National Library of Canada

Acquisitions and Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale du Canada

Direction des acquisitions et des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

UNIVERSITY OF ALBERTA

ADVANCE HEALTHCARE DIRECTIVES AND APPOINTMENT OF HEALTHCARE AGENTS: KNOWLEDGE AND PERCEPTIONS OF NURSES

BY

QUEENIE CHOO 

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

Faculty of Nursing

Edmonton, Alberta

Spring, 1995

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: QUEENIE CHOO

TITLE OF THESIS: ADVANCE HEALTHCARE DIRECTIVES AND APPOINTMENT OF HEALTHCARE AGENTS: KNOWLEDGE AND PERCEPTIONS OF NURSES

DEGREE: MASTER OF NURSING

YEAR THIS DEGREE GRANTED: 1995

Queenie Choo

QUEENIE CHOO
15512-68 STREET,
EDMONTON, ALBERTA
T5Z 2W5

DATE: 4 January, 1995

ISBN 0-612-01566-1

UNIVERSITY OF ALBERTA

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 ADVANCE HEALTHCARE DIRECTIVES AND APPOINTMENT OF HEALTHCARE AGENTS: KNOWLEDGE AND PERCEPTIONS OF NURSES submitted by QUEENIE CHOO in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

Janet C. Ross Kerr

Dr. Janet C. Ross Kerr

Anne Neufeld

Dr. Anne Neufeld

John Dossetor

Dr. John Dossetor

DATE: December 21, 1994

Abstract

The aging population is a significant factor in the increasing study of issues in the field of biomedical ethics. With advancement in medical technology and increased prevalence of dementia, a recurring issue is the question of when decisions must be made about the nature and degree of health care treatment to extend life. Most people do not have living wills or advance healthcare directives and most have not discussed their care preferences with those who may be responsible for health care decisions on their behalf. Families often turn to health care professionals for advice and decisions particularly when the patient is decisionally incapacitated. Advance healthcare directives and appointment of healthcare agents may help patients to specify their healthcare preferences when they become incapable of decision making. Since nurses are members of a professional group which has close contact with patients and families, it is important to assess their perceptions and knowledge about their role in facilitating the decision making process in advance health care planning. In this exploratory, descriptive study, a survey questionnaire which was developed by the investigator was mailed out to a random sample of nurses in Alberta.

The results of this study indicated that despite a significant lack of knowledge of advance healthcare directives and appointment of healthcare agents, the majority of respondents were in favour of the use of these directives and healthcare agents in specifying patients' treatment preferences. While there was a scarcity of agency policies and procedures on advance healthcare directives, nurses were very positive about providing patient counselling and information in this area. No significant differences were shown between nurses' knowledge about advance directives and their

education. However, inservice education may have some effect in increasing nurses' knowledge in this area. The findings of this study are of relevance to health care educators, administrators, policy makers and healthcare professionals. This information contributes to an understanding of nurses' perceptions and knowledge of advance healthcare directives and appointment of healthcare agents.

Acknowledgements

I gratefully acknowledge the assistance of:

My advisor, Dr. Janet Ross Kerr, Professor (Nursing) from the University of Alberta for her guidance and encouragement throughout the study.

The other members of my thesis committee, Dr. Anne Neufeld, Professor (Nursing) from the University of Alberta and Dr. John Dossetor, Director of the Bioethics Centre for their advice and support.

The participating nurses for their time and willingness to share their perceptions.

The Canadian Gerontological Nursing Association and Sancella for their financial support with the CGNA/Sancella Scholarship.

The Alberta Association of Registered Nurses for the Diane C. Davidson Memorial Scholarship from the AARN Educational Trust.

Joyce Johnson, Director of Resident Care Services and other staff members from St. Joseph's Auxiliary Hospital, Edmonton for their support and encouragement.

Caroline, Rita, Jeannette and Dr. Coulson for their ideas and valuable suggestions.

My husband, Frank and my daughter, Sheryl, for their assistance with data input, and their considerate actions and thoughtfulness throughout the program.

Table of Contents

List of Tables

CHAPTER 1: INTRODUCTION

Across Canada, over one-quarter million people (255,090) are long-term residents of healthcare institutions and homes for seniors, representing about one percent of the total Canadian population. Seventy nine percent of the people living in these institutions have disabilities and are over 65 years of age (Statistics Canada, 1991). By the year 2031, the proportion of the population aged 65 and over will have increased dramatically, to almost a quarter of the total population (Statistics Canada, 1991). The aging of the population is a significant factor in the increasing study of issues in the of field of biomedical ethics. With the emergence of life-prolonging medical technology and increased prevalence of dementia (Appelbaum & Grisso, 1988), a recurring issue is the question of when decisions must be made about the nature and degree of medical treatment to extend life (Libow & Starer, 1989). Most elderly individuals do not have living wills or advance healthcare directives and most have not discussed their care preferences with those who one day may be responsible for decision making on their behalf (Goold, Arnold & Siminoff, 1993). Families often turn to health care professionals for advice and decisions particularly when the patient become decisionally incapacitated. Therefore, it is important to assess nurses' perceptions and knowledge about their role in the discussion of advance healthcare directives in that they constitute the largest group of health care professionals and the one with the most direct and frequent contact with patients.

Statement of Purpose

This study was designed to examine and explore the knowledge and

perceptions of nurses on advance healthcare directives and appointment of healthcare agents. Characteristics of nurses related to their knowledge and perceptions regarding advance healthcare directives and appointment of healthcare agents were also described.

Statement of the Research Problem

The general question addressed in this research was, what are the knowledge and perceptions of nurses towards the advance healthcare directives and appointment of healthcare agents? The following were specific research questions that were investigated.

1. What knowledge and perceptions about advance healthcare directives and appointment of healthcare agents do nurses possess?
2. Who do nurses perceive should be involved in the decision making process for health care when the patient is unable to make decisions?
3. What do nurses perceive as their role and responsibilities in facilitating the decision making process with patients?
4. What characteristics of nurses are related to their knowledge and perceptions regarding advance healthcare directives and appointment of healthcare agents?

Definition of Terms

An advance healthcare directive: is a document intended to govern the kind of life-sustaining treatment that a competent person will receive upon becoming incomplete at a later date (Singer & Siegler, 1991).

A healthcare agent: a person appointed in a directive as a healthcare agent who is

able to make health care decisions on behalf of the individual.

Health care: anything that is done for a therapeutic, preventive, palliative, diagnostic or other health-related purpose, and includes nutrition, hydration, personal hygiene and choice of residence (Alberta Law Reform Institute, 1993).

Health care decision: a consent, refusal to consent or withdrawal of consent to health care. (Alberta Law Reform Institute, 1993).

Health care practitioner: a person responsible for providing health care (Alberta Law Reform Institute, 1993).

Knowledge: a person's awareness or familiarity of information.

Patient: an adult person (aged 18 or older) residing in a health care facility.

Perceptions: the process of the mind taking sense of data and interpreting these data. This experience is resulted from a process of interaction between the environmental stimuli and cognitions of the individual (Woolf, 1980).

Significance of the Study

Avoidance and delay in health care decisions often results in unnecessary ethical dilemmas when caring for a population of dying and chronically ill patients in healthcare settings (Diamond, 1991). The intimate nature of the nurse-patient/family relationship has fostered communication between these two groups. Nurses' availability and ability to act as a liaison between the patient and physician often has placed them in the position of having to communicate the patient's concerns to various members of the health care team. Findings from this study identify nurses' level of knowledge on advance healthcare directives and appointment of healthcare agents as

well as their perceptions of and feelings about their role in facilitating of the decision making process with patients. This information should assist health care professionals in structuring educational programs about advance healthcare directives that are targeted to the needs of the patients within the health care system.

In the United States, it has been reported that only modest progress has been made in getting the patients to use advance healthcare directives even two years after the Patient Self-Determination Act has been in effect (Hudson, 1994). In order to improve the enactment of the advance healthcare directives, it is important to examine the process in introducing advance healthcare directives to patients (Emanuel, 1993). Results of this research may help guide health care institutions in developing the policy and procedure which address the process in completing the advance healthcare directives and appointment of healthcare agents.

Additionally, this survey exploring nurses' perceptions and knowledge in respect to advance healthcare directives may increase nurses' level of awareness and interest in this area. It is hoped that the findings will contribute to the reduction of dilemma surrounding the role and responsibilities of nurses in facilitating patient's decision making process when advance healthcare directives and appointment of healthcare agents are executed.

Limitations

1. No known research instrument was available to address the research problem. The validity of the questionnaire that was developed was limited to face and construct validity.

2. A limited amount of empirical research has been previously conducted on similar stated problem. No specific theories or framework had been previously developed upon which hypotheses could be based.
3. Results of the study are limited to the nurses who are registered with the Alberta Association for Registered Nurses (AARN). Generalizations beyond this group of nurses should be made with caution.
4. A larger sample size would have facilitated further statistical analysis. A number of variables were analyzed; however, chance alone may have resulted in the significance found in the results.

CHAPTER 2: REVIEW OF RELATED LITERATURE

Introduction

There has been growing interest among the public as well as healthcare professionals towards advance healthcare directives and related issues (Hassmiller, 1991). The use of advance healthcare directives to guide healthcare decisions in the event that a patient becomes incompetent has become a topic of intense scrutiny and research interest (Emanuel, 1993). Some physicians, attorneys, ethicists, gerontologists and advocacy groups have stated that advance healthcare directives as a means of protecting patients' autonomy and choices by ensuring a right to refuse unwanted healthcare treatments (Council on Ethical an Judicial Affairs of the American Medical Association, 1989; Emanuel et al., 1991; High, 1987; Orentlicher, 1990; President Commission, 1982; Society for the Right to Die, 1985 & 1988; U.S. Senate Special Committee on Aging, 1987). However, the rates of advance healthcare directive use are exceedingly low (American Medical Association, 1989; Gallup & Newport, 1991; Emanuel & Emanuel, 1989). This chapter includes a review of the literature on the definitions of an advance healthcare directive and its historical development in the United States, Canada, Australia and the United Kingdom. The rationale for and prevalence of advance healthcare directives are presented. Factors that have been identified in the current literature which affect the decision making of patients on advance healthcare directives are discussed and reviewed. Additionally, various characteristics of patient, practitioner and agency that may have asserted influences on the development of advance healthcare directives and appointment of healthcare agents

are presented and discussed.

Definition of an Advance Healthcare Directive

Most literature supports the description of advance healthcare directives as directions given by a competent individual concerning what and/or how health care decisions should be made in the event the individual becomes physically and mentally incompetent to make such decisions (Singer, 1991; Downie, 1992, American Medical Association, 1992; Advance Directives Seminar Group, 1992; Alberta Law Reform Institute, 1993; MacKay, 1992; Canadian Medical Association, 1992, Bastnagel, 1993). Advance healthcare directives may be written or oral (American Hospital Association, 1991). According to MacKay (1992), individual wishes can be expressed through a living will, an enduring power of attorney for health care, or a directive to a physician. While advance healthcare directives are expressed in different ways in the literature, there are generally two main types of advance healthcare directive, namely, the "instruction directive" which specifies the types of care a person would prefer to receive; and the "proxy directive" which specifies the surrogate for such decision-making for a person who becomes decisionally incapacitated (Advance Directives Seminar Group, 1992; Downie, 1992). These two aspects of advance healthcare directives may be combined as the expressed wishes of a particular individual.

Living Will

A living will is an instructional type of advance healthcare directive with which most people are familiar since living wills have been in use since 1969 (MacKay, 1992) when the term "living will" was first suggested by Luis Kutner, an Illinois

attorney. Formally expressing one's desire to receive or to refuse treatment, when in danger or dying from wounds or disease, rests upon the belief that every person has the right to determine what should be done to his or her body - including to let it die (Nanovic, 1990). Christal (1988) refers it to documents that enable individuals to indicate they don't want heroic or extraordinary treatment. Schmeiser (1989) contends that the term "living will" is misleading since the document is not a will, but rather, it deals with dying and not living. He further explains that "this is merely nothing more than a request to be allowed to die a natural death" (p. 32). However, a more recent definition indicates that it is an advance healthcare directive which expresses the person's preferences and instructions with respect to future medical treatment (MacKay, 1991; Robertson, 1991). Bastnadel (1993) suggests that 'living will' is a generic term given to many types of written advance healthcare directives.

Enduring Power of Attorney for Health Care

The second most common form of advance healthcare directives is called enduring power of attorney for health care. Enduring power of attorney for health care decisions builds on the established legal mechanism of durable power of attorney (Downie, 1992). There is a distinct difference between a power of attorney and a power of attorney for health care. The former is a legally binding written instrument in which an individual (principal) gives decision-making authority to another person (attorney) and traditionally, such instruments have been used for decision making in property and financial matters (Demi, 1989). A power of attorney for health care, however, is a proxy directive by which a proxy or an agent is appointed to make

healthcare decisions for the principal (MacKay, 1992; Alberta Law Reform Institute, 1991; Flarey, 1991). Generally, a power of attorney for healthcare becomes effective immediately (Demi, 1989). Nevertheless, it is essential to identify under what circumstances the power of attorney for health care would become effective. Commonly, it is specified that the instrument is effective in the future when and if the principal becomes incompetent and unable to express wishes (Alberta Law Reform Institute, 1991; Flarey, 1991). The agent/proxy would then make such decisions for the individual.

The present Alberta law does not provide for substitute health care decision-making (other than by a guardian) on behalf of a mentally incompetent patient (Alberta Law Reform Institute, 1991). This gives rise to significant concerns in practice if the patient has no guardian and yet health care professionals are required by law to provide valid consent before treating the patient. In common law, certain powers are regarded as being so personal that they cannot be delegated to an agent, and the power to consent to health care may fall within this category. Therefore, the appointment of an attorney with authority to make healthcare decisions on behalf of the principal when the principal becomes mentally incapacitated is ineffective under current Alberta law (Alberta Law Reform Institute, 1991).

Directives to Physicians

Another form of advance healthcare directive that is found in American literature is the Directives to Physician (DTP). Competent adults may also make their wishes for the provision of various life-sustaining measures known before their final

illness through a Directive to Physician (DTP) (MacKay, 1992). The main difference between this DTP and other forms of advance healthcare directive is that the attending physician is required to be the agent or surrogate decision maker for the patient.

Historical Development

United States

Until the late 1950s, there was no practical need to consider a patient's right to die when deciding on courses of treatment. When a patient stopped breathing or the heart stopped, that person died without further human or mechanical interference. Then, cardiopulmonary resuscitation (CPR) was introduced into medical practice (U.S. Congress, 1987). Hospitals began making CPR a standing order for every patient in life-threatening cardiopulmonary distress. By the end of the 1960s however, hospitals were instituting criteria for "Do Not Resuscitate" (DNR) orders to modify that policy.

In 1969, following the first living will developed by Luis Kutner, an Illinois attorney, people were able to express their preferences in treatment based on their beliefs and values when in danger of dying (Nanovic, 1995). By 1976, living wills began to receive recognition, and California enacted the first Natural Death Act, legally recognizing living wills drafted according to certain requirements (California Natural Death Act, 1976). Since then, forty-nine other states and the District of Columbia have enacted similar legislation.

The 1970s brought new healthcare technology which sharply increased ethical dilemmas concerning the issue of right-to-decide. As part of the Omnibus Reconciliation Act of 1990, Senator John Danforth drafted the Patient Self-

Determination Act (PSDA) which passed into law and came into force in December 1991. Under the PSDA, all healthcare institutions receiving Medicare or Medicaid funding must provide written information upon admission, to each patient regarding the individual's right to execute advance directives and make medical treatment decisions. Each of these institutions are required by law to provide written information on the institution's policies concerning such rights. They must document in the medical record whether or not the individual has executed an advance healthcare directive, as well as avoid discriminating against any individual on the basis of whether or not an advance healthcare directive has been executed, and provide education for staff and community on issues concerning advance healthcare directives (Omnibus Budget Reconciliation Act, 1990).

