to allow them some control in answering the questions. The interview guide begins with the demographic data (Appendix I - Section I). Demographic data was collected from each participant at the beginning of the interview to allow for 'getting to know' each other and to develop a comfortable atmosphere with the participant. This provided information about the participant's background and assisted the researcher in identifying potential concerns with memory. Section II begins with a brief introduction of the purpose of the study and a brief definition of a personal directive. Two open-ended questions followed regarding whether or not participants thought it necessary to communicate their health care wishes in writing and how they would define a personal directive. The remainder of the interview questions consisted of being involved in the decision-making process, when personal directives should be completed and informing others of their wishes. In Section III of the interview, the MMSE screening tool developed by Folstein, Folstein & McHugh (1975) was administered as a standardized method for objectively assessing mental status.

Reliability and Validity

The four experts in gerontology and ethics reviewed and commented upon the instrument for face and content validity (Appendix L). Face validity is established by reviewing the questions with experts to verify if the questions will provide the answers the researcher is seeking (Brink & Wood, 1988). With the development of a new instrument, content validity is undertaken to establish if the instrument will measure what it was intended to measure (Brink & Wood, 1988, 1989; Munro & Page, 1993; Wiersma, 1986). In addition to critiquing the instrument for content, the reviewers were asked to review the instrument for format, readability and language usage. The questionnaire items were considered adequate if there was 75% agreement from the reviewers on that particular item (three out of the four).

Internal consistency testing is undertaken to identify the extent in which the instrument questions contribute to the measurement of an overall concept (Brink & Wood, 1988). Internal consistency or reliability of the questionnaire was established using Cronbach's Alpha as the questionnaire items are dichotomous. The results of this reliability analysis for all 75 items of the questionnaire were .5405. When the 19 items of interest were separated out, the reliability results were .6437.

The questionnaire was purposely developed so that if the participant answered 'no' to a question, a section of questions was intentionally missed. Some participants did not wish to state 'yes' or 'no', but indicated they were 'undecided' about a certain question. For the purposes of factor analysis, questions that were not answered with a 'yes' or 'no' response were treated differently for the three runs of this analysis. The first factor analysis included the 'yes' (participants responses of 'jointly with family' were included in the 'yes' category), 'no' and 'undecided' responses and were analyzed using the listwise method. The second and third analysis were completed with the 'undecided' responses treated as missing data for both listwise and pairwise analysis. There was no difference in the three runs of the factor analysis. As results indicate, the instrument is only moderately reliable as the coefficients are not close to 1.0. The questionnaire requires further refinement and modification in order to reliably measure the concepts under study.

Data Analysis

Content analysis may take many different forms, but it is a method to categorize verbal and behavioral data (Field & Morse, 1985; Spradley, 1979; Wilson, 1987). The type of content analysis chosen for this research study will be thematic content analysis (Field & Morse, 1985; Spradley, 1979; Wilson, 1987). The purpose of this method is to identify the words, phrases and themes in the data and review the "entire interview" in context (Field & Morse, 1985, p. 103). This allowed for identification and subsequent coding of "the major thrust or intent of the section and the significant meanings..." in the interview (Field & Morse, 1985, p. 103).

Data analysis began with reviewing the verbal comments made by the participants during the taped interviews to assess the content and the themes that emerged. Once these themes were identified, descriptive summaries were compiled. In addition, the five open-ended questions at the end of 10 interviews (five interviews from the community and five from hospital settings) were transcribed verbatim to illustrate the comments from participants. The results of the content analysis are discussed in Chapter 4.

The demographic data was analyzed using descriptive statistics such as frequencies, means and ranges. The only outlier identified was in relation to the Mini-Mental Status Examination

(MMSE) score. One participant refused to complete the Attention and Calculation, Recall, Language (writing, and copying) sections of the screening tool which accounted for 10 marks. The portions completed, Orientation, Registration, and Language (naming, repetition, three stage command and reading) sections were completed with 100% accuracy (20/20) so the interview was included in the study.

Pearson's correlation tests were undertaken for the MMSE scores in relation to location, gender and age. The individual score of 20 was considered an outlier and correlations were completed with and without this outlier. Chi-square tests were completed to assess if there were differences between location or genders. Significance level was set at $p < .05$ for the chi-square results. Unrotated and rotated factor analysis was undertaken on 19 questionnaire items to identify concepts resulting from the interview questions.

Factor analysis is undertaken for the purposes of "data reduction" (Munro & Page, 1993 p. 246). It is a procedure to determine the number and the nature of attributes that may be under study. These attributes are represented as factors and are grouped into smaller numbers of factors. These factors are generated from the original variables and as a result must be interpreted based on these variables (Wiersma, 1986). The end result is that the researcher is able to concentrate on describing specific variables (Munro & Page, 1993). For this study the researcher completed a factor analysis of the variables in the questionnaire to identify any groupings of variables for the purposes of description and interpretation.

The complete results of the data analysis are described in the following chapter. A detailed description of the content analysis outlining what older adults know and believe about personal directives are then discussed at the end of Chapter 4.

Protection of Human Rights

Informed Consent

Competent individuals are able to give informed consent when they are knowledgeable and aware of the risks and benefits of the specific procedure (Field & Morse, 1985; Williams, 1992). The researcher initially mailed out a letter of introduction and information sheet about the research project to seniors who frequented the senior citizens' club and met the study criteria. The researcher's name and telephone number was on all information sheets so prospective participants could phone for further information or refuse involvement in the study. Once participants decided they wanted to be involved in the study, an appointment time was made. The consent was reviewed with them, any questions were answered and, once signed, a copy of the consent was left with the seniors. The consent, introduction letter and information sheet are at or below Grade 8 reading level (Appendix A, B & C). Participants were reminded at the beginning of the interview that they did not have to answer any question they were not comfortable with and could withdraw at any time without consequence.

The procedure at the rehabilitation hospitals and community health centres was similar with the exception that nurses on the hospital units distributed the letter of introduction and information sheet about the research study. The researcher was introduced to prospective participants once they agreed to speak with her. The researcher believes this alleviated the concern regarding coercion of the patient to participate in the study. Once the senior agreed to participate, the consent was signed and questions were answered. Again, a copy of the consent was left with the participant.

Confidentiality and Anonymity

The elderly are a vulnerable research population and need to be assured of the confidentiality of the information (Williams, 1992). Participants were assured that only the researcher, her thesis committee and the transcriptionist (for 10 interviews) had access to the raw data consisting of the audio tapes and questionnaires. They were also told that all information would be kept in the strictest confidence by the above named individuals. For the entire study period the consent forms were kept in a locked cupboard, separate from the audio tapes. Participants were assured that their identities and individual responses would be known only to the researcher. The questionnaires and the audio tapes were identified by a study number only.

Risk versus Benefit

The perceived risks identified for participants involved in this study were possible distress over the discussion related to potential or eventual incapacity. As the researcher did not know the families or health histories of participants in the community, she was sensitive to this factor. The topic did not visibly distress any of the participants. However, as mentioned earlier, one participant became tearful when talking about a spouse. The researcher had information about services available to the participants in the community if they did become upset. Various religious organizations and psychologists agreed to be available to any of the participants if they wanted to speak with them (Appendix H & K). None of the participants indicated they would rather not discuss the topic further or wished to stop the interview. The researcher was not contacted by the participants in the community to indicate they were upset post interview.

If the topic distressed participants in the hospital settings or if they requested to stop the interview, the researcher would have informed the nurse caring for the participant. Psychology, social work and pastoral care services were available at all the facilities. Again, none of the participants indicated to the researcher or to the nursing staff that these services were necessary or that they were distressed by the interview.

Another risk identified at the outset of this project was the event that participants would disclose information relating to a situation that might indicate a form of elder abuse. If this happened, the researcher would have clarified the information with the participant following the interview. The researcher would ask the older adult if there was a desire to do anything about it. If there was such a desire, she would provide contacts depending on the concern identified (Appendix H & K). No information that would indicate any form of elder abuse was disclosed during the interviews.

In the information sheet and the consent it was stated there was no specific benefit to the participants, other than that with this type of discussion they may decide to plan for their future and initiate a discussion with their families or physicians. The information from this study could potentially assist physicians, other health care professionals, lawyers and legislators in discussing the topic or in developing an appropriate policy or educational programs. Participants understood the information and indicated on numerous occasions that they felt it was important to state their views about the subject. A number of participants indicated they had heard of living wills/personal directives recently and felt it was an important topic to discuss and to encourage awareness.

Ethical clearance was obtained from the University of Alberta Joint Ethics Committee, the senior citizens' club, the two rehabilitation hospitals and the two community health centres. Once ethical clearance was obtained from the hospital settings, meetings were scheduled with the nursing managers and the nursing staff to explain the study and to identify nurses who would act as contact people for the researcher. The contact people agreed to assist the researcher in identifying potential participants. Letters of introduction to the nurse managers were left after each meeting. In addition, after each interview, a letter to the physician and a chart letter were completed and left on the front of the chart. The researcher did not receive any phone calls from physicians in any of the institutions requesting further information about the study.

Summary

In this chapter, the research design and methods undertaken for this study were described. The settings in which the data was collected for this study were the community, two rehabilitation hospitals and two community health centres. The sample was drawn from participants who were aware of the meaning of a living will or a personal directive and those that had an opinion about what type of health care they would want in the future. Demographic data was obtained from both the community and hospitalized group. The interview format was initially structured and ended with an open-ended questionnaire format. The questionnaire was developed by the researcher and evaluated by experts in the field of gerontology and ethics. Validity and reliability issues relative to the questionnaire were discussed. The interview results were analyzed using descriptive statistics. Further analysis to identify if there was a difference between location and gender was undertaken using chi-square. Pearson's correlations were undertaken to establish relationships between variables. The five open-ended questions at the end of the questionnaire were analyzed using content analysis techniques. In addition, all of the interview tapes were reviewed by the researcher to include all pertinent comments. This chapter also includes a section on the protection of the human rights of the study participants.

CHAPTER 4: RESULTS

This study was designed to explore and describe the knowledge and attitudes about personal directives of older adults who were living in the community or receiving treatment in rehabilitation hospitals or community health centres. The research questions related to whether older adults were knowledgeable about the issue, if they thought personal directive documents were necessary and if they wanted to be involved or if they wanted others involved in decision-making about their health care. Also examined was whether or not there was any difference between older adults living in the community and those receiving treatment in a hospital setting and if older adults were able to identify education or information they thought would be beneficial prior to completing an advance care document. As content analysis is part of the study design, the themes that emerged from the five questions that were transcribed and the themes that emerged from listening to all of the interview tapes will be outlined. This chapter was organized by summarizing study participants' demographics, addressing the results of the four research questions, the results of the factor analysis and a discussion of the content analysis.

Demographics

The sixty participants involved this study consisted of 21 (35%) males and 39 (65%) females. Age ranged from 65 to 88 years with a mean of 74 years. The age that appeared most frequently was 67 years (7), followed by 66 and 75 years (5) and 74 and 82 years (4). By separating out the ages into two categories - those from 65 years to 74 years and those 75 years and up - it was determined in this study that 33 (55%) of participants were in the first category and 27 (45%) in the latter. Therefore, the majority of the study group was among the 'young old' age grouping, though both categories were well represented.

Forty-five percent of participants were either married or widowed and 6.7% were divorced (Table 1).

Table 1 Marital Status

	Frequency	Percent	Cumulative Percent
Married	27	45	45
Widowed	27	45	90
Separated	1	1.7	91.7
Divorced	4	6.7	98.3
Never Married	1	1.7	100
Total	60	100	

Chi square analysis of marital status by gender resulted in a $p < .05$ (Table 2). This result should be interpreted cautiously as six out of the 10 cells had less then five participants in them, though this result is consistent with the frequency results. More males were married than females and significantly fewer were widowed. Therefore, in this instance, there was a difference between males and females.

Table 2 Marital Status By Gender

	Male	Female	Row Total
Married	17	10	27
	28.3%	16.7%	45%
Widowed	4	23	27
	6.70%	38.30%	45%
Separated	-	1	1
	-	1.70%	1.70%
Divorced	-	4	4
	-	6.70%	6.70%
Never	-	1	1
Married	-	1.70%	1.70%
Column Total	21	39	60
	35%	65%	100%

χ_2= 17.34, df = 4
p = .00166

Note: - = insufficient data available to fill all cells.

Continuity Correction - not reported.

Minimum Expected Frequency - .350

Sixty-three percent of the participants indicated they lived in a house either by self or with a spouse. The next largest grouping, at 15% resided in a seniors' apartment (Table 3). The majority of participants (38%) had Grade 8 - 11 education with 35% having post-secondary/university education. Of the 21 participants who obtained post-secondary/university education, six had a Bachelor's Degree, six went to technical school, three to nursing school (RN), three held Masters Degrees and three held Doctorate Degrees. Only four of the participants had achieved less than Grade 8 education (Table 3).

Table 3 Living Arrangements and Educational Level

	Frequency	Percent	Cumulative Percent
Living Arrangements			
House (self/spouse)	38	63.3	63.3
House (family)	2	3.3	66.7
Apartment	3	5	71.7
Seniors Apartment	9	15	86.7
Lodge	2	3.3	90
Other	6	10	100
Educational Level			
<Grade 8	4	6.7	6.7
Grade 8 - 11	23	38.3	45
Grade 12 -13	12	20	65
Post Secondary/University	21	35	100

For current occupation, 85% of participants indicated they were retired with seven women (11.7%) indicating they continued to be homemakers. Two participants were still actively working in their field. When participants were asked about previous occupation, 45% were classified in the professional/managerial category. Chi square analysis of previous occupation by gender showed significance $p < .05$ (Table 4).

Table 4 Previous Occupation by Gender

	Male	Female	Row Total
Homemaker	-	10	10
	-	16.70%	16.70%
Labourer	2	-	2
	3.30%	-	3.30%
Technical	1	7	8
	1.70%	11.7%	13.3
Prof/Manager	16	11	27
	26.7%	18.3%	45%
Other	2	11	13
	3.30%	18.3%	21.7
Column Total	21	39	60
	35%	65%	100%

$\chi^2 = 20.06$, df = 4
p = .00049

Note: - = insufficient data available to fill all cells.

Continuity Correction - not reported

Minimum Expected Frequency - .700

The majority classify themselves as in good health (36.7%) with 28% indicating they are in fair health and 23% stating they are in very good health. Sixty-five of the participants indicated they had experienced a change in their health within the last year and of those, 51.7% indicated it had changed for the worse (Table 5).

Table 5 Perception of Health

	Frequency	Percent	Cumulative Percent
No response/unable to assess status for self	1	1.7	1.7
Excellent	3	5	6.7
Very Good	14	23.3	30
Good	22	36.7	66.7
Fair	17	28.3	95
Poor	3	5	100
Total	60	100	

Perception of health status by gender χ_2 (5, N = 60) = 13.909, p < .05 (Continuity Correction not reported, Minimum Expected Frequency .350). This result indicates a difference in how males and females view their health but, because of the low numbers in the sample, this result should be interpreted cautiously. There were no significance results in the chi square analysis by gender when asked if health state had changed, or whether it had changed for better or worse (p = .13263 and p = .18707).

Chi square analysis of those in hospital and in the community regarding their perception of health showed significance, χ_2 = (5, N = 60) = 14.358, p = .01349 (Continuity Correction not reported, Minimum Expected Frequency - .500). More participants in the hospital indicated their health was good or fair, while those in the community indicated good or very good. Chi square results indicated that there was a difference between the hospital and the community participants regarding a change in their health $p < .05$ and of those whose health had changed, it was for the worse $p < .05$ (Table 6 (a) and (b). Again, these results seemed logical given one group was living independently in the community and the other group was hospitalized. Despite this fact, the results should be interpreted cautiously because of the sample size.

Table 6 (a) Perception of Change of Health by Location

	Community	Hospital	Row Total
Yes, a change	13	26	39
	21.70%	43.30%	65%
No change	17	4	21
	28.30%	6.70%	35%
Column Total	30	30	60
	50%	50%	100%
$\chi_2 = 12.38$, df = 1			
p = .0043			

Note: Continuity Correction - 10.55, $p = .00116$

Minimum Expected Frequency - 10.50

Table 6 (b) Type of Change in Health by Location

	Community	Hospital	Row Total
Not Applicable	17 28.3%	4 6.7%	21 35%
Better Health	2 3.3%	6 10%	8 13.3%
Worse Health	11 18.3%	20 33.3%	31 51.7%
Column Total	30 50%	30 50%	60 100%

$\chi^2 = 12.66$ df = 2
p = .00178

Note: Continuity Correction - not reported
Minimum Expected Frequency - .400

Forty-seven percent of study participants indicated they were independent in activities of daily living, with 58.3% indicating they required some assistance which ranged from vacuuming to yard work. In the community group, 19 participants (63%) required no assistance, the remaining 11 participants required light housekeeping, assistance with groceries or yard work. In the hospital setting, only five participants (16%) indicated they currently required no assistance. The remaining 25 (83%) required housekeeping, yard work or groceries assistance. When homemaking assistance by gender was analyzed using chi square results, were not significant, $p > .05$.

When participants were asked if they received homemaking support, there was no difference between genders for chi square. There was a difference between those in hospital and those in the community $\chi_2 = (1, N = 60) = 4.59$, $p < .05$ (Continuity Correction - 3.517, $p = .06$, Minimum Expected Frequency - 11.0). More people in hospital settings currently required assistance or projected that they would need some in the future.

There was a difference between the community and hospital groups in home care nurse support $\chi_2 = (1, N = 60) = 4.04$, $p = .04435$ (Continuity Correction - 2.587, $p = .1077$, Minimum Expected Frequency - 3.5). When the frequency scores are considered, this result is reasonable as more participants in hospital required assistance.

Other areas of interest were the amount of assistance required from a home care nurse by gender. This result showed a $p < .05$. Therefore, the amount of assistance required between genders would appear to be different (Table 7). There was also a difference between community and hospital settings in the requirement for a home care nurse. Only one participant (1.7%) in the community reported requiring assistance from a home care nurse. While in the hospital setting, six participants (10%) indicated they currently had a home care nurse visit and two projected the need, while the rest did not know at this point in time what their requirements would be.

Table 7 Home Care Nurse Requirements by Gender

	Male	Female	Row Total
None	21 35%	32 53.30%	53 88.3
Assistance	-	7 11.70%	7 11.7
Column Total	21 35%	39 65%	60 100%

$\chi^2 = 4.27$, df = 1
$p = .03886$

Note: - = insufficient data available to fill all cells.

Continuity Correction - 2.587, p = .10015

Minimum Expected Frequency - 3.5

Eighty-seven percent of participants in this study had a (MMSE) completed either by the researcher or by a nurse on the unit. Only seven people refused to complete the MMSE. The reasons for refusal ranged from "it is not a valid and reliable tool in my opinion" to "would rather not". As mentioned in Chapter 3, one participant refused to complete sections of the screening tool, though sections completed were done with 100% accuracy. Twenty-two participants (36%) scored 30/30 on the MMSE with a score of 29 being the next largest category (Table 8), the mean score was 28.

Table 8 Mini-Mental Status Examination

	Frequency	Percent	Cumulative Percent
SCORE			
20	1	1.7	1.7
24	1	1.7	3.4
25	1	1.7	5.1
26	4	6.7	11.8
27	5	8.3	20.1
28	4	6.7	26.8
29	15	25	51.8
30	22	36	87.8
Refused to complete MMSE	7	11.7	99.5
Total	53	100	

The community group had higher MMSE scores than those of the hospitalized group and the means were 29 and 28 respectively. When location and MMSE score were analyzed, a low correlation of $r = -.2993$ was evident and a significance level of $p = .029$ which is not statistically significant.

When gender and score on the MMSE was correlated, findings were not significant, ($r = .0199$ and $p = .888$). But when age and score on MMSE was correlated with the score of 20 included, there was a low correlation found $r = -.2838$ $p = .039$. When the outlier, the score of 20, was filtered, the correlation coefficient is $r = -.2645$ ($p = .058$) not a statistically significant result.

Chi square analysis for location and gender showed no significant differences χ^2 (7, N = 60) = 7.16, p = .41247 and χ^2 (7, N = 60) = 4.09, p = .76935 respectively).

Question 1: Are older adults aware and/or knowledgeable about the purpose of advance care documents and do they feel it is necessary to complete one before the onset of a serious illness?

The initial question posed to the participants who agreed to participate was whether they had heard of a personal directive or living will before. When a purposive sampling technique is utilized, participants have prior knowledge or opinions about the topic under study. The terms personal directive and living will were utilized as the majority of this population had heard the term living will previously but only three were familiar with the terminology of personal directives. Using the term personal directive was deliberate to educate the participants about the new terminology. Only five participants were unfamiliar with the terms used. The researcher queried whether they had heard about writing down their health care wishes in advance or had any opinions about the type of health care they would want if they could no longer speak for themselves. When this question was asked, it elicited an immediate response from the participants. They indicated they had 'heard' about writing their wishes down in advance but did not know the name of the document.

The initial question in the interview asked whether the participants thought it was necessary to communicate their health care wishes in writing. The majority (75%) indicated they thought it was necessary to communicate their health care wishes in writing with 20% stating it was not necessary (Table 9).

Table 9 Communicate Wishes in Writing

	Frequency	Percent	Cumulative Percent
Yes, is necessary	45	75	75
No, not necessary	12	20	95
Undecided	3	5	100
Total	60	100	

A sample of comments of those indicating that it was necessary to communicate health care wishes in writing were: "...want family to know what I want done to me ... so they can tell the doctors"; "even if you tell them [family] at the time they may feel they are unable to follow my choices ... so I would put it in writing"; "family don't want to talk about it ... so [I'll put wishes] in writing" or "... to let others know ... [so I can] die in peace." Of those indicating that it was not necessary to communicate health care wishes in writing, some of the comments were as follows: "No need to write [anything down] ... doctor should know what is happening and talk with my family" or "pretty hard to put something like this [health care wishes] into writing."

Eight participants indicated it was a "good idea to communicate wishes in writing" and answered 'yes' to the question with the provision that it was not necessarily for them.

Due to their current family situations they did not feel any need to put their wishes in writing. Some of the comments were "...my family takes care of me" or "unnecessary for me, [I am] happy with my family."

The researcher then asked participants to describe, in their own words, a personal directive or living will. The most common description was reflected in this quote: "[it is a] written statement of my wishes if I am unable to speak for myself". Thirty participants described a personal directive in this manner, each had the components of "[it is a] written statement [if I am] incapacitated [and am unable to speak, my] opinion about hoses and tubes so [my] life [would not be] prolonged unnecessarily." The other descriptions included comments about "[it is an] expression of my desire about life support." A common statement among participants was they did "not want life prolonged unnecessarily, [they wanted] to go peacefully, [to] die with grace without hoses and tubes," and "so there is no conflict family and so [my] children do not suffer." Others ned that they did not want to be a "vegetable, just lying "...do not want to be a burden [to my family]." Regardless ition provided by the participants, no one made direct of treatment they might want in a specific circumstances except in relation to "being free of pain."

Fifty-nine or 98.3% of the participants indicated they wanted to be involved in decision-making. Only one participant indicated that family member(s) would be relied upon and did not want to be involved in making decisions about health care.

In this case the comment was that communication would occur through the personal directive. Comments such as "most certainly I want to be involved [for] as long as I am able, and [I want to be] knowledgeable," reflected that participants felt it was important to them to be involved in this process.

Eighty-one percent indicated that a living will should be completed prior to becoming seriously ill with eight (13.3%) respondents indicating that it was not necessary to complete and three (5%) stating that they were not sure. Of those stating that it should be completed before they became seriously ill, 83.3% stated that it should be done prior to going to the hospital. If an personal directive had not been completed, 26.7% thought it could be completed during the current hospitalization if this was possible. Other participants indicated that once a person is hospitalized it was "too late" or the "worst time" to actually complete a personal directive.

Thirty-one percent indicated that a personal directive should be completed by a certain age with 53.3% indicating this was not feasible. Comments of those indicating that age was not a criterion included: "age has no bearing [it] doesn't matter if you are 40 or 100; [age is] not a viable criteria; [something] could happen [at] any time; not a pleasant subject [for some people], but necessary; age has nothing to do with [whether a personal directive is completed]; state of health [is more important]; [a person could complete a personal directive] when you are young, [it is] like making a will, never too early."

The participants who indicated that a personal directive should be completed at a certain age were then asked at what age they thought this document could be completed. The answers varied from "the key is [the] circumstances [there is] no proper age but 60 to 65 years would be the outer limits"; "age is a good idea [a personal directive should be completed] right now." The age at which to complete a personal directive ranged from 40 - 80 years. The most common age was 60 - 65 plus, others indicated around their ages which was 75 or 80 years of age.

Of the eight participants indicating that it was not necessary to complete a personal directive before an individual becomes seriously ill, all except two indicated that the topic should be discussed "as it could benefit a lot of people" and "because some people want this [personal directive]." The one participant who said 'no' indicated that it should be "[left] to the family." The undecided participant mentioned that "[they are] making a lot out of [personal directives] today."

Question 2: Do older adults want others to be involved in the discussion and/or the completion of an advance care document? If so, who do they want involved?

When the participants were asked if they wanted others to be involved in the discussion and/or the completion of a personal directive and if so whom, 59 (98.3%) indicated they would want someone else to speak for them if they could no longer speak for themselves. One participant indicated that "no need to have [a substitute decision-maker, everyone is] supposed to follow my living will [all the] decisions [are] made through [the living will]." When this participant was asked what would you want done if something happened that was not covered in your personal directive, the response was that the "[my] children and doctor would talk."