Canada

Two significant developments have occurred in provincial legislations in Canada. The first development was legislation passed in Ontario, namely, the Substitute Decisions Act (Bill 108) and Consent to Treatment Act (Bill 109). Both of these bills received third reading on December 7, 1992. However, these pieces of legislation are not expected to be proclaimed for at least one year, to allow the necessary administrative machinery to be put in place. The second development was the recommendations of the Manitoba Law Reform Commission with regard to healthcare directives whic implemented (with some minor modifications) in legislation (Health Care Dir. 992). The Act received Royal Assent in June 1992, but has not yet been pr .

Other provinces, such as Nova Scotia and Quebec, have legislation permitting the use of proxy directives (Medical Consent Act, RSNS, 1989; Public Curator Act, SQ, 1989). In 1990, the Alberta Healthcare Association passed a resolution calling for the introduction of living will legislation in Alberta (HospitAlta, 1991). Similarly, the Rainbow Report also recommended that living will legislation be introduced (Premier's Commission on Future Health Care for Albertans, 1989). Law reform commissions in Alberta and Saskatchewan have also produced reports supporting advance healthcare directives (Alberta Law Reform Institute, 1993; Law Reform Commission of Saskatchewan, 1991).

At the federal level, a private member's bill (Bill C-203) has been introduced amending the Criminal Code to explicitly exclude decisions to forgo life-sustaining treatment from the homicide provisions. It basically proposes that physicians who withhold or withdraw such treatment at the request of a competent patient, or when it is medically useless, should be exempted from these sections of the code. The Canadian Medical Association (CMA) holds the following:

> The right to accept or reject any treatment or procedure ultimately resides with the patient or appropriate proxy...under certain circumstances it may be appropriate for a patient to indicate to the physician and other relevant people, by means of an advance directive, whether he or she wants such resuscitative measures taken should the need arise. A physician should assist a patient in a consultative capacity in the preparation of an advance directive concerning life-saving or life-sustaining measures if the patient requests such assistance

(p. 1072 A).

The above directions indicated of CMA clearly encourage the physician to facilitate the patient to make advance healthcare directive and appointment of healthcare agent by asserting that the patient's duly executed advance healthcare directive shall be honoured by the attending physician.

Despite the absence of enabling legislation throughout all the provinces in Canada, a number of initiatives have been taken in recent years to develop the use of living wills, particularly in the context of long term care facilities, such as the "Health-care Directive" developed by the McMaster University Medical School (Canadian Bar Association, 1991; Fisher & Meslin, 1990; HospitAlta, 1991; Molloy & Mepham, 1992) and the "Management of Serious Worsening Condition Form" developed by Dr. Mark Addision at the Bethany Centre in Calgary. Both forms focus on the "level of care" which the patient wishes to receive in a given situation. The "Code of Ethics for Nursing" developed by the Canadian Nurses Association clearly supports respect for patients in respect of their right to control their own care; it also supports considering the dignity of patients, and autonomy with the death and dying process (Canadian Nurses Association, 1991). This implies that nurses have a responsibility to assess patients' understanding of their care and to provide information and explanation in order to assist the patients to make an informed choice about their care.

Australia

Two Australian states have living will legislation, namely, South Australia and the Northern Territory. Both states are modelled on their United States counterpart,

and contain most of the features typical of living will legislation in the United States (Law Reform Commission of Western Australia, 1991). Legislation in Victoria provides that medical treatment may be withheld from a person who has clearly expressed or indicated a decision to refuse treatment, either generally or of a particular kind. However, the refusal of treatment applies only to the patient's "current condition", that is, the condition at the time of the refusal. Therefore, the scope of the legislation in permitting living wills in the sense of advance healthcare directives regarding a future medical condition is very limited.

United Kingdom

In contrast to the United States and Australia, advance healthcare directives have no legal status in the United Kingdom. There is no living will legislation and the existing legal mechanism of enduring power of attorney excludes healthcare decisions (Higgs, 1987).

The Rationale for Advance Healthcare Directives

As technologic ability to sustain life increases, so does the prevalence of ethical dilemmas accompanying such advances (Diamond, 1992). Patients are no longer passive recipients of health care and they expect to influence and indeed have control over decisions directly affecting them. This involvement has moved the ethical principle of respect for autonomy to its proper place in the forefront of clinical practice (Kohn & Menon, 1988). To respect an autonomous agent is to recognize that person's capability and perspective, including his the right to hold views, to make choices, and to take actions based on personal values and beliefs (Beauchamp &

Childress, 1989). Various researchers have suggested that the use of advance healthcare directives is a means of promoting autonomy of those individuals who would be able to determine the course of their lives and deaths (Downie, 1992; Eisendrath & Jonsen, 1983; Danis et al, 1991; Storch & Dossetor, 1991; Emanuel et al, 1991; Elpern, Yellen & Burton, 1993; Molloy, Guyatt, Alemayehu & McIlroy, 1991). Findings from empirical studies have indicated that most patients think seriously about advance healthcare directives and many of them wish to discuss these with their physicians and or nurses (Lo, McLeod & Saika, 1986; Emanuel et al, 1991).

In health care settings, nurses very often are left facing the life and death decisions when no formal advance healthcare directives and /or appointment of healthcare agents have been identified. Little attention, however, has been focused on the role of nurses in the care of patients in these difficult cases, and yet it is the nurses who provide daily physical and emotional support to patients and their families (Storch & Dossetor, 1991). To be effective in this aspect of nursing practice, along with the courage and ability to address their perceptions and feelings toward advance healthcare directives and appointment of healthcare agents, nurses need to be equipped with the skills which include advocacy, education and communication (Diamond, 1991).

Prevalence of Advance Healthcare Directives

Descriptive research to date has shown that advance healthcare directives enjoy widespread attention but that the rate at which they are actually written is much lower and varies with the population. In 1987, only nine percent of Americans had written advance directives for medical care (Steiber, 1987). Gamble (1991) did a telephone

survey of 1,500 persons in the United States and found that fifteen percent had signed a living will compared to eight percent from a Harris poll of the general population (United States President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). A membership survey by the Society for the Right to Die also conducted in the United States and found that eighty-nine percent had signed a living will, a figure that was considered surprisingly low by that organization (Society for the Right to Die Newsletter, 1988).

Additional empirical data show that the actual use of advance healthcare directives is exceedingly low, ranging from four percent to twenty percent (American Medical Association, 1989; Emanuel & Emanuel, 1989; Gallup & Newport, 1991). Three studies of persons sixty and older, with samples of 75, 40, and 55 respectively have reported usage rates of 0%, 18%, and 4% respectively (Gamble, McDonald & Lichstein, 1991; High, 1988a; Zweibel & Cassel, 1989). No data exists from large scale epidemiological studies across Canada in respect of the prevalence of advance healthcare directives except for two studies conducted in Ontario. Singer and colleagues (1993) conducted a telephone survey of 1000 adults living in Ontario and found that only 12% had completed a living will.

In a more recent survey using a cross-sectional questionnaire design, face-to-face interviews conducted at an internal medicine outpatient clinic of a University teaching hospital showed that of a total of 105 patients only 4 knew about advance healthcare directives and another 20 had discussed them but none had written them down (Sam & Singer, 1993). Not only was the sample size of this study small thus

limiting its generalizability, but also the attitudes and knowledge of the 62 subjects excluded from the study were unknown.

Factors Affecting Decision-making of Advance Healthcare Directives

Setting

Advance healthcare directives are a means of promoting patient autonomy in end-of-life decisions. However, it is clear that they are used infrequently (Danis et al, 1991). Many studies were done in an outpatient setting or community but no empirical study has drawn any conclusions about the conditions that are conducive to discussion of advance healthcare directives with the exception of two studies where the patients claimed to be more comfortable discussing the topic of advance healthcare directives in the outpatient setting (Elpern, Yellen & Burton, 1993; Emanuel, Barry, Stoeckle, Ettelson & Emanuel, 1991). Early communication with the elderly concerning advance healthcare directives has been recommended (Orentlicher, 1990). However, Uhlmann and colleagues (1988) have asserted that the nursing home setting is an opportune locale to collect advance healthcare directive preferences since nursing home patients are frail and more likely to confront death in the foreseeable future. Furthermore, education on advance healthcare directives should be considered as one of the health promotion activities for nursing home patients (Richardson, 1992).

Timing

One question that arises is should advance healthcare directives be articulated by the individual during a time of health, or prior to a pressing need for a decision in a critical illness? In the United States, the PSDA requires that institutions provide

patients with information on advance healthcare directives at the time of admission. An advantage of this approach is that the patient with an illness with a foreseeable clinical course, can focus discussion on treatment preferences rather than making choices in hypothetical situations. The latter would be the situation faced by a healthy person in the community. The drawback of such an approach, however, is that patients may find it distressing to make such decisions in a crisis situation (Advance Directives Seminar Group, 1992).

One study reveals that eighty-eight percent of patients revealed they would not be offended if they were asked on admission to the hospital if they had completed an advance healthcare directive. They would view such a policy as showing evidence of positive concern by the hospital on their behalf (Broadwell, Boisaubin, Dunn & Engelhardt, 1993). In contrast, Towers (1992) indicates that the appropriate time to counsel patients for the development of advance healthcare directives is before the onset of serious illness and hospitalization. Interestingly, Edinger and Smucker (1992) found that a majority of respondents in all age groups in their study thought it was somewhat or very important to discuss this matter both when healthy and when very ill.

While there is no consensus in the literature in respect of the timing of raising a discussion of advance healthcare directives, it is noted that many research studies took place in outpatient or community settings. However, it should be noted that there is very limited knowledge of factors which are important in the institutional setting.

Stability of Decision

The few research endeavours examining the stability of preferences have shown only moderate agreement over time (Everhart & Pearlman, 1990; Silverstein, Stocking & Antel, 1991). Holley and colleagues (1993) studied the effects of providing chronic hemodialysis patients with written material on advance healthcare directives over time and found that written information on advance healthcare directives did not improve patients' understanding of advance healthcare directives and only temporarily improved understanding of a health care proxy. Patients' attitudes about advance healthcare directives and perceived barriers to their use were not different before, shortly after, or a long time after receiving information. However, this study indicated neither how the information was delivered to the patients, nor if the material was written at the level of patients' understanding.

Knowledge

Various studies and literature have explicated the need to increase people's knowledge on advance healthcare directives through education at the level of the public, and also in situations where patients and health care professionals can benefit from programs of information. The likely result is that the rate of advance healthcare directive use in practice may be improved (Sam & Singer, 1993; Kelner, Bourgeault, Hebert, & Dunn, 1993; Advance Directives Seminar Group, 1992). In the United States, this is further reinforced with the PSDA which requires institutions to provide educational programs on advance healthcare directives to patients and staff.

Few researchers have explored the question of whether the rate of advance

healthcare directive use in practice can be improved. In a randomized control trial of an educational intervention, Sachs and colleagues (1992) found that 85% of patients did not implement a living will. Similarly, Hare and Nelson (1991) used an intervention consisting of an educational booklet and physician-initiated discussion, resulting in only eight of fifty-two patients writing an advance healthcare directive. Their study population was constructed using a design stratified by age and gender which resulted in only a quarter of the patients being over 65 years of age. Similar results were found with High's (1993) study on testing the efficacy of educational interventions among the elderly. Interventions increased the use of advance healthcare directives slightly but not dramatically. While these studies have identified the uncertainty of increasing the rate of advance healthcare directive use through educational interventions, there is no empirical data to identify how and what educational programs should be provided to the health care professionals who are in frequent and direct contact with patients.

Danis and colleagues (1991) studied the events that occurred during admission to the hospital or events after a death in the nursing home to determine whether written advance healthcare directives were effective in influencing the care patients had received. Treatment was consistent with advance healthcare directives 75% of the time, but care was significantly more likely to have been consistent in the hospital than in the nursing home ($p = 0.00003$). Care that was inconsistent with the patients' wishes was also examined. Results indicated that care which was inconsistent with the written directive was four times more likely to have occurred in the nursing home than

in the hospital. These findings suggested a need for staff in nursing homes to become much better informed about advance healthcare directives.

Communication

Many researchers have expressed the view that the inherent benefits claimed for advance healthcare directives include improved communication and promotion of patient autonomy (Davidson, Hackler, Caradine & McCord, 1989; Fisher & Meslin, 1990; Kelner, Bourgeault, Hebert & Dunn, 1993; Advance Directives Seminar Group, 1992). Interestingly, the findings of one study suggest that despite physicians and nurses generally favouring patient autonomy through the use of advance healthcare directives, they do not feel they are able to honour the wishes expressed in the directives (Kelner, Bourgeault, Hebert & Dunn, 1993).

In an international study, almost 40% of the physicians surveyed chose a level of care different from that requested in advance by patients who subsequently became incompetent (Alemayehu, Molloy, Guyatt, Singer, Penington, Basile, Eisemann, Finucane, McMurdo, Powell, Zelmanowicz, Puxty, Power, Vitou, Levenson & Turpie, 1991). This finding was further supported by other researchers who have found that the effectiveness of written advance healthcare directives is limited by inattention to them and by decisions to place priority on considerations other than the patient's autonomy (Danis, Sutherland, Garrett, Smith, Hielema, Pickard, Egner & Patrick, 1991). While this study indicates inconsistencies are more likely in the nursing home than in the hospital, it was only performed in one nursing home and one hospital and therefore the results are not generalizable. Moreover, this study did not address if

these failures to follow a directive could be justified in a way which would be acceptable to clients and/or health care professionals.

Age

The increasingly aging population is a significant factor in the recent growth in the field of biomedical ethics. The most difficult ethical dilemmas involve patients who are decisionally incapacitated. Advance healthcare directives would have provided the means to clarify patients' treatment preferences after they become incompetent (Hassmiller, 1991). Unfortunately, few older patients formalize their treatment preferences through the use of advance healthcare directives (High, 1988; Cassel & Zweibel, 1987). In the absence of a formal advance healthcare directive, health care professionals would have to face even more difficult situations for decision-making relative to the appropriateness of particular courses of action in given situations.

Emanuel and colleagues (1991) reported that the desire for advance healthcare directives planning was not correlated with age and health. While 57 percent of the patients wanted a document specifying future care, only 7 percent had one. Although 78 percent wanted a proxy decision maker, only 8 percent had designated one in writing. They also suggested that both the young (65 years of age or younger) and the healthy subgroups expressed at least as much interest in planning as those older than 65 and those in fair-to-poor health.

Similarly, Hague and Moody (1993) reported that there were no significant correlations between level of understanding and respondent age in a large southwestern

city in Florida. However, this study result can be attributed to non-random selection of subjects and previous exposure of a portion of the sample to educational programs on advance healthcare directives. In one study, researchers reported that twenty-nine percent of the sample who had executed an advance healthcare directive were older and considered themselves less healthy than those without advance healthcare directive. The study sample consisted of a nonrandomized convenience sample drawn from a tertiary urban medical centre. Therefore, the results are not generalizable to other settings.

Values

In the United States, advance healthcare directives are recognized as legal instruments for stating medical and care preferences in the future when the individual becomes decisionally incapacitated (President's Commission, 1983). Elisendrath and Jonsen (1983) contend that these directives lack precision and inadequately reflect the patient's values that give meaning to those directives. Doukas and McCullough (1991) introduced the Value History which has two parts: (1) an explicit identification of values, and (2) the articulation of advance directives based on the patient's values. By customizing the Value History, the value-based advance directive of patients can be clarified.

Doukas and Gorenflo (1993) studied the relationship between values and advance healthcare directive preferences in the outpatient setting. The goals of this study were to (1) measure patient evaluation of specific medical values regarding terminal health care; (2) measure patient evaluation of medical interventions of

terminal health care; and (3) measure the relationship between patient values and their attitudes toward medical interventions. The findings indicate an important relationship between family-burden values and patient preferences for advance directives in end-of-life decision making. In the clinical setting, it emphasizes the importance of health care professionals' roles in discussing family burden concerns with their patients when considering advance healthcare directives. This finding corroborates other research results in a multigenerational study on values and advance healthcare directives (Doukas, Antonucci & Gorenflo, 1992). Therefore, apart from providing information on advance healthcare directives to health care professionals, the use of a Values History may also be used as a clinical tool to elicit the values of the patients (Doukas & McCullough, 1991). Documentation of the patient's values will give the health care professionals a deeper and richer understanding of the patient's preferences and directions (Doukas & Gorenflo, 1993).