The participants were also asked to identify who they would want to speak for them in a situation where they could no longer speak for themselves. The majority (80%) of participants indicated they would choose their children as their substitute decision-makers. Depending on the participant, either one child was the main spokesperson or all the children would be involved in 'speaking' for them. Four participants made direct reference to the fact that it was "not fair to put something like this on to the children [I] don't want the family to have to make the decision." If participants chose their doctors as being substitute decision makers, it was stated it would be their family doctor and not just "any doctor." One participant included the home care nurse in the list of participants because of the relationship that had developed between them. All of the participants were asked to rank order their choice of surrogate decision-makers if they had more than one choice (Table 10 & 11).

Men in both the community and the hospital group tended to choose their spouses as their first choice of substitute decision-maker. If the spouse was not chosen, one of the reasons cited was due to the female spouse's ill health. It should be noted, the majority of the men were still married, while in the female population the majority were widowed or without a partner.

TABLE 10 Substitute Decision-Makers - Community Sample

	Men				Women			
Choices	1st	2nd	3rd	4th	1st	2nd	3rd	4th
Parents								
Spouse	6			1	6			
Children (all or one)	2	4			14	4	1	
Brother/Sister						1		
Grandchildren						3		
Nephew/Niece		1						
Other Relative				1				
Doctor	1	1	2		1	6	4	
Health Care Professional			1*					1**
Other		1						

** Participant indicated that substitute decision-maker would be the home care nurse. One participant indicated no substitute decision-maker would be chosen.

The number of males in the community sample were 10 - 8 married and 2 widowed.

The number of females were 20 - 6 married and 14 widowed.

Table 11 Substitute Decision-makers - Hospital Sample

	Men				Women			
Choices	1st	2nd	3rd	4th	1st	2nd	3rd	4th
Parents								
Spouse	8				1			
Children (all or one)	3	5	1		12	1		
Brother/Sister					2	1		
Grandchildren	1	1				1		
Nephew/Niece						2		
Other Relative					1			
Doctor	4	1	1		1	6	2	
Health Care Professional			1**				2	
Other		1*			1*	1*	1*	

Note: * Participants choose lawyer twice, close friend and fiancee.

** Home Care Nurse

Number of men in hospital sample were 11 - 9 married and 2 widowed.

Number of women in hospital sample were 19 - 4 married, 9 widowed, 4 divorced, 1 separated and 1 never married.

This choice was reflected in the chi square result where the sample demonstrated a difference between choice of spokesperson by gender, $p < .05$ (Table 12). Again this is not a surprising result as more men were married, though the sample size was small. There was no gender difference when the other choices for spokesperson (children, siblings, grandchildren, nephew/niece, any other relative, doctor, other health care professional and other) were analyzed using chi square. When participants were asked who should make the decision about their care if something happened that was not covered in their personal directive, there was a difference between genders for choice of spouse as spokesperson. Chi square analysis results were $\chi^2(1, \underline{N} = 60) = 16.81$, $\underline{p} = .0000$. There was no significant difference when location was considered.

Table 12 Choosing Spouse as Spokesperson by Gender

	Male	Female	Row Total
Not Applicable	5	33	38
	8.3%	55%	63.30%
Spokesperson	16	6	22
	26.7%	10%	36.70%
Column total	21	39	60
	35%	65%	100%
$\chi^2 = 21.73$, df $=1$			
$p = .0000$			

Note: Continuity Correction - 19.193, $\underline{p} = .00001$

Minimum Expected Frequency - 7.7

Participants were asked a series of four questions relating to their opinions about discussing their health care wishes with their spouses/families and doctors. They were asked if they wanted to make the decisions about their health care or if they wanted their families/doctors to make the decisions for them. In answering, the majority (91.7%) indicated that they would want to make the decisions about their health care choices after discussing their wishes with their families. Two (3.3%) indicated they would make the decision but would consult with their spouses/families. Only two participants indicated they would discuss their wishes with their family members but would let them make the decisions about the type of health care they received on their behalf (Table 13 a).

Seven participants (11.7%) indicated they would make their health care decisions jointly or in consultation with their families. Only two participants stated they would discuss their health care wishes with their families and let family make the decision (Table 13 b).

Participants were asked if they would make the decisions about their health care after discussing the issue with a health care professional. Forty-three (71.7%) indicated they would make the decisions (Table 13 c). The health care professional the majority of participants indicated they would speak with was their family doctor, "…. as long it is my own doctor I'm speaking to ..." or "... doctor has a great deal to say about [health care wishes] because of their knowledge, but I would still make the decisions." The home care nurse was chosen twice (Table 10 & 11). An interesting result is that 21.7% of participants indicated that they would not discuss their health care wishes with a health care professional. Comments such as: "it is not necessary to talk with my doctor; [I do not feel it is] needed; [my] children would talk with the doctor" reflect their thoughts on this question.

The last question asked if participants would allow the health care professional to make the health care decision(s) on their behalf after a discussion. A majority of participants (78.3%) indicated they would not allow the health care professional (physician) to make the decisions on their behalf. One participant mentioned that "... they [doctors] always want to save you." Others indicated that they would want their doctor involved to give information or as "aid to decision making [about health care]." Only two participants indicated they would allow their physician to make decisions on their behalf but only after they were informed of their physician's decision (Table 13 d).

Table 13 Discussions about Health Care Wishes

	Frequency	Percent	Cumulative Frequency
a) Discuss with Family/Individual's Decision			
Yes	55	91.7	91.7
No	2	3.3	95
Undecided	1	1.7	96.7
Joint/Consult	2	3.3	100
b) Discuss with Family/Family's Decision			
Yes	2	3.3	3.3
No	50	83.3	86.7
Undecided	1	1.7	88.3
Joint/Consult	7	11.7	100
c) Discuss with Health Care Professional/Individual's Decision			
Yes	43	71.7	71.7
No	13	21.7	93.3
Undecided	2	3.3	96.7
Joint/Consult	2	3.3	100
d) Discuss with Health Care Professional/HCP's Decision			
Yes	2	3.3	3.3
No	47	78.3	81.7
Undecided	2	3.3	85
Joint/Consult	9	15	100

When participants were asked if, in their opinion, someone should complete a 'formal' document such as a personal directive while they were still able, the majority indicated that it "would be a good idea, especially if there was conflict [in the family]." Others indicated that they would wait until personal directives were "law" and one participant stated "if he could find out why doctors would accept some treatments and reject others in order to make a truly informed choice" for himself (Table 14).

Table 14 While Still Able Complete Personal Directive

	Frequency	Percent	Cumulative Frequency
Yes	43	71.7	71.7
No	9	15	86.7
Undecided	8	13.3	100
Total	60	100	

When participants were questioned whether their wishes should be followed as documented in a personal directive if one was completed, 93.3% indicated this was important to them. Two people (3.3%) indicated their wishes should not necessarily be followed as "something could come up that wasn't covered [in my personal directive] it should be just a guideline as other things could happen [to me]."

Participants were then asked who should make the decision when something occurred that was not outlined or addressed in their personal directive. Again, the majority of participants chose their children to be involved (78.3%). As previously stated participants were asked to rank order their choices (Table 15 & 16).

Table 15 Substitute Decision-Makers - Community Sample

	Men				Women				
Choices	1st	2nd	3rd	4th	1st	2nd	3rd	4th	N/A
Parents									
Spouse	7			1	5				
Children (all or one)	1	6			12	5	1		
Brother/Sister						1	2		
Grandchildren						2			
Nephew/Niece									
Other Relative			1						
Doctor	1	1	2	1	2	7	3		
Health Care Professional			1*						
Other		1**							
Did not respond									1

Note: * Participant did not name spokesperson.

** Participant indicated that the substitute decision-maker would be a friend.

Total number of men in community sample was 10 - 8 married and 2 widowed.

Total number of women in community sample was 20 - 6 married and 14 widowed.

Table 16 Substitute Decision-Makers - Hospital sample

	Men				Women				
Choices	1st	2nd	3rd	4th	1st	2nd	3rd	4th	N/A
Parents									
Spouse	8				2				
Children (all or one)	2	5	1		13	1			
Brother/Sister					2				
Grandchildren		1				1			
Nephew/Niece						2			
Other Relative					1				
Doctor	1	1	2		1	5	2		
Health Care Professional							1**		
Other						2*			
Not necessary, follow PD document									1

* Participants choose friend and fiancee.

** Participant did not name health care professional

Total number of men in hospital sample was 11 - 9 married and 2 widowed.

Total number of women in hospital sample was 19 - 4 married, 9 widowed, 4 divorced, 1 separated and 1 never married.

Note: Participants rank ordered choices if they had more than one substitute decision-maker.

The majority of participants, 73.3% indicated they would not want any type of legal involvement when or if they complete a personal directive. Two participants stated "it [is a] needless expense [to go a lawyer]," while others stated it was "not necessary" or would only do so if it was "necessary by law." Four respondents were undecided and 12 (20%) respondents indicated they would want a lawyer involved to ensure their wishes would be followed so wishes could not be "pre-empted" (Table 17).

Table 17 Involvement of Lawyer

	Frequency	Percent	Cumulative Percent
Yes	12	20	23.3
No	44	73.3	95
Undecided	4	6.7	100
Total	60	100	

When questioned whether participants had discussed what type of medical treatment they would or would not want, 27 (45%) indicated they had some type of discussion and eight indicated they had a partial discussion with someone. Participants said the discussion included "generalities about my beliefs [that I] don't want to be kept alive"; "[I} don't believe in euthanasia, but should be comfortable [and pain free]; [I] need to think about this [issue] and talk in more depth." The remainder, 25 participants (41.7%), indicated they had not discussed the issue with anyone (Table 18 a).

Of those indicating they had discussed their wishes with someone, the majority said it was with a family member. Interestingly, of those who had not discussed what type of medical treatment they would or would not want, seven (11.7%) indicated they had no plans to discuss the topic with anyone and eight remained undecided. Some comments around this question were: "Doctor says I'm fine and going to live another 20 years," "would like to see the Act first before I talk about it [with anyone]" or "If the occasion arose [with my doctor, I think] it's a good idea [to talk about it]" (Table 18 b).

Table 18 Discussion Regarding Medical Treatment

	Frequency	Percent	Cumulative Frequency
a) Have discussed topic			
Yes	27	45	45
No	25	41.7	86.7
Partial	8	13.3	100
b) Planning to discuss the topic *			
Not Applicable	32	53.3	53.3
Yes	13	21.7	75
No	7	11.7	86.7
Undecided	8	13.3	100

* Note: Participants responding not applicable indicated that even though they may have only partially discussed the topic, they were not planning further discussions.

Only six participants, or 10%, indicated they had already had a discussion with their doctor about what type of health care they would or would not want. Of those, five indicated they raised the topic with the physicians. Two said the discussion occurred before they became ill, one during the hospitalization and one after discharge. The remaining two participants' experiences did not fit into one of the three categories. Their discussions occurred after they were ill but in hospital. These participants indicated the conversation "went well" or were "very good conversations" and that they talked about "resuscitations [and not wanting] to be kept alive with tubes," "a lot of situations were covered [with the doctor]" during this discussion.

Of the 54 participants who had not discussed their wishes with their physicians, 19 (31.7%) indicated they had no current plans to discuss the topic with the physicians. Forty-five percent indicated they were planning to discuss the topic with their physicians and eight remained undecided. Some of the comments were "once the act is in place [I'll talk with my doctor]," "once I become ill," "not going to get personal with him until I need to [I do not think doctors] have time for this today [it is] not like the doctors of the old days [or maybe I would talk with my doctor] if I was real sick" or "I might consider it, but problem is that the doctor you talk with may not be the one that treats you when you are in trouble."

Participants could choose from the following responses as to why they had not discussed the topic with their physicians: not ready, not necessary, too disturbing to discuss or some other reason. No pattern emerged concerning participants rationale for not discussing the topic with their physicians, but it should be noted that no one chose the item the topic was: "too disturbing/ distressing to talk about." Other reasons for not discussing the topic were "hadn't thought about it" (5) "not legal yet" (2) "don't want to give control to doctor, want to live," or "just started with this doctor [so not going to discuss this topic yet]."

There was no difference between gender seniors were asked if they thought it was not necessary or if it was too disturbing. However, there was a difference between genders and locations in why participants did not what to discuss the topic when they supplied their own reason $\chi^2(2, N = 60) = 7.39$, $p = .00896$ (Continuity Correction not reported, Minimum Expected Frequency - 3.5) and $\chi^2(2, N = 60) = 13.47$, $p = .00118$ (Continuity Correction not reported, Minimum Expected Frequency - 5.0) respectively. Some of the reasons cited by participants have been listed in the preceding paragraph.

Following that series of questions, participants were asked if they believed their wishes would be followed by their families and their physicians. All 60 participants indicated their family members would follow their wishes whether expressed or not. Also 43 (71.7%) of participants indicated their physicians would follow their wishes even though only six had discussed their wishes with their physician (Table 19). Comments from participants included: "Not much use having a doctor if you don't have any faith in him," "[I have] been going to the [same] doctor for 20 years," "[a doctor is a] professional person, I think [my doctor] would follow my wishes," or "[I] know doctor well, but not all people would have this level of trust with their doctor." Sixteen (26.7%) indicated they did not know if their wishes would be followed by their physicians because they had not discussed the topic. One participant indicated the family doctor did not have hospital privileges, so it would be the specialist involved in the care. The participant hoped the family doctor could tell the specialists about the discussion. A concern that the physician might not follow the health care wishes was expressed by one participant. The concern raised by this participant was "[my] doctor is not listening to me, [I do not] want some things forced on me, [when] I say 'no' I mean it [and I] feel I'm going to die anyway."