Practitioner Influences

Initiation of Discussion

While it may be unrealistic to expect many patients to develop an advance healthcare directive on their own, the low refusal rate in several studies reveals a willingness and an ability on the part of older patients and their proxies to discuss these issues when raised by someone else (Zweibel & Cassel, 1989; Elpern, Yellen & Burton, 1993; Spears, Drinka & Voeks, 1993). Interestingly, although patients want to discuss these issues, studies indicate that most patients have not done so and would prefer that their physician raise the issue (Lo, Mcleod & Saika, 1986). This is

consistent with another study finding that indicates patients are, in general, hesitant to raise issues on their own but prefer the physician to initiate the discussion (Edinger & Smucker, 1992).

In hospitals, the most visible care provider at the bedside is the nurse. The relationship that ensues between patient and nurse provides an important perspective to considering decisions regarding treatments. Noseworthy and Earle (1992) point out that by incorporating the nurse as a participant in the decision-making process, tension in the nurse-physician relationship would likely be reduced particularly when confronting and resolving a moral dilemma. This is further supported by one study finding where 83% of the participants stated they would be comfortable discussing their advance healthcare directive with either a physician or a nurse (Elpern, Yellen & Burton, 1993).

Knowledge

Despite the increasing interest in advance healthcare directives, several researchers have reported that health care professionals seem reluctant to initiate discussion about them with their patients (Shmerling, Bedell & Lilienfeld et al, 1988; Goold, Arnold & Siminoff, 1993). Currently, no data exists on assessing the health care professionals' knowledge of the process of assisting patient to develop an advance healthcare directive. In one study, researchers reported that discussions occurred in only 10% of the sample of elderly outpatients and that discussions were more likely to occur in older patients and those with more serious prognoses (Goold, Arnold & Siminoff, 1993). Despite a consensus in the literature that discussions about life-

sustaining treatment should take place early while the patient is competent (Lutz, 1988; Emanuel et al, 1991), physicians usually do not ask about treatment preferences until the patient is no longer competent to make decisions. When the patient becomes incompetent, discussions frequently occur with the family. Since families and physicians do not reliably make decisions that reflect patient's choices (Uhlmann, Pearlman & Cain, 1988; Ouslander, Tymchuk & Rahbar, 1989), discussing life-sustaining treatment with families may not result in a decision that the patient would have chosen.

Many previous investigators have found that a low frequency of discussions about advance healthcare directives in both inpatient and outpatient settings and elements such as prognosis, quality of life and specific diseases are associated more frequently with Do Not Resuscitate orders in the inpatient setting (Ouslander et al, 1989; Bedell, Pelle & Mahar et al, 1986; Youngner, Lewandowski, McClish et al, 1985; Frampton & Mayewski, 1987; Pearlman & Jonsen, 1985). Goold and colleagues (1993) have found that dementia apparently influences physicians to discuss the withholding or withdrawing of treatment. This may be attributed to the value physicians themselves place on cognitive ability. Factors such as uncertainty about how to talk to patients about death, fear of emotionally harming the patients and time constraints were suggested by some researchers (Goold et al, 1993) as being critical in health care professionals' failure to initiate discussions on advance healthcare directives. This study only involved a small sample size of twelve physicians and one nurse practitioner, thus limiting generalizability.

Attitude

Using a survey design with a mail-out questionnaire, Davidson and colleagues (1989) found that almost 80% of physicians in Arkansas expressed a positive attitude and fewer than 2% expressed a negative attitude toward advance healthcare directives. There is a positive correlation between their attitude and their experience with employment of advance healthcare directives in critical situations. Improved communication, trust, easier and more confident treatment decisions, lower guilt, and promotion of patient autonomy were substantiated by the results.

A face-to-face interview was conducted with 20 physicians and 20 nurses at a major Canadian teaching hospital regarding the use of advance healthcare directives in clinical care. Results indicated that thirty-nine of the forty participants favoured the use of advance healthcare directives in clinical care; physicians had somewhat less positive attitudes than nurses toward such directives (Kelner, Bougeault, Hebert & Dunn, 1993). However, the small sample size of this study has limited the generalizability of its findings.

Characteristics

Stechmiller and colleagues (1991) used multivariate techniques to predict the likelihood of a healthcare provider favouring a living will. Results revealed the three best predictors were the grouping of values (agnostic/atheist and Christian/non-Christian), length of experience in providing care to someone who is terminally ill and the nature of the relationship with the terminally ill. While the sample size is adequate, the model used in the study has not been tested for external validity, and

more testing would be required before it can be applied in confidence.

Other factors such as health care professionals' fear of death and insecurity in dealing with highly emotional and value-laden issues have been reported (Ruark & Raffin, 1988; Miller & Lo, 1985; LaPuma et al, 1991). It is also likely that communication styles of health care professionals, such as using medical jargon or communicating in an indirect manner, directly affect patient understanding, perceptions and memory (Stolman, Gregory, Dunn & Levine, 1990) are important in determining the effectiveness of health care professionals' attempts to assist patients in developing advance healthcare directives. At this time, there is a paucity of research related to nurses' attributes, knowledge, attitudes and their impact on advance healthcare directives since most work to date has focused on the central role of physicians.

Patient Influences

Various patient characteristics have been studied for their association with use of advance healthcare directives. Generally, level of education was related to familiarity with advance healthcare directives and to their use (High, 1993; Sam & Singer, 1993). In the study by High (1993), those who had completed a college education were most familiar with a living will and appointment of health care surrogate at rates of 97% and 52% respectively. In the same study, race was also associated with familiarity and use of advance healthcare directives. Familiarity with the concept of the living will was 85% for whites compared with 62% for blacks ($p<0.001$). However, thirty-five percent of whites had completed living wills

compared with only 2% of blacks ($p < 0.001$). However, the association of race with appointment of surrogates (14% for whites and 9% for blacks) was not statistically significant. Neither was level of income related to familiarity with and completion of advance healthcare directives (High, 1993). Hague and Moody (1993) reported that there was no significant correlation found between level of understanding on elements related to advance healthcare directives among groups of differing ethnicity. This data was collected from a non-probability stratified sample in a large southwestern city in Florida where 139 out of 157 were Caucasians, 3 were African-American and 8 were Hispanic/Others. Since the ethnic background of this sample was predominantly white, the generalizability of study results is limited to this population.

From the patient's perspective, discussion of a sensitive topic can produce anxiety and forgetfulness (Stolman et al, 1990). In addition, studies have shown that bedridden patients generally do not remember most of the information given to them (Cassileth, Zupkis, Smith-Sutton & March, 1980). Early discussions on advance healthcare directives are more likely to be welcomed by the patient. Such timing of discussions may also raise less anxiety for health care professionals than discussions which are initiated during a time of crisis (Stolman et al, 1990). Because of the deep interpersonal significance of decisions made at the end of life, it is not surprising that religion has played an important role in patient and family decision making (Grodin, 1993). Two studies have identified religion as one of the variables, but none of these studies have analyzed further the impact of religion in decision-making for life-sustaining treatment (Hague & Moody, 1993; Sam & Singer, 1993).

A flurry of studies have documented that procrastination and dependence on others for treatment decision-making are the common reasons given by older adults for not completing advance healthcare directives (Zweibel & Cassel, 1989; Cohen-Mansfield et al, 1991; High, 1988; Elpern, Yellen & Burton, 1993). Many researchers supported the notion of involving the family when giving patients information about the process of developing advance healthcare directives (Cohen-Mansfield et al, 1991; Emanuel, 1989). In actuality, Enderlin (1991) reports, in a study of 135 nursing facilities in Illinois that 16% of the facilities stated that patients made decisions about advance healthcare directives alone and family was involved in 56%.

Despite the fact that older adults tend to leave it to others to make their health care decisions, many studies have reported that health care professionals and family members often do not understand the preferences of the elderly patients relative to health care decisions (Kohn & Menton, 1988; Miles, Siegler & Singer, 1989). Several studies found that proxies were unable to accurately report patient treatment preferences (Uhlmann, Pearlman & Cain, 1988; Zweibel & Lydens, 1989; Zweibel & Cassel, 1989; Ouslander, Tymchuk & Rahbar, 1989; Seckler, Meier, Mulvihill & Paris, 1991; Sonnenblick, Friedlander & Steinberg, 1993; Danis, et al, 1991). Therefore, health care professionals who work with elderly patients should be sensitive to the subtle and complex dynamics of an elderly person's point of view as well as the process of advance healthcare directive use. It is further important to have an understanding of the reasons for rejecting the use of advance healthcare directives by some and the reliance on the forms of autonomy empowered by family relationships

(High, 1988). There are, however, few documented research studies related to the involvement of nurses in such decision-making processes.

Agency Influences

In the United States, the PSDA has further reinforced government funded healthcare agencies in developing policies/procedures on advance healthcare directives. In Canada, while legislation on advance healthcare directives and appointment of healthcare agents has not yet proclaimed into law, the presence of policies on this area in some healthcare agencies has signified a recognition of need. There is no known data in Canada on the number of healthcare agencies where such policy/procedure is in existence. Wilson (1993) articulated that the content of DNR policies may be an influence in policy adherence. In the same study by Wilson (1993), a significant relationship between the type of health care facility and policy adherence was found where acute care hospitals most often adhered to DNR policies in comparison to long term care facilities where DNR policies were only partially adhered to. Policy implementation problems were varied; however, they commonly occurred when patients were not involved in decision-making as was expected by policy (Wilson, 1993). These findings have indicated the significant impact of agency policies in reinforcing the role of health care professionals in facilitating patients in the decision-making process.

Directions from the Literature

There is little doubt that advance healthcare directives and appointment of

healthcare agents have been proposed as a means of empowering patients so that they are able to maintain control over their care even when they become incompetent. It is well documented in research that the rate of advance healthcare directive completion is very low, and many researchers have suggested that different educational methods that need to be employed to increase the use of advance healthcare directives. Many empirical studies have been used to explore the knowledge and attitudes of physicians, patients and the public towards advance healthcare directives. Results of studies examining factors that influence health care practitioners' attitudes about advance healthcare directives, are inconclusive and in some cases methodologically flawed. Further investigation is required to identify these factors and the interrelationship of these factors in the decision-making process for health care.

The perceptions and knowledge of nurses who have frequent and sustained contact with patients, particularly in long term care settings where the majority of the patients may be chronically ill and debilitated, have not been explored in depth. It has been suggested that nurses should be involved in the patient decision-making process in order to prevent future dilemmas in care. However, few research studies have reported that nurses have indeed been involved. There are many plausible explanations for this. Although the situation may reflect in part a lack of knowledge about advance healthcare directives, it may also indicate nurses' uneasiness about discussing the issue with the patients. Further, there would seem to be a lack of institutional support in reinforcing the role of the nurse in this area.

Respect for autonomy means more than leaving people to their own freely

chosen fate. It implies that health care professionals genuinely seek to remain in dialogue with their patients and take great care in selecting proper surrogates. Advance healthcare directives can, if properly used, help bring about situations in which a dialogue between health care professionals and the patient is improved, or, if improperly used, they can prevent dialogue and make a mockery of what they were intended to do. Research indicates that advance healthcare directives still play a limited role in clinical decisions to withdraw or withhold life-sustaining treatments (Smedira, et al, 1990; Lo et al, 1985; Stolman et al, 1989; & Brennan, 1988). Until now, the introduction of advance healthcare directives has not seemed to be consistently welcomed by health care professionals.

CHAPTER 3: RESEARCH DESIGN AND PROCEDURES

Study Design

This study is exploratory and descriptive in nature in order to examine the knowledge and perceptions of nurses in respect of advance healthcare directives and appointment of healthcare agents. As not much is known in this area, an exploratory and descriptive design is appropriate for this study.

Setting and Sample Selection

The target population for this study consisted of registered nurses who were registered with the Alberta Association for Registered Nurses (AARN). Considering the subject of the study, nurses who worked in the pediatric and obstetric areas were excluded from the study population. 18,601 members of the AARN from across Alberta met the inclusion criteria. A simple random sampling technique by computer was used to select three hundred subjects from the sample population meeting the inclusion criteria for this study. The number of subjects chosen was based on cost and time constraints. However, utilizing simple random sampling ensured that each member of the population has the same probability of being selected, hence increasing the generalizability of the study results (McMillan, 1992). While all nurses in the province of Alberta are required to be registered in order to practice, it is possible that some nurses may have repositioned their role or have taken on multiple roles and may not have classified themselves as actively involved in nursing within the clinical setting.

Procedure

Permission was granted by the Acting Executive Director of the AARN on June 3, 1994 to access the Association membership mailing list for the purpose of distribution of the questionnaire (Appendix A). Ethical approval from the Faculty of Nursing and University of Alberta Hospitals was obtained on June 29, 1994. While a face-to-face survey usually results in a higher response rate than a mail survey, the latter was chosen for this study for several practical reasons. A postal survey was not only less costly than face-to-face interviews, it also would seem to protect anonymity to a greater degree. The survey questionnaire was developed following the establishment of face and content validity. The questionnaire was then pretested with a group of ten nurses who are currently working in various clinical settings. These nurses who were not part of the study sample, each completed the survey, providing feedback on item clarity, questionnaire length and content (Appendix B). The final draft of the survey questionnaire was then established after subsequent revision.

Utilizing the AARN computerized files, three hundred nurses were randomly selected from the identified pool of 18,601 registered nurses who met the inclusion criteria. The survey package was addressed and mailed out under the auspices of the AARN. This consisted of a cover letter (Appendix C), a questionnaire (Appendix A) and a pre-stamped envelope which was pre-addressed to the AARN. This procedure ensured that the investigator had no knowledge of subject names nor addresses.

A reminder letter (Appendix D) was sent out by the AARN staff to all subjects three weeks following the first mailing. This provided an opportunity to thank those

who had returned the completed questionnaire while reminding those who had yet to respond. Responses were collected by the investigator from the AARN. The data collection took place over the period of July 15, 1994 to October 15, 1994.

Instruments

Data were collected using a questionnaire (Appendix A) developed by the investigator for the purposes of the study. Relevant information from the literature and consultation with other health care professionals was used as the basis for the development of appropriate questions. Drafts of the questionnaire were reviewed by university professors, ethicists, physicians, graduate nursing students and nurses. A formal evaluation of the questionnaire was completed by four persons with expertise in ethics and related areas. Formats for the items included checklists, rankings, forced-choice and open-ended questions. Following several revisions of the draft, two content experts who were asked to assess the relevance of the items to the objectives and judge the adequacy of the tool in representing the content agreed that it was objectively presented and sufficient in content to identify nurses' knowledge and perceptions on advance healthcare directives and appointment of healthcare agents. The questionnaire was deliberately kept short in order to encourage participation.

The questionnaire included items to examine the following major areas: (1) the demographic data of nurses; (2) the educational preparations of nurses ; (3) current practice in respect to advance healthcare directives and appointment of healthcare agents; (4) nurses' knowledge pertained to internal agency policy and procedure and external information on advance healthcare directives that were

recommended by the Alberta Law Reform Institute; (5) nurses' perceptions and clinical decisions on the application of advance healthcare directives and appointment of healthcare agents. (6) nurses' role and responsibilities in facilitating patients' decision making process; (7) factors that affect nurses' perceptions on advance healthcare directions and appointment of healthcare agents.

Data Analysis

Data generated from this study were coded using the Statistical Package for Social Sciences (SPSS) computer software program, analyzed and reported using descriptive statistics. Demographic data were reported using frequency distributions. The Chi-square statistic was used for analyzing nominal data. Contingency coefficients were used to described the relationship between the variables. Questions related to the degree of familiarity were considered interval in nature and parametric analyses such as t-tests or analysis of variances (ANOVA's) were used. Multiple regression was used to explain the variance in the variables describing the characteristics of the respondents in relation to their degree of familiarity with advance healthcare directives. Content analysis was used to analyze data obtained from the open-end question pertaining to nurses' views on the role and responsibility in facilitating patient decision making process. Main themes were identified and descriptive summaries were completed. This information, together with the descriptive information on sample characteristics and other variables was summarized in tables and charts.

A factor analysis of the questionnaire was done to identify variables on the tool

that were highly correlated with one another. Each factor was interpreted for an emerging concept (Borg & Gall, 1983). If more than one factor was generated, this was indicative of measurement of more than one concept or trait. A correlation coefficient was generated by each variable in the questionnaire for each factor. This coefficient (r) represented how highly intercorrelated each variable was with each factor. The coefficient represents how a variable "loads" on a factor (Borg & Gall, 1983, p. 616). Variables without loadings higher than 0.4 on a factor were not used in the interpretation of the concept. Only those factors that had an eigenvalue greater than one were used in the analysis. Reliability was calculated for the questionnaire using the Kuder-Richardson 20 (K-D 20) procedure to establish internal consistency between questions and the attributes measured. The results of the statistical analysis described follow in the next chapter.

Protection of Human Rights

Following ethical approval for this study through the University of Alberta Faculty of Nursing and the Alberta University Hospitals Joint Ethics Committee, written permission to access the nursing membership listing was obtained from the Acting Executive Director of the AARN. In a covering letter (Appendix C) to the participants, they were informed about the purposes of the study and that their participation in this survey was completely voluntary. Their consent to take part in this study would be assumed with the return of the completed questionnaire to the investigator. There were no direct benefits to participants, nor any repercussions if they decided not to participate. However, the importance of their responses was

highly encouraged and emphasized.

The random selection of subjects from the identified pool of nurses and the mailing out of questionnaires were done under the auspices of the AARN. This procedure ensured the anonymity of the participants. The subjects were informed that all information would be reported as group data so that it would be impossible to identify any individual participant or agency involved. Therefore, the responses were kept completely confidential and anonymous. The traditional coding on the returned envelopes to the subjects was eliminated in order to encourage the subjects to return the completed questionnaire.

CHAPTER 4: RESULTS AND DISCUSSION

Introduction

To answer the first research question in the study, the knowledge and perceptions of nurses about advance healthcare directives and appointment of healthcare agents are described. For the second research question, the rank order of decision makers identified for patients who are unable to make their own healthcare decisions is presented. This result was further explored by comparing nurses' rank ordering of healthcare decision makers identified with that of the recommendations by the Alberta Law Reform Institute. This is followed by a discussion of the third research question on identifying the nurses' perceptions on their role and responsibilities in facilitating the patient's decision making process. Emerging themes from the content analysis are described. To answer the last research question, demographic variables were examined for possible relationships with nurses' familiarity with advance healthcare directives. Since a standardized instrument was not available for measuring the knowledge and perceptions of nurses towards advance healthcare directives and appointment of healthcare agents, the validity and reliability of the questionnaire developed by the researcher were assessed. A discussion on the face validity, construct validity and internal consistency of the instrument follows.

Validity and Reliability of the Instrument

Face Validity

Face validity was determined by having four nurses expert in the use of advance healthcare directives and appointment of healthcare agents evaluate the

instrument. These individuals were asked to evaluate the instrument in terms of the appearance of the questionnaire, adequacy of content, format and use of language (Appendix B). Following revisions, the questionnaire was pretested with ten nurses. These individuals were excluded form the study sample. Each completed the survey, providing feedback on item clarity and questionnaire length.

Construct Validity

A factor analysis was done to identify items on the questionnaire that were highly correlated with one another. A factor analysis correlates discrete concepts or factors into groups. Each factor is interpreted for an emerging concept (Borg & Gall, 1983). The rotated factor loading matrix for the tool generated eight factors for the twenty seven variables in the questionnaire (Appendix E). Those variables which did not load higher than 0.40 on any factor were omitted. Those factors that had an eigenvalue of greater than 1.0 were used in the analysis. Also, as those variables loading on more than one factor would not facilitate interpretation of the factors, they were allocated to the factor where they showed the highest loading. In addition, those factors consisting of only two items were eliminated as they were neither useful nor meaningful. Consequently, four factors accounting for 68% of the variance in the questionnaire were identified. These factors along with the eigenvalues are presented in Appendix F. The emerging concepts related to each factor were described as follows after carefully reviewing all items contributing to each factor.

Factor 1 Support

Factor 2 Practice

Factor 3 Process

Factor 4 Autonomy

Factor 1, support, described the administrative support in relation to nurses' familiarity with the policies and procedures on advance healthcare directives and appointment of healthcare agents within the organization. Factor 2, practice, included the effects of nurses' perceptions on advance healthcare directives and appointment of healthcare agents in relation to their clinical practice. Factor 3, process, delineated the process of how advance healthcare directives should be obtained as perceived by nurses. Factor 4, autonomy, depicted nurses' perceptions on patient's right and autonomy in relation to healthcare decisions. Those variables on the questionnaire which related to each factor are identified in Appendix G. The four concepts identified appeared to correspond to the information to be explored based on the research questions.

Internal Consistency

The questionnaire reliability coefficient was obtained by using the Kuder-Richardson method of rational equivalence (K-R 20) which provides an estimate of internal consistency of an instrument (Borg & Gall. 1989). As this questionnaire consists of items that are of categorical in nature, use of the K-R 20 is appropriate to determine the reliability of the questionnaire. The questionnaire reliability coefficient (K-R 20) was 0.89 which is an acceptable level (McMillan, 1992). To further enhance

the reliability of the tool, the length of the questionnaire could have been increased. However, the questionnaire was deliberately kept short in order to increase the completion rate by the respondents.

Sample Characteristics

Of three hundred questionnaires mailed, 127 were completed and returned, a response rate of 42.3%. Subjects' ages were tabulated and the breakdown of their ages is indicated in Table 1. The most frequent age category was 46-50 years old (20.5%, n=26) and more than half of the study respondents (62.2%) were 45 years old or under. Thirty-eight percent were age 46 or older. The sampling variability indicated 52% of the sample were older than forty years of age with the 95% confidence intervals between 44% and 60%. Table 2 indicates the breakdown of the areas of work for the respondents. Approximately one-half of the respondents (48.8%) were from acute care facilities, while 30.7% were from long term care settings. These two categories constituted the majority (79.5%) of the respondents. Of the remaining 20.5%, 7.9% were involved in nursing education, 5.5% were working in home care, 0.8% in palliative care, 0.8% in occupational health and 5.5% did not specified the area of work.

Length of experience was also examined in this study (Table 3). Over a quarter of the subjects (27%) had four years or less years of experience in their current area of practice. Forty-two percent of the subjects had 5-10 years of experience in nursing, 20.5% had 11-20 years and 10.2% reported over twenty years nursing experience. Groups were collapsed within the two variables in an attempt to correct

Table 1 Distribution of Respondents by Age Group

Age Group (years)	Frequency	Percent	Cumulative Percent
20-25	6	4.7	4.7
26-30	16	12.6	17.3
31-35	19	15.0	32.3
36-40	20	15.7	48.0
41-45	18	14.2	62.2
46-50	26	20.5	82.7
51-55	8	6.3	89.0
56-60	10	7.9	96.9
61-65	2	1.6	98.4
> 65	2	1.6	100.0
Total	127	100.0	

Table 2 Distribution of Respondents by Area of Work

Area of Work	Frequency	Percent
Long Term Care	39	30.7
Acute Care	62	48.8
Nursing Education	10	7.9
Occupational Health	1	0.8
Home Care	7	5.5
Palliative Care	1	0.8
Other	7	5.5
Total	127	100.0

Table 3 Distribution of Respondents by Length of Work

Length of Work (Years)	Frequency	Percent
< 1	5	3.9
1-2	4	3.1
3-4	25	19.7
5-10	53	41.7
11-20	26	20.5
>20	13	10.2
Missing	1	0.8
Total	127	100.0

distribution disparity and increase the validity and reliability of the findings. Consequently, length of work was re-categorized as under 5 years, 5 to 10 years and over 10 years. Types of nursing was collapsed into long term and acute care. Table 4 indicates the cross tabulation of types of nursing by the length of work. Twenty one percent of the long term care nurses reported that they had less than 5 years of experience, 41% of them had 5-10 years of experience and 38.5% had over than 10 years of experience. Similarly, 33.9% of acute care nurses reported less than 5 years of experience, 38.7% 5-10 years of experience and 27.4% more than 10 years of experience. There was no significant difference between long term and acute care nurses in terms of their length of experience (Chi-square = 2.44, df = 2, p = 0.30).

Also assessed was the location of facility where the subjects were working (Table 5). Seventy-five percent (74.8%) were from the urban area whilst approximately twenty-four percent (23.6%) were from the rural area. The 95% confidence intervals for the estimate that 75% of nurses in the population work in urban facilities are 67% and 83%. This corresponds to the 68% of nurses who are working in urban facilities according to the AARN. The urban/rural split of the mail out was 204 to 96. This gives the differential responses of 74.8% and 23.6% from urban and rural areas respectively. Findings may indicate that nurses working in urban settings were more inclined to complete the survey than nurses from rural settings.

Size of the facility was also examined (Table 6). About one third of the respondents (29.9%) were from facilities exceeding three hundred beds whereas approximately one-half of the respondents (48.8%) were from facilities operating less

Table 4 Crosstabulation of Types of Nursing by Length of Work

Types of Nursing	Length of Work < 5 years	5-10 years	> 10 years	Row Total
Long Term Care	8 (20.5%)	16 (41.0%)	15 (38.5%)	39 (38.9%)
Acute Care	21 (33.9%)	24 (38.7%)	17 (27.4%)	62 (61.4%)
Column Total	29 (28.7%)	40 (39.6%)	32 (31.7%)	101 (100.0%)

Table 5 Distribution of Respondents by Location of Facilities

Location	Frequency	Percent
Urban	95	74.8
Rural	30	23.6
Missing	2	1.6
Total	127	100.0

Table 6 Distribution of Respondents by Size of Facility

Size of Facility (Beds)	Frequency	Percent
1-25	9	7.1
26-50	21	16.5
51-99	18	14.2
100-199	14	11.0
200-299	16	12.6
> 300	38	29.9
Not Applicable	11	8.7
Total	127	100.0

than two hundred beds.

The highest education achievement among the subjects was investigated (Table 7). The majority of the subjects achieved either a diploma in nursing (67.7%) or a degree in nursing (24.4%). Eight respondents (6.3%) had a master's degree of whom six had obtained their degree in either education or administration whilst the remaining two had specialized in nursing. There were two respondents (1.6%) who had achieved a doctoral degree. Next, the extent to which advance healthcare directives was covered in the respondents' educational preparation was reviewed (Table 8). Out of the 127 respondents, 2.4% had extensive coverage in this topic area, 16.5% had partial coverage, 34.6% had minimal coverage, 45.7% had no coverage at all in this area and 0.8% did not answer.

The extent of information on advance healthcare directives and appointment of healthcare agents in the nursing program was crosstabulated with the nurses' level of educational achievement (Table 9). Groups were collapsed within the highest educational achievement categories in an attempt to correct distribution disparity and increase the validity and reliability of the findings. Consequently, the highest educational achievement groups were re-categorized as diploma and degree nurses. The extent of information on advance healthcare directives and appointment of healthcare agents in the educational curriculum was collapsed into extensive/partial, minimal and none. Fourteen percent of the nurses with diplomas in nursing reported that they either had extensive or partial information on advance healthcare directives in their educational program whereas 34% had minimal information and 52% had none at

Table 7 Distribution of Respondents by the Highest Educational Achievement

Highest Level of Educational Achievement	Frequency	Percent
Diploma in Nursing	86	67.7
Degree in Nursing	31	24.4
Masters Level		
Nursing	6	4.7
Education/Administration	2	1.6
Doctorate Level	2	1.6
Total	127	100.0

Table 8 Distribution of Respondents by the Extent of information of Advance Healthcare Directives

Extent of Information on AD	Frequency	Percent
Extensively	3	2.4
Partially	21	16.5
Minimally	44	34.6
None at All	58	45.7
Missing	1	0.8
Total	127	100.0

Table 9 Crosstabulation of Education Achievement by Extent of Information on AD

	Extent of Information on AD			
	Extensively/Partially	Minimally	None at All	Row Total
Education	n (%)	n (%)	n (%)	n (%)
Diploma in Nursing	1 (1%)	29 (34%)	44 (52%)	85 (100%)
Degree in Nursing (BScN, MA, PhD)	11 (27%)	15 (37%)	14 (34%)	41 (100%)
Column Total	24	44	58	126

Row percentages are indicated in brackets

all in their program. Similarly, 29% of the nurses with a nursing degree reported that they either had extensively or partial information on advance healthcare directives whereas 37% had minimal and 34% had none at all. While there was no significant difference between the diploma and degree nurses in relation to their educational preparation on advance healthcare directives (Chi-square = 5.25, df = 2, p = 0.07), the majority of the two groups of nurses reported that there was minimal or no exposure to advance healthcare directives in their educational curriculum. This indicates a lack of overall educational preparation on advance healthcare directives in both diploma and degree nursing education.

A breakdown of educational inservice programs on advance healthcare directives attended by respondents within the last two years is illustrated in Table 10. Twenty-eight percent of the nurses had attended such educational inservice and 69.3% of the respondents reported that they had not attended any inservice programs on advance healthcare directives within the last two years. Despite that the fact advance healthcare directives and appointment of healthcare agents are areas recently introduced to Canada, this finding reflects a lack of administrative support in promoting inservice education on advance healthcare directives within recent years.

Current Practice

When asked about the number of patients who had made advance healthcare directives, 1.6% of the nurses reported all patients had made one out, 10.2% indicated the majority of the patients had advance healthcare directives, 12.6% revealed that only some patients had advance healthcare directives, 22.8% said that only a few

Table 10 Educational Presentation on Advance Healthcare Directives and Healthcare Agents

Educational Presentations	Frequency	Percent
Yes	35	27.6
No	88	69.3
Missing	4	3.1
Total	127	100.0

patients had advance healthcare directives and almost one-half of the total respondents (46.5%) reported that none of the patients they were working with had advance healthcare directives (Table 11). These findings further corroborated research findings by Sam and Singer (1993) that a low completion rate on advance healthcare directives was indicated.

Of the 123 subjects who had responded to the question about the existence of policies and procedures on advance healthcare directives within their agency, 22% confirmed such policies/procedures were in place and 35.4% indicated that there were no such policies and procedures. Thirty-nine percent reported that they were unsure if such policies/procedures existed. The crosstabulation between the existence of agency policies/procedures and patients with advance healthcare directives was shown in Table 12. Patients possessing advance healthcare directives was re-categorized as all or the majority of patients, some patients and only a few/none. There was a significant relationship between agencies with policies/procedures on advance healthcare directives and patients with advance healthcare directives (Chi-square = 42.5, df = 4, p = 0.00). Additionally, there were indications that a moderately positive relationship between agency policies and patients with advance healthcare directives (Cramer's V = 0.43). Thus, it is more likely that a patient would have made out an advance healthcare directive if policies and procedures existed within the organization.

When asked to what extent the policies and procedures on advance healthcare directives were followed (Table 13), 78.7% disregarded the question, possibly

Table 11 Patients with Advance Healthcare Directives (A.D.)

Patients with A.D.	Frequency	Percent	Cumulative Frequency
All Patients	2	1.6	1.7
Majority of the Patients	13	10.2	12.6
Only Some Patients	16	12.6	26.1
Only a Few Patients	29	22.8	50.4
None	59	46.6	100.0
Missing	8	6.3	
Total	127	100.0	

Table 12 Crosstabulation of Agency Policy and Procedure by Patients with A.D.