Table 19 Wishes Followed by Doctor

	Frequency	Percent	Cumulative Percent
Yes	43	71.7	71.7
No	1	1.7	73.3
Unknown	16	26.7	100
Total	60	100	

Eighty-five percent of those interviewed did not have a personal directive. Some indicated they "intended" to complete a personal directive and one stated had thought about completing one for "10 years" but still hadn't. Of the nine participants (five in the community and four in the hospital settings) who indicated they had a personal directive document, the majority (four) had one for more than five years (Table 20 a) and the majority (five) indicated that their document had never been updated (Table 20 b). Only one participant indicated that no one knew about the personal directive. Chi square analysis did not show any significant results.

When participants were asked if a personal directive should be reviewed and updated at regular intervals the majority (83.3%) indicated it should be (Table 20 c). The comments varied from "once [I] made the decision(s) it would stay [that way I am] not going to change mind" to "with new scientific advances [and] as condition changes or family changes, [or] with changes in the law" a personal directive should be updated. There was not a clear pattern as to when the document should be reviewed. Comments ranged from yearly to every 3, 4, 5 or 10 years. The most frequent comment made was that a review/update was needed if there was a change in health status or in life situation.

Of the 51 participants without a personal directive, 24 (40%) were planning to complete one (age range 65 to 80s and educational level of Grade 8 to university) and 13 were undecided (Table 20 d). Fourteen participants indicated they had no plans to complete a personal directive. Some of the participants indicated they "were thinking about it," while two indicated they would only complete a personal directive "when it was legal." The nine participants who had completed a personal directive ranged in age from 71 years to 84 years. Education levels ranged from Grade 8 - 11 to post-secondary/university level.

Table 20 Personal Directive Information

	Frequency	Percent	Cumulative Frequency
a) Duration			
Not Applicable	51	85	85
< 1 year	3	5	90
1 -2 years	1	1.7	91.7
3 - 5 years	1	1.7	93.3
> 5 years	4	6.7	100
b) Last Updated?			
Not Applicable	51	85	85
< 2 years ago	2	3.3	88.3
2 years +	2	3.3	91.7
Never	5	8.3	100
c) Review or Update Personal Directive?			
Not Applicable	1	1.7	1.7
Yes	50	83.3	85
No	9	15	100
d) Planning to Complete *			
Not Applicable	9	15	15
Yes	24	40	55
No	14	23.3	78.3
Undecided/ Maybe	13	21.7	100

* Note: Not applicable - participants already have a personal directive.

As to whether being involved in the study had changed their minds about discussing the topic with their families, 17 participants (28%) indicated they would now think about discussing the topic and two were undecided. Forty-one or 68% indicated the study had not changed their minds. These results were very similar to those for the question related to discussing a personal directive with their physicians. Forty-three (71.7%) indicated that being involved in the study had not changed their minds about discussing it with their physicians. These participants commented that they already had plans to discuss the topic with their physicians. There were similar results for completing a personal directive, where 68.3% indicated they had thought about completing one previously. Generally participants indicated the study had "heightened awareness [about the topic]," "spurred me on [to possibly complete a personal directive]," or "brought [the topic] to the forefront."

Question 3: Is there any difference in knowledge and attitudes between older adults living in the community or in a rehabilitation hospital or community health centre?

To answer this question, the researcher analyzed the data using chi square to assess whether or not there was any difference between the 60 participants in the two locations. Significant results of the chi square analysis regarding differences between genders have already been discussed.

When chi square statistics were calculated, some of the cells did not contain enough information for statistical analysis. Therefore, it was difficult to know about independence or dependence since the sample size was very small. For instance, when the question relating to when the personal directive was last updated was posed, results showed significance between the locations χ_2 (3, N = 60) = 9.02, p = .02903 (Continuity Correction not reported, Minimum Expected Frequency - 1.0). However, six out of the eight cells had insufficient data for reliable results.

As the definitions of personal directives provided by the participants were not categorized using a measurement scale that reflected their level of knowledge about this subject, it is difficult to assess and, therefore, make conclusions about the actual knowledge level of this study group.

Question 4: Do older adults describe the type of education and/or information that is necessary prior to completing an advance care document?

Fifty-five percent (33) of the participants indicated that they did not require further education regarding personal directives if they decided at some point in time to complete one. Of the other 27 (45%), the most frequent response was an education pamphlet (25%) or a discussion with their doctor (17%) (Table 21). Those participants who chose 'other' method of education said they would like to have a sample personal directive to review and information about the law once it is passed.

Table 21 Education before Completing Personal Directive

		Frequency	Percent	Cumulative Frequency
Further Education Before Completing PD				
	Yes	27	45	45
	No	33	55	100
Type of Education: *				
a) Pamphlet				
	Yes	15	25	
	No	12	20	
b) Doctor				
	Yes	17	28.3	
	No	10	16.7	
c) Lawyer				
	Yes	5	8.3	
	No	22	36.7	
d) Public Forum				
	Yes	11	18.3	
	No	16	26.7	
e) Other				
	Yes	5	8.3	
	No	22	36.7	

* Note: The participants were able to choose more than one preferred method of education.

When the questions related to further education were analyzed using chi square there was no difference between men and women or the community and hospital group in the need for or type of further education (p>.05).

Factor Analysis

As mentioned in Chapter 3, factor analysis was undertaken to reduce the data so it may be interpreted and described (Munro & Page, 1993). For this study, the researcher completed a factor analysis of 19 items in the questionnaire to identify if there were any groupings of variables for the purposes of description and interpretation.

The first result was the unrotated factor analysis. In this analysis the number of factors accounting for at least 5% of variance or where the eigenvalue is 1 or greater were identified and interpreted (Munro & Page, 1993). These results indicated that only a small proportion of variance was encompassed in the correlation matrix by the first factor (Table 22). The first eigenvalue was 3.104 with a 16.3% variance. Thus, factor 1 was measuring 16% of the variances. Factor 2 was 2.25 and accounted for approximately 12% of the variance. As noted in Table 22, the first seven factors accounted for 65.6% of the variance. Although nine factors are probably more than desirable, this is a reasonable result for the first time this questionnaire has been tested. It nonetheless requires further testing and refinement.

Table 22 Eigenvalues

FACTOR	EIGENVALUE	PERCENT OF VARIANCE	CUMULATIVE PERCENT
1	3.10461	16.3	16.3
2	2.25543	11.9	28.2
3	1.72162	9.1	37.3
4	1.56478	8.2	45.5
5	1.39238	7.3	52.8
6	1.26712	6.7	59.5
7	1.15934	6.1	65.6
8	1.08136	5.7	71.3
9	1.02813	5.4	76.7

Note: Values less than one were not computed.

As unrotated factors can rarely "be meaningfully interpreted," the researcher "rotates" the factor matrix to interpret the results (Munro & Page, 1993 p. 257). Table 23 (Appendix N) demonstrates a rotated factor matrix of the 19 questions related to the topic that is being studied. When the rotated factor analysis is considered, it is listed by the strength of the loading. A "cutoff" point for this study will be .35 which according to Munro and Page (1993) is acceptable. The next step is to interpret the results to identify which variables go with which factor and then name the factor. When factor analysis results are interpreted, it is a process of identifying which "variables go with a factor and then naming the factor based on whatever meanings these variables with high loadings have in common" (Munro & Page, 1993 p. 257).

In naming the factors, the researcher emphasized the variables with the highest loadings. Factor 1 had loadings of 0.77, 0.7 and 0.67 in relation to the question about notifying others of their decisions, hence the naming of this factor. The four factors were named as these accounted for the greatest percentage of variance explained. If the questionnaire was to be used in another study, the questions should be refined and adapted to reflect the results of this factor analysis and then retested.

Content Analysis

The last five questions of 10 interviews, five from the community and five from the hospital group, were transcribed verbatim in order to see if there were any common themes emerging from these open-ended questions. The tapes transcribed were from interviews with three female participants in the community who classified their perception of their health as "very good" and two males that stated they were in "excellent" health. The women in the institutional setting classified their health as "fair" (2) or "poor" (1), and the two men indicated they were in "fair" health. Four of the participants in the community were independent in activities of daily living, both instrumental and functional, with one requiring assistance with light housework every two weeks. The participants in the hospital settings ranged from requiring no assistance prior to hospitalization (1), to cleaning every two weeks or assistance with yard work (3), to one having a home care nurse "check" on her twice a year. Participants chosen were articulate and elaborated in detail on the five open-ended questions. Three of the participants were educated at the Grade 8 - 11 level, four at the Grade 12 - 13 level and three had obtained further education at the post secondary/university level. Other participants indicated they had nothing further to add other than what had already been discussed during the interviews. As a result, their comments in this section were very brief and, therefore, their tapes were not chosen for transcription.

This section will be organized according to the question that was asked in the qualitative section of the interview. The comments from the 10 tapes transcribed verbatim will be outlined first, with general comments regarding the other interview tapes following. All of the interviews were reviewed by the researcher to gain additional comments and insight relating to the last five questions.

Question 1: Describe your thoughts about being involved in decisions about your health care.

Ninety (90%) of the participants followed a common theme of wanting to be involved saying such things as "it is my body," or "I should have complete and ultimate authority [over my body], I should decide [and] physicians should pay great regard." One participant indicated it was important that a spouse was also involved.

The theme of wanting to be involved in the decision-making was reflected in the majority of the other 50 interviews. Comments such as: "It's my body, [it is] important and [I] want to be involved [in making decisions]," "things [should be] done my way [and I] definitely want to be informed," [I would also be] governed by recommendations of [my] doctor," "medical practitioners need to be involved [as] they know medicine." Four participants made direct reference to involvement of the family, "[my] children can [make decisions] better [than I can]," and "my daughter would be involved with me," or "[I] trust my family."

Three participants made comments about the current health care system "[H]ard the way medicare is now [I] would like to know type of care available for older people in future" or "seniors may not have much say with this government [about choices] for health care."

It is evident the majority of participants would want to be involved, with or without their families, in decisions about their health care. This adds to the quantitative data previously gathered at the beginning of the interview where 98.3% of the participants responded positively to the question about being involved in decision-making about health care.

Question 2: Describe how you view your family's/doctor's involvement in making choices about the type of health care your receive.

Seven out of the 10 transcribed interviews (70%) indicated it "is important for [family] to be involved [and I think they] would make the right choices." Three mentioned that besides trusting their family members, doctors should be consulted for their "expert advice." One person mentioned a doctor "wouldn't assume responsibility [about making decisions on behalf of a patient] unless protected [by law]."

In the other interviews, the themes followed the above statements. Participants indicated that both family member(s) and doctors should be involved, but their wishes or their personal directive should "guide them." "It will be in the children's hands and I trust them to make the decisions [and] do the best for me," or "[my] family will discuss [situation] with the doctor then make the decision [based] on knowing me."

In both the quantitative and qualitative portions of the interview, the majority of participants in this study indicated they would want their families involved and trust their decisions relating to health care once they become incapacitated. In addition, a number of participants felt comfortable with the choices their physicians might make for them in conjunction with their families.

Question 3: Describe what you feel are the reasons why you would complete an advance directive or living will.

Five participants out of the 10 (50%) made reference to decreasing the stress level of family members as "they would know ahead of time [and there would be] no guilt for [my] family if [it is decided] to unplug the machine, as a decision [has already been] made by me, [family would] just follow through with my wishes." Three statements indicated that it was "not enough to verbally tell people [a person needs] to put in writing, to make certain my life is not prolonged unnecessarily." One participant said the personal directive "grants me another privilege in life."

Two mentioned they would only complete a personal directive once it became protected by law.

When the other interviews were analyzed the most common theme was that others knew their wishes and would follow them. Comments such as "important [to] let others know how we feel [that we] don't want machinery when [there is] no hope or I would be a vegetable; if it's my time [just] let me go, [I] don't want to be a burden." A second theme emerged relating to reducing the stress and/or guilt for their spouses and families. Comments such as "So [my] family aren't stressed or traumatized especially if [they] don't understand, death is bad enough" or "To relieve stress on [my] spouse or children in making the decision [about what will happen to me, I] don't want them to feel guilty [afterwards]."

One participant emphasized the need for a personal directive as it related to conflict in the current family situation. Two other participants indicated they would complete a personal directive because of their age (75 years and over). During discussions, some participants related experiences they or other family members had with a loved one who had died.

In one situation, the older adult related an experience with a positive outcome regarding advance planning. The older adult's son was dying of cancer at a young age. As he had discussed and outlined his wishes in writing in advance, there was "less stress during the final days as [the family] knew what to do." As a result the older adult indicated a positive attitude about personal directives.