	Patients with A.D.			
	All /Majority	Only Some	A Few/None	Row Total
Agency P &P				
Yes	12 (42.9%)	7 (25%)	9 (32.1%)	28 (24.1%)
No	0 (0 %)	6 (14.3%)	36 (85.7%)	42 (36.2%)
Unsure	2 (4.3%)	3 (6.5%)	41 (89.1%)	46 (39.7%)
Column Total	14 (12.1%)	16 (13.8%)	86 (74.1%)	116 (100%)

Table 13 Adherence to Agency Policy and Procedure

Adherence to Policy & Procedure	Frequency	Percent
At All Times	12	9.4
Often	8	6.3
Sometimes	6	4.7
Rarely	1	0.8
Missing	100	78.7
Total	127	100.0

indicating they were unsure about whether such policies and procedures existed. Of twenty-seven nurses who had responded the question, 44.4% reported that they adhered to the policy and procedure "at all times", 30% said they "often" adhere to them whereas approximately one-quarter said that they only "sometimes" or "rarely" followed the agency policy and procedure on advance healthcare directives. Despite such a small number of nurses responding to the question, there are indications that nurses are likely to follow the policies and procedures if such policies/procedures are made known to them.

Eighty-four percent of the nurses reported that there was either no policy on appointing healthcare agents or they were unsure whether or not such a policy existed within their agencies. Of nurses who reported the existence of a policy on appointing healthcare agents, 40% indicated that the appointment of healthcare agents was emphasized at all times when advance directives were made, 40% had sometimes and 20% had none at all. Again, agency policy on appointing healthcare agents may have some effect on encouraging nurses to facilitate the decision making process for patients developing advance healthcare directives.

Knowledge Related to External Recommendations

Table 14 illustrates the results on familiarity of nurses with advance healthcare directives. Interestingly, almost half of the respondents (48%) indicated that they were either "very familiar" or " somewhat familiar" with advance healthcare directives. Thirteen percent said they were aware of advance healthcare directives. More than one-third of the respondents (37.8%) stated that they were either "somewhat

unfamiliar" or "unfamiliar" with advance healthcare directives.

Conversely, 73.3% indicated that they were either "somewhat unfamiliar" or "unfamiliar" with the recommendations prepared in 1993 by the Alberta Law Reform Institute and the Health Law Institute on "Advance Directives and Substitute Decision-Making in Personal Healthcare". Only 9.4% stated that they were aware of these recommendations and one out of six respondents (16.6%) indicated that they were either very or somewhat familiar with these recommendations (Table 15).

These findings may indicate that nurses were somewhat familiar with advance healthcare directives. However, this result might be attributed to social desirability in answering the question in the manner which seems most socially favourable. On the other hand, it is very obvious that the majority of nurses were not familiar with the recommendations made in 1993 by the Alberta Law Reform Institute on "Advance Directives and Substitute Decision-making in Personal Healthcare". When "familiarity" was treated as a dependent variable, t-tests were used to compare the means of two groups of nurses, namely, acute care and long term care nurses. The results showed that acute care nurses were significantly less familiar with advance healthcare directives and the recommendations by the Alberta Law Reform Institute on advance directives compared to nurses working in long term care settings ($p < 0.05$). Given that one group of nurses were less familiar with advance healthcare directives than the other, there remains a definite need for education on advance healthcare directives and appointment of healthcare agents.

Table 14 Familiarity with Advance Healthcare Directives

Familiarity	Frequency	Percent
Very Familiar	15	11.8
Somewhat Familiar	46	36.2
Aware	17	13.4
Somewhat Unfamiliar	22	17.3
Unfamiliar	26	20.5
Missing	1	0.8
Total	127	100.0

Table 15 Familiarity with the Advance Healthcare Directives Recommended by the Alberta Health Law Reform Institute

Familiarity	Frequency	Percent
Very Familiar	2	1.6
Somewhat Familiar	19	15.0
Aware	12	9.4
Somewhat Familiar	11	8.7
Unfamiliar	82	64.6
Missing	1	0.8
Total	127	100.0

Ranking of Decision-Makers

Respondents were asked to rank the decision maker in the order of priority such as "1" is the first decision maker, "2" is the second decision maker if the first one is unavailable, and so on. In scenario A, the patient who had not named a healthcare agent, was terminally ill and mentally incapable of making healthcare decisions. The only difference in scenario B, was that the patient had named a healthcare agent. Nurses were asked to rank the order of decision makers. Table 16 provides a summary of the ranking orders of decision makers of the two scenarios by nurses compared to the recommendations of the Alberta Law Reform Institute (1993) (p. 38).

In scenario A where there was no named healthcare agent and the patient was unable to make healthcare decisions, the majority of nurses chose the patient's spouse as the first person for healthcare decisions followed by the patient's children, parents, siblings, relative, healthcare practitioner, and guardian. Interestingly, the sequence of both lists is similar except "guardian" was named as the first decision-maker by the Alberta Law Reform Institute whereas it was named the last by the majority of the nurses. In the proposed recommendation by the Institute (1993), a guardian is "the one who is appointed under the Dependent Adult Act with authority to make healthcare decisions on behalf of the patient" (p. 38).

In scenario B, where there was a named healthcare agent, the majority of nurses stated that the appointed healthcare agent should be the first decision maker followed by the patient's spouse, children, parents, siblings, relative, healthcare

Table 16 Ranking of Decision Makers in Two Scenarios in Comparison to the Recommendations by the Alberta Law Reform Institute

Scenario	A	B
Decision Maker	Order	Order
Guardian	7 (1)	8 (1)
Spouse	1 (2)	2 (3)
Children	2 (3)	3 (4)
Parents	3 (4)	4 (5)
Siblings	4 (5)	5 (6)
Relative	5 (6)	6 (7)
Healthcare Practitioner	6 (7)	7 (8)
Healthcare Agent	Not Applicable	1 (2)

Rank ordering of decision makers recommended by the Alberta Law Reform Institute is presented in brackets

Scenario A: The patient who has not named a healthcare agent, is terminally ill and mentally incapable of making healthcare decisions

Scenario B: The patient who has named a healthcare agent, is terminally ill and mentally incapable of making healthcare decisions

practitioner and guardian. This result was similar to previous findings in that the guardian was still the least preferred choice on the list as decision maker.

Knowledge Related to Agency Policy and Procedure

The frequency of existing agency policies and procedures on advance healthcare directives is presented in Table 17. Less than one-quarter of nurses reported that there were policies and procedures on advance healthcare directives in their agencies. Of nurses who claimed that there were existing policies/procedures within their agencies, 74% stated that they were either very or somewhat familiar with these, less than 1% were aware and 16% were either somewhat unfamiliar or unfamiliar with such policies/procedures. Given the lack of agency policies/procedures on advance healthcare directives, there were indications that nurses were somewhat familiar with such policy and procedure if they existed within the agencies. Furthermore, there was no significant difference in nurses' familiarity with their agency policies/procedures on advance healthcare directives between long term and acute care settings ($p > 0.05$).

Of nurses who reported that there were agency policies and procedures in place on advance healthcare directives, 12% were just implementing their policies and procedures, 4% had theirs set up for less than one year, approximately one-half were established 1-2 years ago, one-quarter were established 3-4 years ago and 12% over 4 years ago (Table 18). This shows that not only was there a scarcity of agency policies and procedures on advance healthcare directives in existence, but also most of these policies and procedures had been recently established. Converting the responses for

Table 17 Agency Policy and Procedure on Advance Healthcare Directives

A.D. Policy & Procedure	Frequency	Percent
Yes	28	22.0
No	45	35.0
Unsure	50	39.4
Missing	4	3.1
Total	127	100.0

Table 18 Recency of Policy and Procedure on A.D.

Recency of Policy & Procedure	Frequency	Percent
Pending Implementation	3	2.4
7-11 months ago	1	0.8
1-2 years ago	12	9.4
3-4 years ago	6	4.7
> 4 years ago	3	2.4
No Policy & Procedure or Unanswered	102	80.3
Total	127	100.0

agency policies/procedures into ranks, acute and long term care facilities were compared using the nonparametric statistical technique, Wilcoxon. The analysis showed that the policies and procedures on advance healthcare directives were significantly more present in long term care than in acute care facilities (Wilcoxon, significant).

Similarly, the majority of nurses (74%) reported that there was no policy on healthcare agents or that they were unsure if such a policy existed, and only approximately one-quarter of nurses claimed that there was policy on healthcare agents in their facilities. In contrast, there was no significant difference in policy on healthcare agents between long term care and acute care settings (Wilcoxon, non-significant).

Perceptions Related to Advance Healthcare Directives and Healthcare Agents

A majority of nurses (83.5%) reported that they were in favour of the use of advance healthcare directives. Similarly, 66.9% of the nurses were in favour of the use of the appointment of healthcare agents (Table 19). There was no difference between nurses in acute and long term care settings (Wilcoxon, non-significant). Furthermore, the majority of the nurses (89%) who had worked with patients with advance healthcare directives indicated they were either completely or mostly comfortable in following the patients' advance healthcare directives (Table 20). These findings demonstrated an overwhelming agreement among the nurses in supporting the use of advance healthcare directives and appointment of healthcare agents. While there was a lack of education in this area, most nurses felt comfortable in following these

Table 19 Favour the use of Advance Healthcare Directives and Appointment of Healthcare Agents - A Comparison

	Favour the use of A.D.	Favour the use of healthcare agent
Yes	106 (83.5%)	85 (66.9%)
No	1 (0.8%)	12 (9.4%)
Undecided	18 (14.2%)	27 (21.3%)
Missing	2 (1.6%)	3 (2.4%)
Total	127(100.0)	127(100.0)

Table 20 Levels of Comfort in following Patients' Advance Healthcare Directives

Levels of Comfort	Frequency	Percent
Completely Comfortable	30	23.6
Mostly Comfortable	27	21.3
Undecided	4	3.1
Somewhat Uncomfortable	3	2.4
Has Not Worked with Patients with A.D. or Unanswered	63	49.6
Total	127	100.0

directives by the patients. These results corroborate findings of Kelner, Bougeault, Hebert and Dunn (1993) where 39 of the 40 study participants favoured the use of advance directives in clinical care and nurses held positive attitudes toward such directives.

Perceptions Related to Patient Autonomy

Eight-nine percent of the respondents expressed that the patient should have the final authority in making decisions regarding treatment preferences if mentally capable of doing so. Additionally, over 90% of nurses agreed either absolutely or under most conditions that patients should use advance healthcare directives and healthcare agents to specify their treatment preferences. Again, the majority (96.1%) concurred either absolutely or under most conditions that patients have the right to refuse treatment. These findings revealed that most nurses were in favour of patients' being able to exercise autonomy in making healthcare decisions through the use of advance healthcare directives and appointment of healthcare agents (Table 21-23).

Perceptions Related to Patient Counselling

Over one-half of the nurses (54.3%) felt that the best time to provide counselling on advance healthcare directives and appointing healthcare agents to long term care patients was while patients were competent. About one third of the nurses (30.7%) preferred counselling to be done on admission. Only 3.9% felt that it should be provided to the patients when terminal disease was diagnosed. Less than 1% felt that it should be done at a specific age whereas 5.5% had never considered any

Table 21 Final Authority in Making Decisions for Treatment

Final Decision Maker	Frequency	Percent
Patient	113	89.0
Family	8	6.3
Physician	2	1.6
Others	3	2.4
Missing	1	0.8
Total	127	100.0

Table 22 Use of Advance Healthcare Directives and Healthcare Agents to Specify Treatment Preferences

Use of A.D. & Healthcare Agents	Frequency	Percent
Yes	106	83.5
No	1	0.8
Undecided	18	14.2
Missing	2	1.6
Total	127	100.0

Table 23 Patients Right to Refuse Treatment

Patients Right to Refuse Treatment	Frequency	Percent
Yes, absolutely	92	72.4
Yes, under Most Conditions	30	23.6
Undecided	1	0.8
No, but with Some Exceptions	3	2.4
No, absolutely Not	1	0.8
Missing	1	0.8
Total	127	100.0

specific time (Table 24).

When asked if nurses should inform patients about advance healthcare directives and the appointment of healthcare agents, 71.6% felt either absolutely or under most conditions that nurses should inform patients about these. Fourteen percent were undecided and the remaining 10.2% indicated they did not support the use of advance healthcare directives (Table 25). Additionally, it was noted that the majority of respondents (74.8%) agreed either absolutely or under most conditions that nurses should be trained to counsel patients on advance healthcare directives and the appointment of healthcare agents (Table 26). Neither these findings nor previous research studies indicate a consensus on any particular time when advance healthcare directives should be addressed. Nevertheless, many nurses in this study felt that it was important to raise this issue while the patient was competent. Given that timing is a crucial factor, it is equally significant to consider the process of how the advance healthcare directives should be presented to the patient.

Should advance healthcare directives be treated as an admission criterion for patients entering long term care facilities? One-half of the nurses (50.8%) answered "yes", 22% answered "no" and 26% were undecided. Ideally, if the topic of advance healthcare directives is introduced sensitively and in appropriate settings, this should not pose a problem, even it is considered as a criterion for admission. However, it becomes a concern when the patient is relatively powerless, because the individual wishes to please staff on whom there is dependence of, or has internalized negative paradigms of aging, and low self-esteem. Boetzkes (1993) also suggested that there

Table 24 Timing for Counselling Patients on Advance Healthcare Directives and Appointment of Healthcare Agents

Timing	Frequency	Percent
On Admission	39	30.7
While Patient is Competent	69	54.3
When Terminal Illness diagnosed	5	3.9
At a Specific Age	1	0.8
Never Considered It	7	5.5
Other	3	2.4
Missing	3	2.4
Total	127	100.0

Table 25-26 Nurses as Informant and Counsellor on Advance Healthcare Directives

	Nurses as Informant	Nurses Trained as Counsellor
Yes, absolutely	39 (30.7%)	54 (42.5%)
Yes, under most conditions	52 (40.9%)	41 (32.3%)
Undecided	18 (14.2%)	16 (12.6%)
No, but with some exceptions	12 (9.4%)	9 (7.1%)
No, absolutely not	1 (0.8%)	3 (2.4%)
Missing	5 (3.9%)	4 (3.1%)
Total	127 (100.0%)	127 (100.0%)

should be safeguards in place against overt coercion by bribes or threats in order to guarantee that health care decisions reflect an individual's wishes, and thus are an expression of autonomy.

Professional Influences

Sixty-four percent of nurses stated that their views on advance healthcare directives were influenced by their previous professional nursing experience (Table 27). Among these nurses, long term care nursing (30.7%) was the most commonly reported type of nursing, followed by acute care nursing (25.9%) and palliative care nursing (6.3%) (Table 28). Since the two commonly identified types of nursing are long term and acute care nursing which constitute one-half of the responses, findings may suggest that experience in both long term and acute care nursing do have significant impact on nurses' views on advance healthcare directives.

Roles and Responsibilities

In Table 29, a summary is presented of the people with whom nurses would consult in the event of disagreement over treatment choices. Some nurses also provided comments such as using an interdisciplinary approach in resolving the disagreement over treatment choices. Among the list of people with whom the nurses preferred to resolve treatment disagreement, the physician was the most preferred category, followed by the nursing supervisor, the patient and the family. Additionally, 70.9% felt that nurses should facilitate patients in their decision making process either absolutely or under most conditions (Table 30). There was no significant difference between long term care and acute care nurses in relation to

Table 27 Influenced by Previous Nursing Experience

Influenced by Previous Experience	Frequency	Percent
Yes	81	63.8
No	13	10.2
Undecided	26	20.5
Missing	7	5.5
Total	127	100.0

Table 28 Influenced by Area of Practice

Area of Practice	Frequency	Percent
Long Term Care	39	30.7
Acute Care	33	25.9
Palliative Care	8	6.3
Surgery/Intensive Care	7	5.5
Emergency Room	1	0.8
Home Care	2	1.6
Others	11	8.7
Missing	26	20.5
Total	127	100.0

Table 29 People to Discuss Issues with When Disagreement Arises

People to be Discussed	Frequency	Percent
Patient	59	46.5
Physician	72	56.7
Supervisor	67	52.8
Family	51	40.2
Social Worker	27	21.3
Do Nothing About It	16	12.6
Others	7	5.5

Table 30 Nurses as Facilitator for Decision Making

Facilitator	Frequency	Percent
Yes, absolutely	41	32.3
Yes, under most conditions	49	38.6
Undecided	18	14.2
No, but with some exceptions	10	7.9
No, absolutely not	6	4.7
Missing	3	2.4
Total	127	100.0

facilitating patients in their decision making process ($p > 0.05$). These findings reveal an overall agreement that nurses should be involved in facilitating patients in healthcare decisions. The common theme of the importance of the nurse's responsibilities in facilitating patients in healthcare decisions was identified through content analysis and will be described in the following paragraphs.