In the other situation the outcome was more traumatic for the individual involved. The older adult related that both of her parents were admitted to hospital within three weeks of each other and both were dying. No one in the family knew what the parents' wishes would be in the specific situations and neither parent was able to be involved in the decision-making process. The older adult remembers how stressful that time was and the feelings of not knowing if what was chosen on the parents' behalf would have been what they would have wanted. Due to these experiences the participant would not want family members to experience a similar situation so the participant would complete a personal directive.

The most common theme in the interviews was that these participants wanted others to know their wishes so their life would not be prolonged and to relieve their families of any stress and/or guilt at that time. It should be noted though that these comments did not necessarily reflect participants' commitment to actually completing a personal directive. If there was conflict in the family, participants indicated they would complete a personal directive to ensure their wishes would be followed.

Question 4: Describe what you feel are the reasons why you would not complete an advance directive or living will.

In the transcribed tapes, five out of the 10 (50%) participants made reference to "[there is] no reason" or "[I] can't think of any reason not to complete" a personal directive in the interview. The comments included that everyone should have a personal directive and that individuals should consider quality of life and financial cost of various types of care to the family and to society. Others mentioned that perhaps personal directives were not completed because people were generally unaware of them or that "you may change your mind later [and are] afraid to complete [one now]." Two respondents mentioned that, because there was "no Act" to ensure the protection of "myself, my family, doctors or health care facility, I may be in" a personal directive would not be completed.

In total, 31 of the 50 participants (62%) - 21 in the community and 10 in the hospital sample - made direct statements that there is "no reason" not to complete a personal directive and that it was a "good idea." The next most common theme was that the family would speak for them. Comments such as "It is just not necessary [my] family will speak for me" or "My family is my living will." A concern about euthanasia was mentioned in one interview where the participant said a personal directive would not be completed so management and other personal care could be received. Another participant mentioned that, if in a lot pain, relief would be wanted and that perhaps that would not be provided if there was a personal directive. It was commented that perhaps if "you were a young person" a personal directive would not be completed. Again, one person mentioned that as there was no Act in place, this was a reason not to complete.

The majority of the participants in this study expressed support for a personal directive document in principle and they could not, at that moment, identify a reason not to complete one. Others indicated there was no need for the document because of a supportive family situation.

Question 5: Outline the type of assistance or information that would be most helpful to you if you decided to fill out an advance directive or a living will.

Two common themes emerged, one was related to reading material or workshops (four participants out of the 10 or 40%) and the other to discussing the topic with their doctor and their families (40%). Two mentioned understanding the laws so they could know "what the doctor could do" and if the documents "could stand up in court." One participant also mentioned it would be helpful to discuss issues/treatments with the medical profession and ask doctors what type of care they would accept. This question would be asked to achieve an understanding of what treatment or procedures doctors would accept for themselves. This participant felt with this knowledge, a truly informed decision could be made about the acceptance or refusal of specific procedures.

Not all the participants answered the last question as nine out of the 60 participants had already completed a personal directive so did not feel a need to respond. Those participants answering the question indicated that information to read, workshops, discussions with family, doctor and/or nurses would be beneficial along with obtaining the forms to review. Three people said knowing about the laws in Alberta and what the doctor could or could not do would be beneficial. Having guidelines available to follow would also be helpful. Only one person mentioned it would be "helpful to have Dr. Kevorkian on the panel."

There was no clear direction for education or assistance in the comment section of this study (Table 21). Areas that were raised included having some type of print media available to them to read, review and follow to ensure, that if completing a personal directive, it was completed accurately. Interestingly, four participants responding to this question identified the issue of discussing the topic with families and doctors, but this was not necessarily reflected in the quantitative section of the interviews.

Summary

In this chapter the results of the statistical analysis from the interviews of 60 participants were discussed. The participants who took part in this study were already knowledgeable and had an opinion about personal directives and wanted to be involved in making decisions about their health care. This knowledge and opinions were reflected in both the quantitative and qualitative results. Frequencies were calculated for demographic and quantitative sections of the questionnaire. Statistical analysis including chi square was completed to establish if there were any differences between genders or locations of the interview. Finally, a content analysis of the last five questions of the questionnaire was undertaken through the verbatim transcription of 10 interviews. A frequency analysis was also included in the discussion. For a more in-depth analysis, all 60 participants' comments were reviewed for common statements and themes.

CHAPTER 5: DISCUSSION

In this chapter, the results of this exploratory/descriptive study investigating the knowledge and opinions of 60 older adults about personal directives are discussed. The chapter is organized by sample characteristics and results focusing on areas of interest from the analysis. The chapter concludes with the identification of major themes found in the content analysis from the interview tapes from this group of older adults.

Significant Sample Characteristics

The average participant in this study was 74 years of age with the majority classified in the 'young old' category (55%) and cognitively intact. More women took part in the study than men. The majority of the participants were either married or widowed, each group accounting for 45% of the sample. More men than women were married. Participants were more likely to be living in their own home. A slight majority (38%) of the participants had between Grade 8 - 11 education, with 35% having some form of post secondary or university education which included masters and doctoral degrees. Therefore, the participants in this study were considered to be well educated.

Sixty-six percent of the participants perceived their health status as good or better. The majority in the hospital sample perceived their health good to fair and that it had changed for the worse during the last year. There was a difference in the amount of support or assistance between the two groups. The hospital group required more homemaking and home care assistance than those in the community.

Awareness of Personal Directives and Completion

As mentioned in Chapter 4, the participants in this study were selected because they had some awareness of what personal directives were and an opinion about the type of health care they might want in the future. When participants were asked to describe a personal directive in their own words, definitions varied in completeness and depth. The most common definition provided by study participants was a written expression of their wishes that could be utilized when they could no longer speak for themselves. Most participants focused on refusal of treatment, not wanting to be left as a "vegetable," quality of life and dying with dignity issues. The researcher noted that no participant specifically stated that a personal directive should specify acceptance of specific treatment modalities. Further, comments focused on the refusal of treatment.

Studies investigating the knowledge and awareness of older adults suggest many elders do not understand the "language used in the living will" such as "extraordinary means" and "terminal and incurable" (Gamble et al, p. 278). Sam and Singer (1993) found similar results in their study with the general public, "patients' knowledge about life-sustaining treatments and personal directives is limited" (p. 1500). This research team also suggested that patients with higher levels of education demonstrated more knowledge about personal directives and were more likely to document their health care choices in writing. This finding is similar to Stelter et al (1992) whose research results indicate that even though older adults agreed with the concept of personal directives, few had completed one. Those who had completed one were generally more highly educated and did not consider the form too long. These results were not found in this study. There was no relationship to participant age or educational level between those who had already completed a personal directive and those who said they were going to complete one.

The majority of participants (75%) indicated that personal directives should be completed prior to becoming seriously ill. Though not all the participants thought it was necessary for them personally to complete a personal directive, they stated it was a "good idea." The preferred option was that a personal directive should be completed prior to hospitalization and interestingly, only a minority indicated that if one had not been completed, then one could be completed at that point. More than half of the participants stated that making age a criterion for completion of personal directives was not feasible. Comments reflected that age had no bearing on when the document should be completed as something could happen at any time and "one never knows." Of those choosing age as a criterion, there was no clear age though the most common age cited was 60 or 65 years.

Research on patients' awareness and attitudes about personal directives has suggested that overall, older adults and the general public are positive about the principle of personal directives in theory (Sam & Singer, 1993; Emanuel et al, 1991; Gamble et al, 1991; Stelter et al, 1992). This research suggests similar findings. The older adults in this study indicated that documenting their wishes in writing may be beneficial to prevent future misunderstandings. Note that agreement in principle with personal directives did not necessarily translate into the completion of one. Additionally, a key component of this documentation is the knowledge about personal directives and the discussion with families and physicians to clarify issues or to avoid either myths or misunderstandings about the medical jargon and treatments available to them. In the next section, older adults' opinions about involvement in decision-making is discussed.

Involvement in Decision-Making

The results from this study indicate that an overwhelming majority (98.3%) of older adults want to be involved in the decision-making process regarding their health care. The degree or level of involvement varied with participants. The most common comment was that they wanted to be informed about their health care and their options in medical treatments. Only one participant stated that any communication about health care would occur through the personal directive.

Sachs et al (1992), Stelter et al (1992) and Gamble et al (1991) found that older adults do want to be involved in decisions about health care and planning for their possible incapacity. Emanuel et al (1991) found that both outpatients and the general public expressed an interest in having a personal directive regardless of age or current state of health. These studies supported the findings in this exploratory/descriptive study. Results suggested people did want to be informed and involved regarding their health care and, if possible, involved in making choices about the type(s) of treatments they may or may not receive. As one participant stated "it is my body."

Substitute Decision-Making

The majority (98.3%) of older adults in the study stated that they would want someone else involved in making decisions on their behalf when they were no longer able to make decisions for themselves. The most frequent choice of substitute decision-maker was children, especially for female participants as the majority were widowed. The men in the study tended to choose their spouse first and their children second. It is clear, though, that family members were chosen more often to speak for older adults then other people. Health care professionals were named in a minority of situations and of these, the majority named their physicians as substitute decision-makers. If participants chose their doctors, they stated it would be their family doctors, not just "any doctor."

Studies completed by High (1988, 1989, 1990) and High & Turner (1987) suggested that older adults want their family members to be their substitute decision-makers. If older adults did not have family members available, they then wanted either a close friend or physician to make the decisions on their behalf.

Despite choosing their family members to be their substitute decision-maker in the event of their incapacity, only 45% indicated they had discussed their wishes with them and 13.3% had a partial discussion. Comments from participants indicated that some of these discussions were very general and did not go into depth about their beliefs or wishes on their health and lives. Even though less than half of the participants had discussed this topic with family, all 60 participants believed their wishes would be followed by their family members.

This finding is consistent with the beliefs of patients in the literature. Secler et al (1991) found that patients anticipated that family members could speak for them, even though it was found that family members were unable to accurately reflect the patients' wishes. The same problem existed in that only a few patients had actually communicated their preferences or their beliefs with the people they wanted to be their substitute decision-makers. However, when patients reported having communicated their wishes with their substitute decision-makers, the accuracy of choices between the two groups improved (Libbus & Russell, 1995).

Ninety percent of the participants in this study indicated they had not discussed their wishes with their physicians and of those, 31.7% indicated they had no plans to enter into a discussion with them. The most frequent responses were that they were not ready or did not feel it was necessary. Despite not having discussed their wishes with their physicians, 71.7% indicated they felt their physicians would follow their wishes.

Research on physicians' abilities to predict patients' preferences has found they are unable to do so accurately (Secler et al, 1991; Zweibel & Cassel, 1989; Uhlmann et al, 1988). Therefore, according to research completed to date, participants in this study may be misguided in asking their physicians to represent their wishes when they have not discussed their options with their physicians. Upon reflection, another question relating to who should initiate the discussion about personal directives, seemed to be one that could have been usefully included in the questionnaire. This may have shed some light on another reason for participants not discussing their health care wishes with their physicians.

Reasons for Completing an Personal Directive

The participants in this study stated that one reason they would complete personal directives was to reduce the level of stress for family members. The thought was that if the discussions could occur ahead of time, there would be les or no guilt when it came to make decisions on behalf of the older adult. The other common theme that emerged in this category was the idea of informing others of their wishes. Expressions included "letting others know" and "put in writing [my wishes] so [my] life is not prolonged unnecessarily."

Research studies, to date, have focused more on barriers to the completion of personal directive documents. In the Emanuel et al (1991) study, researchers found that, generally, there was an interest in completing a personal directive document, but this study did not cite reasons for actually completing one. Similar results were found in studies conducted by Sam and Singer (1993). Stelter et al (1992) and Sachs et al (1992) demonstrated that participants wanted to be involved in health care decisions and those with higher levels of education were more likely to document their preferences. Any reference to comments such as reducing the stress or guilt of family members was generally found in theoretical rather than empirical literature about personal directives.

Reasons for Not Completing a Personal Directive

During the interviews participants mentioned it would be a good idea to complete a personal directive. It became apparent that the majority of participants felt that there was 'no reason' not to complete a personal directive, except if individuals were unaware that these documents existed. Barriers to completing a personal directive were addressed by some participants. The most common theme was that it was not necessary to have a personal directive because of a supportive family situation. As one participant put it, "My family is my living will." This was consistent with the findings of High (1988), that older adults wanted "to keep it all in the family" and that they trusted their children to know what to do (p. 50).

Other participants stated during the interviews that they had "intended" to complete a personal directive for some time but had not yet done so. This comment may indicate that the individual is procrastinating, a reason found by Stelter et al

(1992) for lack of completion of personal directives, though it may also relate to findings suggested by High (1993). In High's study the suggestion was that perhaps older adults were avoiding or refusing to become involved in personal directive discussions because they trusted their children.

Educational Needs

There was no clear indication of the type of assistance that participants would want if and when they decided to complete personal directives. Of those choosing to respond to this question, the most frequent choices were that having print information available to read and that a discussion with their family doctor would be most helpful to them. All of the participants (58) who accepted the resource material were positive about receiving it and many felt this would be sufficient information. Some of the participants indicated they were interested in reading the draft legislation and eventually the new bill to be knowledgeable about the law in Alberta.