Provision of support to patients and families in their decisions

Most respondents asserted that it was important and essential to provide continuing support not only to the patient but also to the family in their decisions through listening to patients' and families' concerns, communicating openly on this issue, teaching the disease process and providing information about advance healthcare directives, healthcare agents and the available options. As a nurse from an acute care area put it, "I feel that nurses are in a position to provide valuable information and support to patients to help develop their advance healthcare directives and appointment of healthcare agents." A nurse in a long term care setting said, "The nurses' role is to support the patient and family in their decision regarding advance healthcare directives rather than offering decisions to patients and families." Another nurse from the psycho-geriatric area said, "Patients must be aware of their options. This can be facilitated through teaching and support of both the patients and their families. Whenever possible, decision making must involve the patients and their wants must be honoured and supported."

Liaison with Other Professionals and Resources

Many respondents indicated part of their roles and responsibilities was to act as

a liaison among the interdisciplinary members such as the physician, social worker, minister or even a lawyer to ensure that a patient's wishes were communicated clearly and accurately. A nurse from home care commented, "Clients should be able to discuss their desires with their personal physician and family in relation to continuing or discontinuing treatment and its side effects." A nurse from acute care said, "Nurses should involve other health care professionals as necessary such as social workers, physicians or chaplains. Information should be made available even from a physician's office." A long term care nurse pointed out, "Nurses should encourage patients to seek legal counsel when considering advance healthcare directives and appointment of healthcare agents." A nurse educator put it, "I do see the role falling in the domain of a nurse who has received advanced preparation in the area, such as clinician, practitioner, master's prepared nurses. This would be a member of a team involving other specialties/services, such as medicine, social work, and palliative care."

Assistance to Patient to Develop Advance Healthcare Directives

Another key responsibility of nurses was to provide assistance to a patient and family to develop advance healthcare directives. As many patients and family members were uncomfortable in raising this issue, it would be of the utmost importance to initiate the discussion and help them to make an informed choice. A nurse in long term care remarked, "The nurse must fully understand the disease process (and aging) which applies to the patient. Also it would help to facilitate the decision making process by gaining understanding of the family dynamics and relationship." In this way, the nurse would be able to offer the necessary information to the patient and family. Another nurse in long

term care asserted, "The topic of advance healthcare directives should be discussed with the patient and family and provide them with information which they would require to make an informed decision." An acute care nurse put it, "Nurses spend more time with the patient and understand about the patient's needs medically and emotionally. This is the reason to believe that nurses should have the responsibility for patients in developing their advance healthcare directives and the appointment of healthcare agents." A nurse in long term rehabilitation setting put it this way, "Nurses should be self-directed in community development such as facilitating patients in the development of healthcare directives. I firmly believe that in order to get patients to develop their own, it needs to start off with our nursing population to start believing in it and developing our own as well." Another acute care nurse spoke of the nurses being in a position to provide valuable information and support to patients to help them to develop their advance healthcare directives and identify healthcare agents.

Nurses Need More Knowledge and Training

Despite the fact that many respondents felt that it was the nurse's responsibility to support and help patients to develop advance healthcare directives and appoint healthcare agents, several of them expressed a need to develop further skill and knowledge in this area. As an acute nurse put it, "I think nurses have some of this training but would need more before assuming they could counsel patients with regards to living wills." Another acute care nurse commented, "I don't know much about advance healthcare directives. It would seem to be an area where nurses would need to be involved. But I think nurses require more education and skill in this area." A care

consultant in long term care asserted, "Nurses should be trained in advance healthcare directives so they can guide patients through the decision making process."

Patient Advocate

Most of the respondents suggested that nurses should act as patient advocate who could communicate clearly about patients' wishes and act in their interests. A nurse reported, "I believe the nurse should be an advocate for the patient when necessary. I have seen a number of cases where a family member insisted that a ninety year old plus family member with life threatening problems be coded. I believe situations such as this is a real infringement on the dignity and the rights of the patient. If this was discussed beforehand in one's advance healthcare directive, it would be much easier for the family and staff to deal with." A home care nurse commented. "We all often close to our clients and advocate on their behalf. I think it is our duty to keep patients informed on advance healthcare directives where one's wishes can be made known especially when we often deal with client placement." A nurse educator said, "Nurses need to understand their role as advocate and the ethical and legal implications of advance healthcare directives."

Analysis of the Demographic Variables in Relation to Familiarity with Advance Healthcare Directives

Considering familiarity with advance healthcare directives as a dependent variable, the combined effects of the demographic variables such as age, types of nursing, experience, education, extent of information on A.D., inservice education, size of facility and location of facility were examined using a regression analysis.

Inservice education was found to be a significant predictor of familiarity with advance healthcare directives ($t = 4.81$, $p = 0.00$). Thus, the more inservice education that a nurse receives on advance healthcare directives, the more likely they are familiar with the topic. Results also revealed that educational inservice explained to 16 % (R sq = 0.16) of the variation in the measure of familiarity with advance healthcare directives (Appendix H).

In the step two of the regression (Appendix I), the second independent variable entered into the equation was age. The multiple R was 0.44, reflecting the contribution of both inservice education and age. Nineteen percent of the variation in familiarity with advance healthcare directives was accounted for by both inservice education and age. Using the 0.05 level of significance, age ($p = 0.04$) and inservice education ($p = 0.00$) contributed significantly to regression. Age, the second variable made relatively little improvement in the prediction. This is explained by the fact that the two predictor variables, inservice education and age, are likely to correlate highly with each other. Because of this overlap, age did not improve dramatically upon the prediction made by inservice education, which was entered into the multiple regression analysis first.

Analysis of variance was used for comparisons involving more than two groups and t-tests for comparisons of two groups to indicate whether or not there were significant differences between means of the dependent and independent variables. A summary table of results is presented in Table 31. Using familiarity with advance healthcare directives as the dependent variable, results revealed there were no

Table 31.1 Results of Analysis of Variance : Familiarity by Facility Size

Source	DF	Sum of Sq	Mean Sq	F Ratio	Prob
Between Groups	5	17.81	3.56	2.05	0.08
Within Groups	109	189.18	1.74		
Total	114	206.99			

Table 31.2 Results of Analysis of Variance: Familiarity by Age Group

Source	DF	Sum of Sq	Mean Sq	F Ratio	Prob
Between Groups	9	26.07	2.90	1.63	0.11
Within Groups	116	205.90	1.78		
Total	125	231.97			

Table 31.3 Results of Analysis of Variance: Familiarity by Experience

Source	DF	Sum of Sq	Mean Sq	F Ratio	Prob
Between Groups	5	16.15	3.23	1.79	0.12
Within Groups	119	214.84	1.81		
Total	124	230.99			

Table 31.4 Results of Analysis of Variance: Familiarity by Extent of Information on A.D.

Source	DF	Sum of Sq	Mean Sq	F Ratio	Prob
Between Groups	2	10.18	5.09	2.85	0.06
Within Groups	122	217.69	1.78		
Total	124	227.87			

Table 31.5 Results of t-test: Familiarity by Inservice Education

t-value	DF	2-tail Sig	SE of Diff	95% CI for Diff
-6.99	89.11	0.00	0.21	(-1.85, -1.03)

Table 31.6 Results of t-test: Familiarity by Academic Education

t-value	DF	2-tail Sig	SE of Diff	95% CI for Diff
1.74	124	0.08	0.26	(-0.02, 0.96)

Table 31.7 Results of t-test: Familiarity by Facility Location

t-value	DF	2-tail Sig	SE of Diff	95% CI for Diff
0.46	122	0.64	0.29	(-0.44, 0.71)

Table 31.8 Results of t-test: Familiarity by Types of Nursing

t-value	DF	2-tail Sig	SE of Diff	95% CI for Diff
-3.18	99	0.002	0.27	(-1.38, -0.32)

significant differences between familiarity with advance healthcare directives and age, extent of information on A.D., experience, education, location or size of facility. However, there was a significant difference between types of nursing and familiarity with advance healthcare directives in that nurses from long term care settings were more familiar with advance healthcare directives than nurses in acute care ($p < 0.05$). In addition, there was a significant difference between inservice education and familiarity with advance healthcare directives in that the more inservice education on advance healthcare directives the nurses received, the more familiar they were with this area ($p < 0.05$).

Summary of Results

The following is a summary of the important findings in the study.

1. The questionnaire was interpretable using a factor analysis of four factors and twenty seven variables. These factors explained 68.3% of the variance in the questionnaire.

2. The questionnaire reliability coefficient (KR- 20) was 0.89 which is considered good for this new tool.

3. There was no significant difference in educational preparation on advance healthcare directives between diploma and degree nurses. However, the majority of nurses reported that they had not only received minimal or no educational preparation on advance healthcare directives in their nursing education, but also no inservice education in this area with the last two years.

4. A very low completion rate on advance healthcare directives and appointment

of healthcare agents was reported and the policies/procedures on advance healthcare directives scarcely existed within the agencies.

5. There was a significant relationship between agencies with policies/procedures on advance healthcare directives and the completion rate of advance healthcare directives in that a patient was likely to complete an advance healthcare directive if such policies/procedures existed within the agency.

6. While respondents were somewhat familiar with advance healthcare directives and appointment of healthcare agents, the majority of them indicated they were unfamiliar with the recommendations prepared in 1993 by the Alberta Law Reform Institute on "Advance Directives and Substitute Decision-Making in Personal Healthcare".

7. Acute care nurses were significantly less familiar with advance healthcare directives in comparison with those in long term care settings.

8. The majority of respondents ranked the patient's spouse as the first person to be approached for healthcare directives and guardian as the last when the patient had no named healthcare agent, was terminally ill and mentally incapable of making healthcare decisions. This order of healthcare decision-makers was slightly different from that recommended by the Alberta Law Reform Institute.

9. There was no significant difference in familiarity with agency policy/procedure on advance healthcare directives between acute and long term care nurses.

10. While there was a scarcity of agency policies/procedures on advance healthcare directives, there were significantly more of such policies/procedures in place in long

term facilities than in acute care settings.

11. The majority of nurses were in favour of the use of advance healthcare directives and appointment of healthcare agents in specifying patients' treatment choices. They were positive about providing patient counselling and information on advance healthcare directives when facilitating patient's decision making process.

12. The roles and responsibilities identified by the majority of nurses were as follows:

-Provision of support to patients and families in their decisions

-Liaison with other professionals and resources

-Assistance to patients in developing advance healthcare directives

-Nurses need more knowledge and training

-Patient advocate

13. Inservice education and age both accounted for 19% of the variation in familiarity with advance healthcare directives in a stepwise multiple regression equation with other demographic variables which included age, types of nursing, experience, academic education, extent of information on A.D., size and location of facility. Thus, inservice education and age significantly predicted nurses' familiarity with advance healthcare directives.

14. There were no significant differences in familiarity with advance healthcare directives between the independent and dependent variables except for inservice education and the type of nursing in which the nurses engaged. Nurses from long term care settings were more familiar with advance healthcare directives than nurses in

acute care and those who had received more inservice education on advance healthcare directives were more familiar with this area.

Discussion

Nurses' Knowledge and Perceptions

This study identified registered nurses' knowledge and perceptions of advance healthcare directives and appointment of healthcare agents. Highlighted by these data were several components of critical importance in addressing, clarifying and establishing advance healthcare directives and appointing healthcare agents. Data revealed that almost half of the nurses were familiar with advance healthcare directives. On the other hand, the majority of respondents expressed unfamiliarity with the recommendations that were prepared by the Alberta Law Reform Institute on "advance directives and substitute decision-making in personal healthcare". The Institute recommended that legislation be introduced to give legal force to healthcare directives and to remedy the major deficiencies of the current law. Despite the fact that some felt that they were familiar with advance healthcare directives and appointing healthcare agents, nurses were lacking in knowledge about these external recommendations. Although results in relation to the familiarity with advance healthcare directives may have been affected by social desirability, it is likely that this would have been randomly distributed among acute and long term care nurses and therefore would not have affected the comparisons between these groups.

The nurses surveyed overwhelmingly identified the patient's spouse as the first healthcare decision maker when the patient was terminally ill and mentally incapable

of making health care decisions. On the contrary, the Alberta Law Reform Institute recommended that a guardian appointed under the Dependent Adults Act with authority to make healthcare decisions on behalf of the patient should be the first decision maker, followed by the healthcare agent appointed by the patient pursuant to the healthcare directive if one was made out in advance. If all these failed, the individual in the third order of priority would be the patient's spouse. These results further supported the previous observation that the respondents were lacking in knowledge about the current recommendations pertaining to advance healthcare directives and appointment of healthcare agents. However, the respondents may have interpreted the guardian as not being a family member and subsequently chose the spouse over the guardian.

The majority of nurses revealed that there were no agency policies or procedures relative to advance healthcare directives or appointment of healthcare agents. Similarly, almost one-half of the nurses surveyed said none of the patients they were working with had advance healthcare directives. Significant differences between the low completion rate of advance healthcare directives and the absence of agency policies and procedures was shown. This indicated that the presence of agency policies might have some impact on the completion rate of advance healthcare directives. However, the findings of this study only revealed a very small number of facilities where policies on advance healthcare directives were in place. Therefore, caution should be exercised when interpreting the impact of agency policy and the adherence rate to such a policy. Similarly, only a small number of nurses disclosed

that the policy on appointment of healthcare agents was emphasized. In addition, the majority of these policies and procedures were only established very recently, that is, within the last two years. This might have contributed to the lack of knowledge of many relative to advance healthcare directives and appointment of healthcare agents.

Data revealed that majority of the nurses were in favour of the use of advance healthcare directives and appointment of healthcare agents by an individual. Many supported the notion of respect for the patient's autonomy through promoting decision making for one's own health care preferences, supporting the patient's right to refuse treatment and using advance healthcare directives to specify treatment. These findings corroborated a survey by Davidson and colleagues (1989) of the attitudes of Arkansas physicians towards advance healthcare directives and another study by Kelner and colleagues (1993) regarding the views of health care professionals on advance directives. Over one-half of the nurses surveyed believed that counselling patients on advance healthcare directives and appointment of healthcare agents should take place while the patient was competent and about one third of the respondents asserted that it should be done on admission. Very few nurses identified that the counselling should begin when terminal illness was diagnosed nor at a specific age. This finding was consistent with findings of the study cited by Broadwell, Boisaubin, Dunn and Engelhardt (1993).

Respondents in this study believed that it should be part of the nurse's role to inform patients about advance healthcare directives and appointment of healthcare agents and strong agreement was shown for nurses' obtaining further education on

counselling patients in this area. Conversely the study by Honan and colleagues (1991) revealed that physicians and laypersons did not perceive discussion of resuscitative status as a responsibility of the nurse. Given that the topic of advance healthcare directives and appointment of healthcare agents has extended beyond the scope of resuscitation, it must be realized that nurses are integral members of the health care team and should assume responsibility to actively pursue discussions with patients as well as physicians.