High (1993) suggested lack of information might not be a significant barrier to completing a personal directive, rather that older adults' trusted their families to make the decisions. Given the results of this question, the researcher wondered whether it might be best to promote awareness of individuals' abilities to make health care decisions as a first step and with this, their awareness and need for further information may increase.

Questionnaire

Both the internal reliability results and the factor analysis indicate the questionnaire requires modification and refinement. Considering these results, certain questions may either be rephrased or omitted from the questionnaire. In addition, further testing of the questionnaire would be necessary if used in another study.

Summary

This chapter considered the significant findings of this research study. Older adults, in this study, were aware of the intent and purpose of personal directives, though these documents were generally defined in terms of the refusal of medical treatments. It is apparent that this group of older adults, whether living in the community or hospitalized, wanted to be involved in making choices about the health care they received and wanted their wishes respected. It was also evident that the majority of these older adults trusted and wanted their families involved in discussions about their health care and to be their substitute decision-makers.

Although participants indicated support for these documents in principle, whether or not they would actually complete them was uncertain. There did not appear to be a pattern established in relation to age, level of education and the completion of personal directive documents. For a minority of participants, comments indicated that there was need for a law which had not been passed at the time of this study, to protect their rights before completing a personal directive.

A reason to complete a personal directive cited in this study was to reduce the stress and guilt of family members. Older adults in this study emphasized the importance of their wishes being respected if they actually completed a personal directive. A majority of participants indicated there was no reason for not completing a personal directive and that it was a good idea. A few participants stated there was no need to document their wishes because of the trust they had in their families. Older adults' statements regarding further education indicated that the preferred method of education was in the form of a pamphlet or through a discussion with their family physicians. If this study is replicated, modification and refinement of the questionnaire would have to be undertaken.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

This chapter focuses on the major conclusions from this exploratory/descriptive study. In addition, recommendations for health care professionals and areas of further research will be addressed.

Conclusions

Awareness of Personal Directives and Completion of the Document

Participants in this study did have a basic awareness of what personal directives were as evidenced by their definitions. It is important to note that none of the participants verbalized awareness that these documents could indicate acceptance of specific procedures or treatments. Participants also indicated that it was preferable to complete personal directives prior to becoming seriously ill and that age should not be used as a criterion for the completion of personal directives. Generally, participants in this study were positive about the documents, though this did not necessarily mean they thought it was necessary to complete personal directives.

Involvement in Decision-Making and Substitute Decision-Makers

Participants in this study wanted to be involved, to varying degrees, in decisions relating to their health care. Only one participant responded negatively to this question and felt all communication would occur through the personal directive. This comment could still be interpreted as involvement as an individual's wishes would be documented to guide others. Comments from participants suggest they want their health care wishes respected and, if possible, followed by their family members and health care professionals.

The majority of older adults in this study wanted family members involved in making decisions on their behalf in the event they were unable to provide them. If a health care professional was to be involved or consulted, the most frequent choice was the family physician. Despite the reliance on family and possibly physicians to speak for them, the majority had not discussed their wishes fully, or not at all, with the individuals chosen to make the decisions for them.

Reasons for Completion and Against Completion of Personal Directives

Reasons cited for completion of the document were to reduce the stress and guilt of family members, to ensure that their wishes would be respected and to provide direction if there was conflict in the family situation. Reasons cited for non completion of a personal directive were: did not want to give too much control to health care professionals; want to ensure they received pain relief if experiencing pain and individuals thought they were too young to complete personal directives. Age or educational level did not appear to be a factor in the completion or possible completion of personal directives.

The majority of the reasons cited by these study participants for completion or non-completion of personal directives have already been documented in the theoretical and empirical literature. This researcher concluded that barriers to completion of personal directives may be very complex and multi-faceted.

Education

The results of this study reflected and confirmed results of previous studies. Findings suggest that some older adults needed further information about the intent and the purpose of these documents, that the language used in these documents required clarification and that communication with significant others and health care professionals required further encouragement.

Recommendations

Education

Further education for older adults about personal directives would be beneficial. This education could reinforce or emphasize the desirability of communicating beliefs and values with family members and health care professionals in personal of a crisis situation. A program could be provided on an ongoing basis through organizations such as seniors centres to reinforce the intent behind these documents and the importance of communicating health care wishes in advance. Education may be provided through seminars, print or audiovisual means. A standardized educational package could be developed so a consistent message is being portrayed to older adults about this topic. In addition, health care professionals could discuss with seniors and family members the process of decision-making in the clinical area. This information may assist seniors and family members in understanding how decisions are made and the circumstances surrounding the decision. Any misunderstandings about what may happen in the clinical situation, when a personal directive is available, may be alleviated.

In conjunction with an educational process about the concept and the intent of personal directives, it would be equally important to include education about the new Personal Directives Act. The familiarization of older adults to the requirements specified in this Act would be beneficial so they are informed and able to complete their personal directives in accordance with the conditions (i.e., ensuring the appropriate individual(s) witness the personal directive). In addition, information could be added to a telephone information line already available in the Edmonton area for seniors and the general public.

Education for family members, health care professionals and religious leaders would be advantageous as they will probably remain involved in either assisting or making the decisions for older adults whether they are aware of these wishes or not. Therefore, it would be beneficial if family members had prior knowledge of their potential roles and responsibilities when speaking on behalf of the older adult. Educational sessions for family members could take the form of formalized presentations for care givers of older adults, or more informally through print information in physicians' and lawyers' offices, public health units, community health centres, acute care hospitals, religious organizations and public libraries. In addition, information that may be accessed through the print or visual mediums may be beneficial in informing the general public about personal directives.

It should be emphasized with family members and health care professionals that this topic does not appear to be distressing and many older adults may even welcome the discussion. With further education and communication, myths and misunderstandings about disease processes and chronic conditions may be alleviated for both older adults and the public in general. In addition, any stress or guilt felt by family members may be lessened if this topic were to be discussed openly.

It would be beneficial if health care professionals familiarize themselves and become knowledgeable about the purpose and intent of these documents. This familiarization would allow health care professionals to discuss the topic in a knowledgeable and factual manner, no matter the age group or the practice setting. Ultimately, this may enhance the relationship between patient and health care professional. Education sessions for health care professionals could involve formal and informal methods, such as lecture series within the facility the health care professional practices. Information could also be disseminated in newsletters or through pamphlets available throughout the facility (i.e., in cafeteria). Information about the new Act and how practice may be impacted would be a necessary component of any educational session for health care professionals.

Although the provision of information was seen as important, it would also be beneficial if sample personal directives and guidelines were provided for interested parties to review. This would allow individuals to examine the documents and decide which one might ‘fit’ with their belief and value systems. It could also assist in avoiding the vague or ambiguous statements that have plagued personal directives since their inception.

Future Research

If a similar study was undertaken in the future an additional question should be added regarding the most appropriate person to initiate the discussion regarding personal directives and perhaps the setting in which this discussion should occur. Questions may be answered about what setting, such as physicians’ offices, the home environment or inpatient settings, would be the most appropriate place to introduce the topic. Studies with health care professionals regarding barriers to introducing this topic with older adults would be advantageous. It would be beneficial if there were guidelines regarding the review or updating of a personal directive form. If a procedure was recommended, this would ensure that the most recent wishes of the individual would be documented and potentially implemented.

Though this study focused on older adults, further studies with different age groups may aid health care professionals in introducing and discussing this topic with a variety of people. It would be beneficial to understand if there is a difference in how other age groups view these documents and what they may cite as reasons to complete or not to complete personal directives. Research studies could be undertaken regarding the introduction of the topic of personal directives with a variety of age groups. This may increase the awareness and the discussions between family members as these documents are applicable to anyone and not just older adults.

Summary

In this chapter the major conclusions of this study were outlined. These conclusions centered on the need for clarification of the purpose of personal directives expressed by participants who understood that the document is not just for refusal of medical treatment. Older adults also indicated their desire to be involved in making decisions regarding their health care and their choice of family as their substitute decision-makers. Older adults had not discussed their beliefs and values about health and their lives fully, yet were confident that their family and their physicians could make the decisions on their behalf. There was no relationship in this study between age and level of education, regarding the current or future completion of a personal directive.

Educational strategies were outlined for older adults, family members and health care professionals that stressed the importance of communicating in advance of any crisis situation. Areas for further research were suggested which included the most appropriate health care professional to introduce the topic and the setting in which it should be introduced. The potential benefit of either further education or research into these areas would be to assist health care professionals and to promote and enhance older adults' decision-making ability and, therefore, autonomy.

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APPENDICES

APPENDIX A

CONSENT FORM TO BE COMPLETED BY THE STUDY PARTICIPANTS

PROJECT TITLE: RESEARCH STUDY OF THE KNOWLEDGE AND ATTITUDES OF OLDER ADULTS REGARDING ADVANCE DIRECTIVES

RESEARCHER: PEGGY J. SAWCHUK, R.N., BScN.
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TELEPHONE:

FACULTY SUPERVISOR: DR. JANET ROSS KERR
FACULTY OF NURSING, UNIVERSITY OF ALBERTA
TELEPHONE:

PURPOSE:
The purpose of this study is to explore and describe the knowledge and attitudes of older adults (65 years or over) about Advance Directives/Living Wills. The questions in the interview will be about the ability of the individual to provide direction on the type of health care desired in the event of a serious illness. Some brief questions about your thinking will also be asked.

PROCEDURE:
- The researcher will interview you once.
- The interview will take place in private. At the Seniors Club, in your own home or in a private room on the unit.
- The interview will last one hour.
- The interview will be tape-recorded.
- The total time for this study will be less than two hours.
- If necessary, phone contact may occur after the interview to check some of the information.

PARTICIPANT:
- You may refuse to answer any of the questions during the interview.
- You may stop the interview at any point.
- You may decide to drop out of the study at any time by telling the researcher.

- You may not benefit directly from this study. By being in this study you may assist other nurses in discussing this topic with other seniors in the future.
- You may find this topic upsets you. If you do, the researcher will provide you with names of people who may talk with you about your feelings.

Your name will not be identified on any written material. You will be given a study number. Only this number will appear on any written material. Your name will be erased from the interview tapes. The thesis committee will read the summary of the comments from the interviews. Consent forms will be stored separately and will be destroyed after five years. All the tapes will be kept in a locked cabinet. The tapes will be kept a minimum of seven years after the study is completed. The interview notes will remain in a locked file. The tapes may be used for another study in the future. This will only occur once the researcher has received the approval from the appropriate ethical review committee.

The information and findings of this study may be published or presented at conferences. Your name or any information that may identify you will not be used. If you have any questions or concerns about this study now, or at any time, you can call the researcher at the __________.

CONSENT:
I have read the preceding information sheet. The research study has been explained to me. All questions have been answered to my satisfaction. If I have further questions I may contact the person named below. I understand that I may withdraw from this study at any time without any consequences. I understand that I may not benefit from being in this study. The possible risks of this study have been explained to me. I have been assured that records relating to this study will be kept confidential. I have been given a copy of this form to keep. I agree to participate in this study.

______________________________	______________________________
Signature of Participant	Name of Participant (please print)

____
Signature of Researcher

____
Name of Researcher
(please print)

____
Date

Please indicate if you wish to receive a summary of the final report:
Name: ____

APPENDIX B

INFORMATION SHEET

Project Title: Knowledge and Attitudes of Older Adults regarding Advance Directives.

Researcher: Peggy J. Sawchuk, R.N., BScN. Phone:

I will be doing a research study about older adults' (65 years or over) knowledge and attitudes about Advance Directives/Living Wills. This is to find out if older adults feel it is necessary to give health care directions before a serious illness. If there are procedures that older adults want or do not want a living will tells others about their wishes. Some brief questions about your thinking will also be asked.

At present there is no Advance Directive/Living Will law in Alberta but it is currently being discussed. However, the basic principles of these documents have been upheld in Canadian courts of law.

Your time in this study will consist of being interviewed once. The interview will be tape recorded and will last about one hour. The interview will take place at the Senior Citizen's Club, your home or in a private room on the unit. If necessary, I may contact you by phone after the interview is done.

Your name will never be identified on any written material. You will be assigned a study number. Only the thesis committee members and I will read the comments from the interview. All information will be kept in a locked cupboard. Consents will be destroyed after five years. The tapes will be kept a minimum of seven years after the study is completed. The interview notes will remain in a locked file and may be used for another study in the future. If this occurs, I will receive approval from the appropriate ethical review committee.

The findings from this study may be published or presented at conferences. Your name or any other identification will not be used. If you have questions or concerns at any time, you can call me at __________.

You may refuse to answer any question or to have information included in the study. Your participation is voluntary and you may withdraw at anytime from the study without consequences. If you wish to withdraw just let me know. If you have any concerns because of talking about this topic, I will talk with you about possible people to talk with. You will not benefit directly from the study, but may assist other nurses in talking with older adults about this topic.

Thank you.

If you <u>do not</u> wish to be involved in this research project, please:
1) contact the researcher at ________,
2) fill out the section below. You may leave this with the Executive Director or with a staff member,
3) tell your nurse.