Roles and Responsibilities

Interestingly, many nurses in this study indicated that patients, family, physicians and their own immediate supervisor were the top four persons with whom they would discuss issues and problems should there be any disagreement on patients' treatment preferences. Many of these nurses also suggested that an interdisciplinary approach to these disagreements was essential. Nevertheless, it is necessary to differentiate between situations in which health care practitioners are unwilling to comply with advance healthcare directives for clinical reasons and situations in which a patient's request violates the moral beliefs of the nurse. Making decisions about life-sustaining treatments is a complex process. The exercise of clinical judgement is a cornerstone of professional education for health care practitioners. If the treatment preferences of patients are to be honoured, health care practitioners may face the difficult prospect of relinquishing, at least in part, this central element of their professional role. Using an interdisciplinary approach in trying to resolve the disagreement seemed to be a more practical way in dealing with this issue. This

approach was further supported by Dubler's (1993) commentary:

> Decisions were rarely made by any one individual especially in matters as important as those of life and death. Many different people, from a wide range of disciplinary and experiential backgrounds were likely to become involved. Indeed, in many hospitals decision-making processes, even about more mundane clinical matters, have become so complex and involve so many different participants. . . (p. 23)

Forty percent of the respondents believed that nurses should act as facilitators for health care decision making with the patients. This was further expanded and clarified from the emerging themes of the last open ended question. Nurses believed that it was important to provide support to patients and families through listening to their concerns, communicating openly on the issues, teaching the disease process, providing information about advance healthcare directives and the available options. However, participants in this study seemed to assume that if patients were well informed they would make the same decisions as health care practitioners about the treatment choices. This assumption overlooks the fact that these decisions not only require clinical expertise but also involve patients' personal values. It is entirely possible that the choices of health care practitioners may differ from the preferences of patients and their families, even when all have the same information. The notion of giving meaning to these advance healthcare directives by supplementing a patient's value history was strongly supported by Doukas and Gorenflo (1993).

These survey results corroborated the view that nurses should be patient

advocates, mobilizing the other resources and expertise in order to help patients to develop their advance healthcare directives. As Diamond (1992) stated, "Advocacy is not paternalism; rather, it is giving information to patients and families to facilitate their informed, personal decision making. Advocacy involves "going to bat" for the patient, for example, as liaison between the patient and physician." (p. 895).

The majority of nurses in this study asserted that more education was required by nurses in order to better equip them to fulfill this role in facilitating decision making of patients relative to developing advance healthcare directives. Data collected on the extent to which the topic of advance healthcare directives and appointment of healthcare agents was covered in nurses' educational preparation revealed that this was minimal or absent from programs of study. The deficit of nursing education in this area was significant and somewhat astounding.

Demographic Characteristics

The findings of this study showed that there were no significant differences between familiarity with advance healthcare directives and age, experience, academic education, extent of information on A.D., location and size of facility. However, a significant difference was found between familiarity with advance healthcare directives and the type of nursing in which the respondents engaged. Nurses in long term care settings were more familiar with advance healthcare directives than acute care nurses. More nurses expressed the view that their professional practice in the long term care area had influenced their views towards advance healthcare directives. This might have contributed to their familiarity with the directives in long term care settings.

Respondent's age and inservice education seemed to have an impact on predicting their familiarity with advance healthcare directives. Also, a significant difference between inservice education on advance healthcare directives and familiarity with advance healthcare directives was shown in that the more inservice education nurses received, the more knowledgeable they were in facilitating advance healthcare planning with patients. However, survey results revealed that over one-half of the respondents had not attended any inservice education program or other presentation on advance healthcare directives within the previous two years. This may explain the phenomenon that nurses were not knowledgeable in this area. Despite growing public interest in advance healthcare directives and its significant clinical application within the health care system, it appears that information on this area has not been widely disseminated within the profession.

CHAPTER 5: CONCLUSIONS & SUMMARY

Implications

Nursing Education

If nurses lack knowledge about advance healthcare directives and skills in assisting patients in decision making, they are unlikely to be able to provide patients with information and guidance to effectively develop their advance healthcare directives and appoint healthcare agents. Educators could take the opportunity to introduce this concept in the basic nursing curriculum to prepare nurses more adequately in clinical settings. Conducting interdisciplinary workshops on advance healthcare directives and appointing of healthcare agents involving case studies and group discussions could promote open communication on this topic. Inviting lawyers with expertise in healthcare to clarify the legal implications and terminology of advance healthcare directives could also expand nurses' knowledge in this area. Education and open communication could foster the realization that nurses are integral members of the health care team and should assume responsibility to actively pursue discussions with patients as well as other interdisciplinary team members.

Educators could also introduce the concept of an Ethics Committee and thus could provide the opportunity for health care practitioners to learn the role and functions of such committees in guiding decision making. Education of patients, family and health care practitioners will be an important component for the success and overall important implementation of advance healthcare directives.

Clinical Practice Implications

The use of advance healthcare directives to guide healthcare decision making in the event that a patient becomes incompetent has become a topic of interest as it has significant impact on clinical decision making. While there is some evidence to show that nurses are supporting the concept of advance healthcare directives and appointment of healthcare agents, implementation of this concept involves a great deal more than simply handing patients written information. As it has been seen in the study by Hare and Nelson (1991), patients receiving only written information on advance healthcare directives are unlikely to complete one, and very few initiate discussions with their physicians. In reality, many elderly patients also have reading and various cognitive impairments which nurses need to address before any meaningful communication to be taken place. These results, however, point to the need for broader approaches in how the information of advance healthcare directives should be presented to patients. It is not a foregone conclusions that advance healthcare directives, even when completed, will be followed or that the documentation will be transferred with patients to other healthcare facilities. Thus, nurses will need to gain a better understanding of planning for advance healthcare directives in order that dynamic protocols for implementing these are developed to monitor care rendered.

Administrative Implications

Data revealed that there was a scarcity of agency policies and procedures on advance healthcare directives where emphasis on the appointment of healthcare agents was minimal. Additionally, a majority of the nurses surveyed disclosed that they were

unsure whether such policies and procedures existed within their agency. This lack of knowledge about existing policies is an area that all educators need to understand and address on a priority basis. Educators and administrators can play key roles by opening discussions in this area, serving as leaders in pursuing educated decisions on the definitions and providing the follow-up education to disseminate the information to promote consistency in implementing advance healthcare directives within the organization.

The low completion rate of advance healthcare directives and appointment of healthcare agents suggests that barriers to use of these directives still exist and that measures to deal with such impediments must be developed by hospital administrators, legislators and educators. However, if advance healthcare directives and appointment of healthcare agents are to become an integral part of health care, more legislation and regulations will be needed. Formalized policies and procedures in this area within the institution will provide support and direction for health care practitioners in clinical settings.

Research Implications

Advance healthcare directives and appointment of healthcare agents have been considered as the mechanism to empower patients so that they may maintain control of their care and treatment even when they become incompetent. The use of advance healthcare directives is still in its infancy and it will take time and effort to grapple with different issues and limitations. Since there is a paucity of research in this area, this study serves only as a preliminary effort in trying to explore nurses'

perceptions and knowledge of advance healthcare directives and appointment of healthcare agents. Since nurses are one group of health care professionals which has close contact with patients and families on a daily basis and since nurses have considerable interpersonal influence, they can have power to ensure that decisions are made in accordance with patients' values and wishes. However, more research is needed to examine how well patients can maintain their control of their care and treatment through advance healthcare directives and appointment of healthcare agents. We also need to explore possible approaches to defining and implementing optimal procedures to make health care decisions on behalf of incompetent adults, and how to construct a good clinical process for advance planning that is practical, maximizes benefits and minimizes risks. More research in examining these issues must be sought before substantial social resources are committed to any particular strategy.

Summary

This study identified registered nurses' perceptions and knowledge on advance healthcare directives and appointment of healthcare agents. Data revealed that there was a lack of knowledge about these directives and the recommendations by the Alberta Law Reform Institute. However, they viewed such directives and appointment of healthcare agents very favourably. Long term care nurses were more familiar with the directives than acute care nurses. While there were no significant differences between familiarity and other demographic variables such as age, experience, academic education, location and size of facility, inservice education and age together predicted respondents' familiarity with advance healthcare directives. The majority of nurses

identified minimal or no content in their educational preparation pertaining to advance healthcare directives and appointment of healthcare agents. Very few nurses actually had received inservice presentations on this topic within the last two years. Most nurses concurred with the notion that competent patients should be the final decision maker in their own health care and supported the patient's right to refuse medical treatment and to use advance healthcare directives to specify treatment choices. In spite of the need to develop further knowledge and skill in this area, nurses agreed that they should be able to facilitate the patient's decision making process and provide relevant information to patients and families through counselling, listening and teaching. They believed that counselling on the directives should be initiated as long as the patient was still competent. A strong notion of using the interdisciplinary approach in dealing with disagreements on treatment emerged and nurses believed that they should act as a liaison among the health care team members in order to advocate for respecting patients' personal values and treatment choices.

Implications for education, clinical practice, administration and research were discussed. Education for health care practitioners, patients and families together with administrative support are essential elements for successful implementation of advance healthcare directives and appointment of healthcare agents. Further research is required in exploring an optimal clinical process that is practical and effective in planning for difficult health care decisions, many of which can be described as ethical dilemmas.

References

Advance Directives Seminar Group, Centre for Bioethics (1992). Advance directives: Are they an advance? Canadian Medical Association Journal, 146(2), 127-134.

Alberta Law Reform Institute (1990). Enduring powers of attorney. Report for discussion, no. 7. Edmonton, AB: Author.

Alberta Law Reform Institute (1991). Advance directives and substitute decision-making in personal healthcare. Report for discussion, no. 11. Edmonton, AB: Author.

Alberta Law Reform Institute (1993). Advance directives and substitute decision making in personal healthcare. Report for discussion, no. 64. Edmonton, AB: Author.

American Medical Association (1989). Physician and public attitudes on health care issue. Chicago: Author.

American Hospital Association Technical Panel (1991). Hospitals and advance directives. Q & A, 1-4.

Applelbaum, P. S. & Grisso, T. (1988). Assessing patient's capacities to consent to treatment. New England Journal of Medicine, 319(25), 1635-1638.

Bastnagel, S. (1993). Risk analysis: The patient self-determination act-living will and other types of advance directives. Hospital Risk Control, Critical Care, 13(1), 1-34.

Beauchamp, T. L., & Childress, J. F. (1989). Principles of biomedical ethics. New York: Oxford University Press.

Bedell, S. E., Pelle, D., & Maher, P. L. (1986). Do-not-resuscitate orders for critically ill patients in the hospital: How are they used and what is their impact? Journal of the American Medical Association, 256, 233-238.

Boetzkes, E. (1993). Autonomy and advance directives. Canadian Journal on Aging, 12(4), 441-452.

Brennan, T. A. (1988). Ethics committees and decisions to limit CPR: The experience at the Massachusetts General Hospital. Journal of American Medical Association, 260, 803-807.

Brink, P. J. & Wood, M. J. (1988). Basic steps in planning nursing research: From question to proposal (3rd ed.). Boston: Jones & Bartlett Publishers.

Broadwell, A. W., Boisaubin, E. V., Dunn, J. K., & Engelhardt, H. T. Jr. (1993). Advance directives on hospital admission: A survey of patient attitudes. Southern Medical Journal, 86(2), 165-168.

California Natural Death Act (1976). Cal Code Health and Safety, s7185-7195.

Canadian Bar Association (1991). Doctor recommends wider use of living wills. Ottawa: Author.

Canadian Medical Association (1992). CMA policy summary: Advance directives for resuscitation and other life-saving or sustaining measures. Canadian Medical Association Journal, 146(6), 1072A.

Canadian Nurses Association (1991). Code of Ethics for Nursing. Ontario: Author.

Cassileth, B. R., Zupkis, R. V., Sutton-Smith, K., & March, V. (1980). Informed consent: Why are its goals imperfectly realized? New England Journal of

Medicine, 302, 896-918.

Cohen-Mansfield, J., Rabinovisch, B. A., Lipsen, S. Gerber, B., Fein, A.,& Weisman, S. (1991). The decision to execute a durable power of attorney for health care and preferences regarding the utilization of life-sustaining treatments in nursing home residents. Archives of Internal Medicine, 151, 289-294.

Council on Ethical and Judicial Affairs of the American Medical Association (1989). Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association. Chicago: Author, Opinions 2.20, 2.21.

Christal, L. A. (1989). Legal forum, Nursing Administration Quarterly, 12(3), 84-88.

Danis, M., Southerland, L. I., & Garrett, J. M. (1991). A prospective study of advance directives for life-sustaining care. New England Journal of Medicine, 324, 882-888.

Davidson, K. W., Hackler, C., Caradine, D. R., & McCord, R. S. (1989). Physicians' attitudes on advance directives. Journal of American Medical Association, 262(17), 2415-2419.

Demi, A. (1989). Durable power of attorney for health care: Planning for substitute decision making. Journal of Neuroscience Nursing, 21(5), 322-325.

Diamond, E. P. (1992). The oncology nurse's role in patient advance directives. Oncology Nursing Forum, 19(6), 891-896.

Doukas, D. J., Antonucci, T. A., & Gorenflo, D. W. (1992). A multigeneral study on the correlation of values and advance directives. Ethics and Behaviour 2, 51-59.

Doukas, D. J., & Gorenflo, D. W. (1993). Analyzing the values history: An evaluation of patient medical values and advance directives. The Journal of Clinical Ethics, 4(1), 41-45.

Doukas, D. J., & McCullough, L. B. (1991). The value history: The evaluation of the patient's values and advance directives. The Journal of Family Practice, 32(2), 145-153.

Downie, J. (1992). Where there is a will, there may be a better way: Legislating advance directives. Health Law in Canada, 12(3), 73-89.

Dubler, N. N. (1993). Commentary: Balancing life and death - proceed with caution. American Journal of Public Health, (83), 23-25.

Earle, C., & Noseworthy, T. (1992). The role of nurses in making clinical decisions. The Bioethics Bulletin. Edmonton: University of Alberta Printer.

Edinger, W., & Smucker, D. R. (1992). Outpatients' attitudes regarding advance directives. Journal of Family Practice, 35(6), 650-653.

Eisendrath, S. J., & Jonsen, A. R. (1983). The living will: Help or hindrance. Journal of American Medical Association, 249(15), 2054-2058.

Elpern, E. H., Yellen, S. B., & Burton, L. A. (1993). A preliminary investigation of opinions and behaviours regarding advance directives for medical care. American Journal of Critical Care, 2(2), 161-167.

Emanuel, L. (1993). Advance directives: What have we learned so far? The Journal of Clinical Ethics, (4)1, 8-16.

Emanuel, L. L., Barry, M. J., Stoeckle, J. D., Ettelson, L., & Emanuel, E. J. (1991).

Advance directive for medical care. The New England Journal of Medicine, 324(13), 889-895.

Emanuel, L. L., & Emanuel, E. J. (1989). The medical directive: A new comprehensive advance care document. Journal of the American Medical Association, 261, 3288-3293.

Enderlin, A., & Wilhite, M. J. (1991). Establishing incidence and administrative protocols for do not resuscitate orders. Journal of Gerontological Nursing, 17(2), 12-16.

Everhart, M. A., & Pearlman, R. A. (1990). Stability of patient preferences regarding life-sustaining treatment, Chest 97, 159-164.

Fisher, R. H., & Meslin, E. M. (1990). Should living wills be legalized? Canadian Medical Association Journal, 142(23).

Flarey, D. L. (1991). Advance directives: In search of self-determination. Journal of Nursing Administration, 21(11), 16-22.

Frampton, M. W., & Mayewski, R. J. (1987). Physicians' and nurses' attitudes toward withholding treatment in a community hospital. Journal of General Internal Medicine, 2, 394-399.

Gallup, G., & Newport, F. (1991). Mirror of American: Fear of dying. Gallup Poll News Services, 55, 3-5.

Gamble, E. R., McDonald, P. J., & Lichstein, P. R. (1991). Knowledge, attitudes, and behaviour of elderly persons regarding living wills. Archives of Internal Medicine, 151(2), 277-280.