If I <u>do not</u> hear from you I will contact you for your decision about being in the study:
1) within one week if you are currently living in the community,
2) the next day if you are currently receiving treatment in the rehabilitation hospital.

Your participation is voluntary and you may withdraw at any time from the study.

I <u>do not</u> wish to be involved in this study:

Name: ___________________________________

APPENDIX C

Letter of Introduction to Seniors
St. Albert Senior Citizen's Club

Project Title: Knowledge and Attitudes of Older Adults regarding Advance Directives.

Researcher:	Supervisor:
Peggy J. Sawchuk	Dr. Janet Ross Kerr
M.N. Candidate	Faculty of Nursing
University of Alberta	University of Alberta

Dear ____________________

My name is Peggy Sawchuk, and I am a nurse completing a Masters of Nursing program at the University of Alberta. I am proposing to conduct a research study entitled: "Knowledge and Attitudes of Older Adults regarding Advance Directives." I obtained your name from the list at the St. Albert Seniors Citizen's Club after receiving permission from the Board of Directors.

The purpose of this study is to explore and describe the knowledge and attitudes of older adults (65 years or over) about Advance Directives/Living Wills. The questions asked will be about an older adult providing health care direction before a serious illness.

The study will involve one interview of approximately one hour. The interview will be done at the Senior Citizen's Club in a private room, or if more convenient, in your home. The study will take place from April to May 1995. If additional information is required I may telephone you.

I hope that the information obtained in this study will assist nurses in discussing this topic with older adults. This will increase our level of understanding of what older adults believe and prefer when completing an advance directive or a living will.

If you have an opinion about advance directives/living wills, or the type of health care you would want if you could no longer speak for yourself, please consider being involved in this study. Further information about the study is on the sheet with this letter. If you have any questions or concerns regarding this study I would be pleased to answer them. I may be contacted at __________.

If you decide you do not want to take part in this study you may telephone me directly or leave the bottom portion of the sheet with the Executive Director, Mrs. Reita Grylls. I will telephone you in one week if I do not hear from you.

Thank you for your time.

Sincerely yours,

Peggy J. Sawchuk, R.N. BScN.
M.N. Candidate
Faculty of Nursing
University of Alberta

APPENDIX D

Letter of Introduction to Executive Director
St. Albert Senior Citizen's Club

Project Title: Knowledge and Attitudes of Older Adults regarding Advance Directives.

Researcher:	Supervisor:
Peggy J. Sawchuk	Dr. Janet Ross Kerr
M.N. Candidate	Faculty of Nursing
University of Alberta	University of Alberta

Dear ____________________

My name is Peggy Sawchuk, and I am a M.N. Candidate at the University of Alberta. I am proposing to conduct a research study entitled: "Knowledge and Attitudes of Older Adults regarding Advance Directives."

The study will involve one interview of approximately one hour. The interview will be completed at the Senior Citizen's Club in a private room, or if more convenient, in the participant's home. The study will take place from April to May 1995. If additional contact is required to clarify a comment, this will be completed by telephone.

I would appreciate a list of seniors that frequent the club to obtain names of prospective participants. A mail out and follow up telephone call to seniors will occur in March to inform them of the study and to solicit volunteers. A mail out may lessen any pressure the senior may feel to participate. The participants should meet the following criteria: 65 years or over, mentally and physically stable and able to converse in English.

It would be helpful if a sealed box would be placed in a secure place, possibly your office. This will be for the seniors to indicate they do not want to be involved in the study. The senior may also approach yourself or another staff member to indicate his or her refusal.

In the unlikely event that while discussing this topic the senior becomes upset, I will provide names of professionals the seniors may contact for counseling or support.

I hope that the information obtained in this study will assist other health care workers in discussing this topic with older adults. This will increase our level of understanding of what older adults believe and prefer in respect to completing an advance directive or living will.

If you have any questions or concerns regarding this study I would be pleased to answer them. I may be contacted at __________.

Thank you.

Sincerely yours,

Peggy J. Sawchuk, R.N. BScN.
M.N. Candidate
Faculty of Nursing
University of Alberta

APPENDIX E

Letter of Introduction to the Nurse Managers

Project Title: Knowledge and Attitudes of Older Adults regarding Advance Directives.

Researcher:	Supervisor:
Peggy J. Sawchuk	Dr. Janet Ross Kerr
M.N. Candidate	Faculty of Nursing
University of Alberta	University of Alberta

Dear ____________________

My name is Peggy Sawchuk, and I am a M.N. Candidate at the University of Alberta. I am proposing to conduct a research study entitled: "Knowledge and Attitudes of Older Adults regarding Advance Directives."

The study will involve one interview of approximately one hour in length. The interview will be done in the patient's private room or in an appropriate area on the unit. The study will take place from April to May 1995. If further participants are required, the interviews will take place in June, 1995.

Participants for the study will be selected on the following criteria:

1. 65 years or over.

2. Cognitively intact.

3. Physically stable.

4. Able to converse in English.

5. Awareness of advance directives or living wills.

It would be very helpful for me if I could approach your nursing staff for assistance in these areas:

1. Assisting the researcher to identify potential participants who meet the above criteria and distribute the letter of introduction and information sheet.

2. Introduce the researcher to the prospective participant.

3. If the patient agrees to participate in the study, but is not in a private room, the nursing staff will identify a quiet room on the unit where the interview could take place.

The researcher will explain the study to the prospective participant. If he/she agrees to take part in the study, the researcher will obtain the consent and leave an information sheet with the patient and a copy for the chart.

It is not expected that the patient will experience any negative effects from taking part in this study. In the unlikely event the patient becomes visibly upset during the interview, the nurse caring for the patient will be notified immediately and will resume responsibility for the patient's care. Psychology, social work and/or pastoral care may be able to assist in these situations.

I hope that the information obtained in this study will assist other health care workers in discussing this topic with older adults. This will increase our level of understanding of what older adults believe and prefer in respect to completing an advance directive or a living will. It may also assist with planning education or policy's related to this topic.

If you have any questions or concerns regarding this study I would be pleased to answer them. I may be contacted at ____________. I would appreciate your sharing this information with your nursing staff so that they are aware that I will be coming to the unit.
Thank you.

Sincerely yours,

Peggy J. Sawchuk, R.N. BScN.
M.N. Candidate
Faculty of Nursing
University of Alberta

APPENDIX F

Letter of Introduction to the Physicians

Project Title: Knowledge and Attitudes of Older Adults regarding Advance Directives.

Researcher:	Supervisor:
Peggy J. Sawchuk	Dr. Janet Ross Kerr
M.N. Candidate	Faculty of Nursing
University of Alberta	University of Alberta

Dear ______________________

My name is Peggy Sawchuk, and I am a M.N. Candidate at the University of Alberta. I am proposing to conduct a research study entitled: "Knowledge and Attitudes of Older Adults regarding Advance Directives."

The study will involve one interview of approximately one hour in length. The interview will be done in the patient's private room or in an appropriate area on the unit. The study will take place from April to May 1995. If further participants are required, the interviews will take place in June, 1995.

If the patient agrees to participant in this study, an information form will be left at the front of his or her chart at the time of the interview. It is not expected that patients will experience any negative effects from participating in this interview, though it may stimulate further questions or discussion about advance directives/living wills and planning for their incapacity. In the unlikely event that while talking about this issue the patient becomes visibly upset, the nurse caring for the patient will be notified immediately, and will resume responsibility for the patient's care.

I hope that the information obtained in this study will assist other health care workers in discussing this topic with older adults. This will increase our level of understanding of what older adults believe and prefer in respect to completing an advance directive or living will. It may also assist with planning education or policy's related to this topic.

If you have any questions or concerns regarding this study I would be pleased to answer them. I may be contacted at ___________.

Thank you.

Sincerely yours,

Peggy J. Sawchuk, R.N. BScN.
M.N. Candidate
Faculty of Nursing
University of Alberta

APPENDIX G

Information Form for Patient's Chart

Project Title: Knowledge and Attitudes of Older Adults regarding Advance Directives.

Researcher:	Supervisor:
Peggy J. Sawchuk	Dr. Janet Ross Kerr
M.N. Candidate	Faculty of Nursing
University of Alberta	University of Alberta

Date: _______________

Today, ____________________________ participated in the above study. Permission from the research committee to approach the patient and informed consent from the patient have been obtained.

The study involved a taped interview of approximately one hour in length, and included questions about the following:

- the patient's knowledge about living wills
- the patient's beliefs about completing a living will
- who the patient would like to have speak for them if they were unable to do so
- the patient's background information such as age, educational level, perception of health
- Mini-Mental State Examination questions, if not already completed at the hospital

The purpose of this study is to investigate the older adults' knowledge and attitudes are about advance directives/living wills and how involved they would like to be in the decision-making process (choosing their substitute decision-maker). It is not expected that patients will experience any negative effects from participating in this interview, though the discussion may stimulate further questions or discussion about advance directives/living wills and planning for incapacity. The nurse caring for the patient is aware of the patient's involvement in this interview, and will be monitoring the patient for any indications of emotional distress.

If you have any questions or concerns regarding this study I would be pleased to answer them. I may be contacted at __________.

Thank you.

Sincerely yours,

Peggy J. Sawchuk, R.N. BScN.
M.N. Candidate
Faculty of Nursing
University of Alberta

APPENDIX H

Letter of Introduction to Community Contacts

Project Title: Knowledge and Attitudes of Older Adults regarding Advance Directives.

Researcher:	Supervisor:
Peggy J. Sawchuk	Dr. Janet Ross Kerr
M.N. Candidate	Faculty of Nursing
University of Alberta	University of Alberta

Dear ____________________

My name is Peggy Sawchuk, and I am a M.N. Candidate at the University of Alberta. I am proposing to conduct a research study entitled: "Knowledge and Attitudes of Older Adults regarding Advance Directives."

The study will involve interviewing senior citizens currently living in the St. Albert area. These interviews will occur from April to May 1995. Further telephone contact may occur during June.

In the unlikely event that while discussing this topic the senior becomes upset, I will provide them with a list of individuals they may contact for further counseling or support.

I hope that the information obtained in this study will assist other health care workers in discussing this topic with older adults. This will increase our level of understanding of what older adults believe and prefer in respect to completing an advance directive or living will.

Thank you for allowing your name to be on the list of potential contacts. If you have any questions or concerns regarding this study I would be pleased to answer them. I may be contacted at ___________.

Thank you.

Sincerely yours,

Peggy J. Sawchuk, R.N. BScN.
M.N. Candidate
Faculty of Nursing
University of Alberta

APPENDIX I

STUDY NO: __________

THESIS QUESTIONNAIRE

Section I of Questionnaire-Demographic Information

1. Male ___ (1) Female ___ (2)

2. Marital Status: Married ___ (1) Widowed ___ (2)

   Separated ___ (3) Divorced ___ (4) Never Married ___ (5)

3. Your age (actual years)

   65-70 ___ 71-75 ___ 76-80 ___ 81-85 ___ 86-90 ___ 91+ ___

4. Living Arrangements:

   House (self/spouse) ___ (1) House (family) ___ (2)

   Apartment ___ (3) Seniors Apartment ___ (4)

   Lodge ___ (5) Long Term Care Setting ____ (6)

   Other ____ (7)

5. Support Arrangements:

   Spouse ____ (1) Family Member ____ (2) Friend ____ (3)

   Homemaking ____ (4) Home Care ____ (5)

   Assistance required:

   ____

6. Education Level:(highest grade or degree completed)

   < Grade 8 ___ (1) Grade 8-11 ___ (2) Grade 12-13 ____ (3)

   Post-secondary/University ___ (4)

7. Occupation: (i) <u>Current</u>: Homemaker ___ (1) Labourer ___ (2)

Technical ___ (3) Professional/Managerial ___ (4)

Other ___________ (5)

(ii) <u>Previous</u>: Homemaker ___ (1) Labourer ___ (2)

Technical ___ (3) Professional/Managerial ___ (4)

Other ___________ (5)

8. How would you describe your current health?

Excellent ___ (1) Very Good ___ (2) Good ___ (3)

Fair ___ (4) Poor ___ (5)

9. Has your health changed in the last year? Yes ___ (1)

No ___ (2)

a) If yes,

Better ____ (1) Worse _____ (2)

Comments

APPENDIX J

Section II of Questionnaire-Interview

The topic we will be discussing today is planning for the type of medical care or treatment you may want in the future (e.g., cardiopulmonary resuscitation, antibiotics). This pre-planning is done in case you are unable to speak for yourself at some point in time. Advance Directives/Living Wills allow people to state ahead of time in writing how they would like to be treated if they become seriously ill and unable to speak for themselves.

As a reminder: You may refuse to answer any of the questions included below and/or may withdraw from the study at any time without consequences. Your thoughts and beliefs are important, there are no right or wrong answers to the questions . Please feel free to add your comments to any of the following questions. There will be an opportunity to expand on your thoughts at the end of this section.

Global Question: Do you think it is necessary to communicate your health care wishes in writing?

Yes ____ (1) Tell me about that

No ____ (2) Tell me about that

----

1. How would you describe an advance directive or a living will?

----

2. Do you want to be involved in making decisions about the type of health care you would want?

Yes ____ (1) No ____ (2)

a) If yes, do you believe it is necessary to fill out an advance directive or a living will in writing before you become seriously ill?

Yes ____ (1) No ____ (2)

b) If yes, when should an advance directive or a living will be filled out: <u>CHOICES</u>

(i) Before you become seriously ill (pre-planning)?
Yes ____ (1) No ____ (2)

(ii) While you were in hospital? Yes ____ (1) No ____ (2)

(iii) When you reach a certain age? Yes ____ (1) No ____ (2)

Age ________

c) <u>If no</u>, do you believe this topic should be discussed at all?
Yes ____ (1) No ____ (2)

Comments ____

3. If there came a time when you could not speak for yourself would you want someone else to speak for you (such as a health care agent or substitute decision-maker)?

Yes ____ (1) No ____ (2)

a) If yes, who? (rank order):

_____ parent (1)

_____ spouse (2)

_____ children (all or one) (3) ________________

_____ brothers or sisters (") (4) ________________

_____ grandchildren (") (5) ________________

_____ nephew or niece (6)

_____ any other relative (7)

_____ your doctor (8)

_____ other health professional (9)

_____ other (10)

(i) Have you discussed your feelings/wishes with the person you want to make these decisions for you?

Yes ____ (1) No ____ (2)

b) **<u>If no</u>**, you would rather not have someone else speak for you, how would you want your decisions to be communicated?

(i) In an advance directive or a living will?
Yes ____ (1) No ____ (2)

(ii) Other method

----

4. What is your opinion about the following: Should you while you are able:
a) Talk to your spouse/family about your wishes in advance and you make the decision(s)?

Yes ____ (1) No ____ (2)

b) Talk to your spouse/family in advance and let them make the decision(s)?

Yes ____ (1) No ____ (2)

c) Talk with a health care professional about your wishes in advance and you make the decision(s)?

Yes ____ (1) No ____ (2) Health professional ________

d) Talk with a health care professional in advance and let him/her make the decision(s)?

Yes ____ (1) No ____ (2) Health professional ________

e) Fill out a 'formal' document (Advance Directive/Living Will)?

Yes ____ (1) No ____ (2)

5. Do you believe your wishes should be followed as you have them written in the document?

Yes ____ (1) No ____ (2)

a) If yes, what would you want done if something happened that was not covered in your advance directive? Who should make the decision then (health care agent/substitute decision maker? (Rank order)

_____ parent (1)

_____ spouse (2)

_____ children (all or one) (3) ________________

_____ brothers or sisters (") (4) ________________

_____ grandchildren (") (5) ________________

_____ nephew or niece (6)

_____ any other relative (7)

_____ your doctor (8)

_____ other health professional (9)

____ other (10)

6. Would you want a lawyer involved when you complete your advance directive or living will?

Yes ____ (1) No ____ (2)

If yes or no, comments ______________________________

____

7. Have you already spoken to someone about what type of medical treatment you would or would not want?

Yes ____ (1) No ____ (2)

a) If yes, who did you speak with?

Spouse ____ (1) Family member ____ (2) Doctor ____ (3)

Other ____ (4) ______________________________

b) <u>If no</u>, are you planning to do so?

Yes ____ (1) No ____ (2)

8. Have you spoken to your doctor about your wishes?

Yes ____ (1) No ____ (2)

a) If yes,

(i) Did you raise the issue? Yes ____ (1) No ____ (2)

(ii) Did the doctor raise the issue? Yes _ (1) No _ (2)

b) If yes, did the discussion occur:

(i) Before you got ill? Yes ___ (1) No __ (2)

(ii) While you were in the hospital? Yes _ (1) No _ (2)

(iii) After discharge from the hospital? Yes __ (1) No __ (2)

c) How did this conversation go from your perspective?

----

d) **<u>If no</u>**, are you planning to discuss this topic with your doctor?

Yes _____ (1) No ____ (2)

(i) **<u>If no</u>**, is there a reason you would rather not discuss this?

1. Not ready? Yes ____ (1) No ____ (2)

2. Do not feel it is necessary? Yes ____ (1) No ____ (2)

3. Too disturbing/distressing to talk about?

Yes ____ (1) No ____ (2)

4. Other reason _____ (1)

Comments

----

9. Do you believe your wishes will be followed by:

(i) Your spouse/family? Yes ____ (1) No ____ (2)

(ii) Your doctor? Yes ____ (1) No ____ (2)

<u>If no</u>, does this concern you? Yes ____ (1) No ____ (2)

----

10. Do you have an advance directive or a living will now?

i) Yes ____ (1) No ____ (2)

a) If yes, for how long?

<1 year ____ (1) 1-2 years ____ (2) 3-5 years _____ (3)
>5 years ____ (4)

b) If yes, when was it last updated?

< 2 years ago ____ (1) 2 years ago or more (2)

Never _____ (3)

c) Do you think this document should be updated at regular intervals?

Yes ____ (1) No ____ (2)

d) Do others know about this document and where you keep it?

Yes _____ (1) No _____ (2)

(i) Who has a copy of this document? Select all that apply.

Spouse ___ (1) Family member(s) ___ (2) Friend ___ (3)

Doctor ___ (4) Lawyer ___ (5) Hospital ____ (6)

Other ___ (7)

(ii) Are the people who have copies of the document listed on the advance directive/living will?

Yes ___ (1) No ___ (2)

(iii) Is your health care agent (substitute decision-maker) identified on your advance directive/living will?

Yes ___ (1) No ___ (2) Person ____________________

ii) **If no,** are you planning to complete an Advance Directive or a Living Will?

Yes ____ (1) No ____ (2)

11. Has being involved in this study changed your mind about:

a) Talking to your spouse/family about advance directives or living wills?

Yes ____ (1) No ____ (2)

b) Talking to your doctor about advance directives or livi wills?

Yes ____ (1) No ____ (2)

c) Making out an advance directive or a living will?

Yes ____ (1) No ____ (2)

12. Do you feel education and/or further information is needed before you can fill out an advance directive or a living will?

Yes ____ (1) No ____ (2)

a) Type of education:

(i) Information pamphlet? Yes ____ (1) No ____ (2)

(ii) Discussion with doctor? Yes ____ (1) No ____ (2)

(iii) Discussion with lawyer? Yes ____ (1) No ____ (2)

(iv) Public forum? Yes ____ (1) No ____ (2)

Other ____ (3)

This next section is to allow you the opportunity to expand on some of the areas that have only been covered briefly during the interview. There are no right or wrong answers, your thoughts and opinions is what is important. You do not have to answer any question you do not wish to.

1. Describe your thoughts about being involved in decisions about your health care.

____

____

2. Describe how you view your family's/doctor's involvement in making choices about the type of health care you receive.

____

____

3. Describe what you feel are the reasons why you would complete an advance directive or living will?

____

____

4. Describe what you feel are the reasons why you would not complete an advance directive or living will.

____

____

5. Outline the type of assistance or information that would be most helpful to you if you decided to fill out an advance directive or a living will.

____

____

We are now finished the interview. Do you have any questions or further comments for me?

You have been very helpful and I appreciate the time you have taken to talk with me about this topic. If you have any further questions or comments about this study you may contact me at the number indicated on the information sheet. Thank you again, it has been a pleasure talking with you.

APPENDIX K

Community Contacts

List of Possible Contacts:

1. Clergy from the different religious denominations:
    1) Roman Catholic Parishes:
        Holy Family Parish - 459-3694
        St. Albert Catholic Church - 459-6691
    2) Sturgeon Valley Baptist Church of St. Albert - 458-3777
    3) St. Albert United Church - 458-8355
    4) Braeside Presbyterian - 459-6585
    5) First Nations Community Church - 470-2033
    6) St. Matthews Anglican Church - 458-5488
    7) St. Albert Alliance Church - 458-5335
    8) Salvation Army - St. Albert - 458-1937
2. Charted Psychologist *- 2 agreed

* Blue Cross covers senior citizens $20.00/visit or $100.00/family per year.

APPENDIX L

LETTER TO INSTRUMENT EVALUATORS

Date: ________________

Dear ___________________

Thank you for agreeing to evaluate my instrument for this research study. For my Master's thesis, I am planning to interview older adults living in the community and currently receiving treatment in a rehabilitation hospital. I am interested in discussing with them their knowledge and attitudes about advance directives or living wills. To date, there is very limited information in the literature about what older adult's know and/or believe about this topic. Therefore this study will at an exploratory/descriptive level.

I would appreciate your comments on the instrument in the following areas:

1. Content: Are the questions logical and relevant to the topic of advance directives and older adults' knowledge base? Are there areas that have not been addressed that should be included?
2. Format: Is the order/flow of the questions logical? Does one question follow the next? Are the choices for answering clear?
3. Language: Is the language clear? easily understandable? concise? Is the vocabulary appropriate? Do the items lead the participants in any way? Is the wording sensitive to this issue, is

free to write your comments on the questionnaire.

persons with expertise in the areas of gerontology will also be evaluating this instrument. Once I ne's feedback, I will revise the instrument and again for further input. The instrument will be equate when each item is agreed upon by three of our persons reviewing the instrument.

If you have any questions, or require further information please call me at __________ or ______________.

Thank you for taking the time to review this instrument. I look forward to your reply.

Sincerely yours,

Peggy J. Sawchuk, R.N., BScN.
M.N. Candidate
Faculty of Nursing
University of Alberta

APPENDIX M

RESOURCES

1. Senior's Centres/Organizations

- Society for the Retired and Semi-Retired
  Coordinator, Guardianship Program 423-5510
  (By appointment)

- Alberta Council on Aging - 423-7781
  Information available in Library and will direct the caller to the appropriate source

- Alberta Women's & Senior's Secretariat
  Seniors Policy & Programs - 427-6358
  Information pamphlet on Living Wills - A Background Paper (1985).

2. Bookstores

- Molloy and Mepham - Let Me Decide (1992, Canadian)

- Parsons & Parsons - When Older is Wiser - A guide to health care decisions for Older Adults and their Families (1994, Canadian) *

- Molloy - Vital Choices: Life, Death and the Health Care Crisis (1994, Canadian)*

  * Note: Also available in the Library.

3. Physicians

- discuss with him or her regarding your wishes and documentation of your wishes.

4. Lawyers

- contact your lawyer, he/she may have sample forms that you may wish to use.

5. MLAs

- information regarding Bill 58 and progress of the legislation.
- Some authorities are indicating that it may be beneficial to wait until the legislation is passed before completing an Advance Directive.

6. Libraries

- St. Albert Public Library -

  - Numerous articles, magazines and books related to the subject.

  Books available (sample)
  - <u>When Older is Wiser - A guide to health care decisions for older adults and their families</u> (1994, Canadian)
  -<u>Vital Choices: Life, Death and the Health Care Crisis</u> (1994, Canadian)

- Edmonton Public Library -

  Numerous articles, magazines and books related to the subject.
  - General Heading = Right to Die - 28 Books
  - Specific Heading = Aged, Medical Care, Health Care, Decisions, etc.

  Books available (sample)
  - <u>Living Wills and More</u> (American)
  - <u>When Older is Wiser - A guide to health care decisions for older adults and their families</u> (1994, Canadian)

APPENDIX N

Table 23 Rotated Factor Matrix

Factor	1	2	3	4	5	6	7	8	9
1. Is it necessary to communicate health care wishes in writing.	0.67				0.84				
2. Involvement in making decisions about type of health you would want.			0.51				-0.3		0.62
3. Believe it is necessary to fill out an advance directive in writing before you become seriously ill.	0.77				0.5				
4. Would you want someone else to speak for you?								0.67	
5. Discussed feelings or wishes with person you want to make these decisions for you.		0.7							
6. Discussed with spouse/family about wishes in advance and you make decisions.	0.58			-0.6					
7. Discussed with spouse/family about wishes in advance and they make decisions.			-0.47				-0.4	0.37	

Factor	1	2	3	4	5	6	7	8	9
8. Discussed with health care professional about wishes in advance and you make decisions.	0.6		0.4		0.48				
9. Do you believe your wishes should be followed as you have them written in the document?	0.48								
10. Have you spoken to someone about what type of medical treatment you would or would not want?		0.6			-0.4				
11. Have you spoken to your doctor about your wishes?		0.6				0.48		-0.4	
12. Are you planning to discuss this topic with your doctor?	0.71								
13. Do you believe your wishes will be followed by your doctor?		0.38	0.65						
14. Do you have an advance directive now?		0.66				-0.56			
15. Do you think this document should be reviewed/ updated at regular intervals?					0.62	-0.4			

Factor	1	2	3	4	5	6	7	8	9
16. Do you feel education and further information is needed before you can fill out an advance directive?			0.47		0.4	0.4			

Note question regarding 'Do you believe your wishes will be followed by your family' did not load well.

Factor 1 - Notifying others.

Factor 2 - Identifying substitute decision-makers.

Factor 3 - Involvement in decision making process.

Factor 4 - Written instructions.