Goold, S. D., Arnold, R. M., & Siminoff, L. A. (1993). Discussions about limiting treatment in a geriatric clinic. American Geriatrics Society, 41, 277-281.

Grodin, M. A. (1993). Religious advance directives: The convergence of law, religion, medicine and public health. American Journal of Public Health, 83(6), 899-903.

Hassmiller, S. (1991). Bringing the Patient Self-Determination Act into practice. Nursing Management, 22(12), 29-32.

Hare, J., & Nelson, C. (1991). Will outpatients complete living wills? A comparison of the two interventions. Journal of General Internal Medicine, 64, 41-46.

Higgs, R. (1987). Living wills and treatment refusal. British Medical Journal, 295(6608), 1222.

High, D. M. (1987). Planning for decisional incapacity: A neglected area in ethics and aging. Journal of the American Geriatric Society, 35(8), 814-820.

High, D. M. (1988a). All in the family: Extended autonomy and expectations in surrogate health care decision making. The Gerontologist, 28, 46-51.

High, D. M. (1993). Advance directives and the elderly: a study of intervention strategies to increase use. The Gerontologist, 33(3), 342-349.

Holley, J. L., Nespor, S., & Rault, R. (1993). The effects of providing chronic hemodialysis patients written material on advance directives. American Journal of Kidney Dialysis, 22(3), 413-418.

Honan, S., Helseth, C., Bakke, J., Karpiuk, K., Krsnak, G., & Torkelson, R. (1991). Perception of "No Code" and the role of the nurse. The Journal of Continuing Education in Nursing, 22(2), 54-61.

Hospitalta (1991). Ethicist calls for advance directives laws, 4(5).

Hague, S. B., & Moody, L. E. (1993). A study of the public's knowledge regarding advance directives. Nursing Economics, 11(5), 303-323.

Hudson, T. (1994). Advance directives: Still problematic for providers. Hospitals and Health Networks, 3.

Kelner, M., Bourgeault, I. L., Hebert, P. C., & Dunn, E. V. (1993). Advance directives: The views of health care professionals. Canadian Medical Association Journal, 148(8), 1331-1338.

Kohn, M., & Menon, G. (1988). life prolongation: Views of elderly outpatients and health care personnel. Journal of American Geriatric Society, 36, 841-844.

LaPuma, J., Orentlicher, D., Moss, R. J. (1991). Advance directives on admission: Clinical implications and analysis of the patient self-determination act of 1990. Journal of American Medical Association, 266, 405-405.

Law Reform Commission of Saskatchewan (1991). Proposals for an advance directive act. Saskatoon: Author.

Libow, L. S., & Starer, P. (1989). Care of the nursing home patient. New England Journal of Medicine, 321(2), 93-96.

Lo, B., Saika, G., & Strull, W. (1985). Do not resuscitate decisions: A prospective study at three teaching hospital. Archives of Internal Medicine, 322, 1115-1117.

Lo, B., Mcleod, G. A., & Saika, G. (1986). Patient attitudes to discussing life-sustaining treatment. Archives of Internal Medicine, 146, 1613-1615.

Lutz, H. A. (1988). Informed consent: A process of shared decision making. Washington Hospital Centre Medical Staff Bulletin, 4-5.

MacKay, S. (1992). Durable power of attorney for health care. Geriatric Nursing, 3(4), 99-108.

McMillan, J. H. (1992). Education research: Fundamentals for the consumer. New York: Harper Collins Publishers.

Miles, S. H., Singer, P. A., & Siegler, M. (1989). Conflicts between patients' wishes to forgo treatment and the policies of health care facilities. New England Journal of Medicine, 321, 48-50.

Miller, A., & Lo, B. (1985). How do doctors discuss do-not-resuscitate orders? Western Journal of Medicine, 143, 256-258.

Molloy, D. W., Guyatt, G., Alemayehu, E., McIlroy, W. E. (1991). CMA ethics: Treatment preferences, attitudes toward advance directives and concerns about health care. Humane Medicine, 7(4), 285-290.

Molloy, W., & Mepham, V. (1992). Let me decide. Toronto: Penguin Book.

Nanovic, S. J. (1990). The living will: Presentation of the right to die demands clarity and consistency, Dickinson Law Review, 95(1), 109-234.

Noseworthy, T., & Earle, C. (1992). The role of nurses in making clinical decisions. The Bioethics Bulletin, 4(1), 1-2.

Omnibus Budget Reconciliation Act (1990). U.S. Public Law 101-508, s4206, 4751.

Orentlicher, D. (1990). Advance medical directives. Journal of American Medical Association, 263, 2365-2367.

Ouslander, J., Tymchuk, A., & Rahbar, B. (1989). Health care decisions among elderly long-term care residents and their potential proxies. Archives of Internal Medicine, 149, 1367-1372.

Pearlman, R. A., & Jonsen, A. (1985). The use of quality-of-life considerations in medical decision-making. Journal of American Geriatric Society, 33, 344-352.

Premier's Commission on Future Health Care for Albertans (1989). Rainbow Report. Alberta: Author.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research. (1983). Making health care decisions: Report on the ethical and legal implications of informed consent in the patient/practitioner relationship. Washington, DC: U.S. Government Printing Office.

Richardson, J. P. (1992). Health promotion for the nursing home patient. Journal of American Family Practice, 5(2), 127-136.

Robertson, G. B. (1991). Advance directives - A legal view. Health Law Review, 1(1), 3-6.

Ruark, J. E., Raffin, T. A., & the Stanford University Medical Centre Committee on Ethics. (1988). Initiating and withdrawing life support: Principles and practices in adult medicine. New England Journal of Medicine, 318, 25-30.

Sachs, G. A., Stocking, C. M., & Miles, S. H. (1992). Failure of an intervention to promote discussion of advance directives. Journal of the American Geriatric Society, 40(3), 267-273.

Sam, M., & Singer, P. A. (1993). Canadian outpatients and advance directives: Poor

knowledge and little experience but positive attitudes. Canadian Medical Association Journal, 148(9), 1497-1502.

Schmeiser, D. A. (1989). Living wills and medical treatment of the terminally ill. Forum, 2(3), 32-37.

Shmerling, R. H., Bedell, S. E., & Lilienfeld, A. (1988). Discussing cardiopulmonary resuscitation: A study of elderly outpatients. Journal of General Internal Medicine, 3, 317-321.

Seckler, A. S., Meier, D. E., Mulvihill, M., & Cammer Paris, B. E. (1991). Substituted judgement: How accurate are proxy predictions. Annals of Internal Medicine, 115(2), 92-98.

Silverstein, M. D., Stocking, C. B., & Antel, J. P. (1991). Amyotrophic lateral sclerosis and life-sustaining therapy: Patients' desires for information, participation in decision making and life-sustaining therapy. Mayo Clinic Proceedings, 66, 906-913.

Singer, P. A., Choudhry, S., & Armstrong, J. (1993). Public opinion regarding consent to treatment. Journal of American Geriatric Society, 41(2), 112-116.

Singer, P. A. & Siegler, M. (1991). Elective use of life-sustaining treatments. In G. H. Stollerman (Ed.), Advances in internal medicine (Vol. 36, pp. 57-79). New York: Yr Bk Med Pubs.

Smedira, N. G., Evans, B. H., & Grais, L. S. (1990). Withholding and withdrawal of life support from the critically ill. New England Journal of Medicine, 322, 309-315.

Society for the Right to Die (1988). Newsletter, Winter, 1.

Sonnenblick, M., Friedlander, Y., & Steinberg, A. (1993). Dissociation between the wishes of terminally ill parents and decisions by their offspring. Journal of American Geriatric Society, 41(6), 599-604.

Spears, R., Drinka, P. J., & Voeks, S. K. (1993). Obtaining a durable power of attorney for health care from nursing home residents. Journal of Family Practice, 36(4), 409-413.

Statistics Canada. (1991). Profile of persons with disabilities residing in health care institutions in Canada (Catalogue: 82-615). Ottawa: Author.

Stechmiller, J. K., Conlon, M., & Anderson, G. C. (1991). Selected characteristics of nurses and physicians who have living wills. Death Studies, 15, 119-130.

Steiber, S. R. (1987). Right to die: Public talks at deciding for others. Hospitals, 61(5), 72.

Stolman, C., Gregory, J. J., Dunn, D., & Levine, J. L. (1990). Evaluation of patient, physician, nurse, and family attitudes toward do not resuscitate orders. Archives of Internal Medicine, 150, 653-658.

Storch, J. L., & Dossetor, J. B. (1991). Public attitudes towards end-of-life treatment decisions: Implications for nurses. Manuscript submitted for publication.

Towers, J. (1992). Advance care directives: Counselling the patient and family in the primary care setting. Nurse Practice Forum, 3(1), 25-27.

U. S. Congress (1987). Office of technology assessment institutional protocols for decisions about life-sustaining treatments, (special report). Washington, D.C.:

U. S. Government Printing Office.

Uhlmann, R., Pearlman, R. A., & Cain, K. C. (1988). Physicians' and spouses' predictions of elderly patients' resuscitation preferences. Journal of Gerontology, 43(5), M115-121.

U. S. Senate Special Committee on Aging (1987). A matter of choice: Planning ahead for health care decisions. Washington, D. C.: U. S. Government Printing Office.

Waltz, C. F., Strickland, O. L., & Lenz, E. R. (1991). Measurement in nursing research (2nd ed.). Philadelphia: F. A. Davis.

Wilson, D. M. (1993). The influence for do-not-resuscitate policies and end-of-life treatment or non-treatment decisions. Unpublished doctorate thesis, University of Alberta, Edmonton, Alberta.

Woolf, H. B. (Eds.). (1980). Webster's new Collegiate dictionary. Massachusetts: G & C Merriam.

Youngner, S. J., Lewandowski, W, & McClish, D. K. (1985). Do not resuscitate orders: Incidence and implications in a medical intensive care unit. Journal of American Medical Association, 253, 54-57.

Zweibel, N. R., & Cassel, C. K. (1989). Treatment choices at the end of life: A comparison of decisions by patients and their physician-selected proxies. The Gerontologist, 29, 615-621.

Zweibel, N. R., & Lydens, L. A. (1989). Incongruent perceptions of older adults/caregiver dyads. Family Relations, 29-32 .

APPENDIX A:
SURVEY QUESTIONNAIRE ON ADVANCE HEALTHCARE DIRECTIVES AND APPOINTMENT OF HEALTHCARE AGENTS 'LIVING WILL'

(Please check or fill in an appropriate response)

1. The area in which you are working is primarily: (check one)
   - a long term care/continuing care setting _____1
   - an acute care setting _____2
   - other (specify) _____3

2. How long have you worked in this area? (check one)
   - < 1 year _____1
   - 1-2 years _____2
   - 3-4 years _____3
   - 5-10 years _____4
   - 11-20 years _____5
   - > 20 years _____6

3. What is the size of your facility? (check one)
   - 1-25 beds _____1
   - 26-50 beds _____2
   - 51-99 beds _____3
   - 100-199 beds _____4
   - 200-299 beds _____5
   - > 300 beds _____6

4. Your facility is located in ... (Check one)
   - Urban area _____1
   - Rural area _____2

5. What age group do you belong to? (Check one)
   - < 20 years old _____1
   - 20 - 25 years old _____2
   - 26 - 30 years old _____3
   - 31 - 35 years old _____4
   - 36 - 40 years old _____5
   - 41 - 45 years old _____6
   - 46 - 50 years old _____7
   - 51 - 55 years old _____8
   - 56 - 60 years old _____9
   - 61 - 65 years old _____10
   - > 65 years old _____11

6. Please check off your highest level of academic achievement. (Check one)
   Diploma in nursing _____1
   Degree in nursing/other, specify: _____2
   Master's level preparation, specify: _____3
   Doctorate's level education, specify: _____4
   Other (specify) _____5

7. To what extent was the topic of advance healthcare directives covered in your educational preparations? (Check one)
   Extensively___1 Partially____2 Minimally_____3 None at all____4

8. Have you received any educational presentations related to advance healthcare directives and the appointment of healthcare agents within the last 2 years? (Check one)
   Yes_____1
   No_____ 2

9. Are you familiar with advance healthcare directives? (Check one)
   Very familiar _____1
   Somewhat familiar _____2
   aware _____3
   somewhat unfamiliar _____4
   unfamiliar _____5

10. Is there a policy/procedure on advance healthcare directives in your agency? (Check one)
    Yes _____1
    No _____2
    Unsure _____3

10a. If the answer to question 10 is yes, when was the policy/procedure established? (Check one)
    pending implementation _____1
    0-6 months ago _____2
    7-11 months age _____3
    1-2 years ago _____4
    3-4 years ago _____5
    > 4 years age _____6

10b. If the answer to question 10 is yes, how familiar are you with the policy/procedure on advance healthcare directives in your agency? (Check one)
    very familiar _____1
    somewhat familiar _____2
    aware _____3
    somewhat familiar _____4
    unfamiliar _____5

10c. If the answer to question 10 is yes, to what extent do you think this policy/procedure is followed? (Check one)

at all times	_____1
often	_____2
sometimes	_____3
rarely	_____4
never	_____5

11. Are you familiar with the recommendations that were prepared by the Alberta Law Reform Institute and the Health Law Institute in 1993 on 'Advance Directives and Substitute Decision-Making in Personal Healthcare'? (Check one)

very familiar	_____1
somewhat familiar	_____2
aware	_____3
somewhat familiar	_____4
unfamiliar	_____5

12. To your knowledge have any of the patients you have worked with had an advance healthcare directive made? (Check one)
(If the answer is 'none', proceed to question 13)

yes, all patients	_____1
yes, majority of the patients	_____2
yes, only some patients	_____3
yes, only a few patients	_____4
none	_____5

12a. If the answer to question 12 is yes, how comfortable were you in following the patient's advance directives? (Check one)

completely comfortable	_____1
mostly comfortable	_____2
undecided	_____3
somewhat uncomfortable	_____4
very uncomfortable	_____5

13. Do you think your views toward advance healthcare directives [illegible] influenced by your previous nursing professional experience? (Check one)
(If the answer is 'no' or 'undecided', proceed to question 14)

yes	_____1
no	_____2
undecided	_____3

13a. If the answer to question 13 is yes, which area of practice influenced you most?

long term care/continuing care	_____1
acute care (specify)	_____ _____2
other (specify)	_____3

14. Are you in favour the use of a healthcare agent who is appointed by a patient to make health care decisions on his/her behalf when this patient is unable to make health care decisions? (Check one)

Yes _____1
No _____2
Undecided _____3

14a. Does your agency have a policy which allows patient to specify a healthcare agent? (If the answer is no, proceed to question 15)

Yes _____1
No _____2

14b. If the answer to question 14a is yes, is there emphasis on appointing a healthcare agent when the patient is making an advance healthcare directive? (Check one)

yes, at all times _____1
yes, sometimes _____2
no, none at all _____3
Unsure _____4

15. Do you favour the use of advance healthcare directives for competent patients who provide instructions about their future health care decisions to be make on their behalf when they are mentally incapable of making healthcare decisions? (Check one)

yes _____1
no _____2
undecided _____3

16. The final authority in making decisions regarding the treatment preferences of a terminally ill competent patient is the... (check one)

patient _____1
family _____2
physician _____3
nurses _____4
other (specify) _____5

17a. If the patient who has <u>not</u> named a healthcare agent, is terminally ill and mentally incapable of making a healthcare decision, , who should be asked to make a decision on treatment choices? (Rank order on the list below . e.g. '1' is the first person to be asked to make the decision, '2' is the second person to be asked if the first person is unavailable, etc.)

a guar[illegible]ted under the Dependent Adults Act with authority to make health [illegible]n behalf of the patient _____1
the patie[illegible] partner _____2
the patie[illegible] _____3
the patient _____4
the patient's [illegible]s _____5
any other relative of the patient _____6
the patient's healthcare practitioner _____7

17b. If the patient who has named a healthcare agent, is terminally ill and mentally incapable of making a healthcare decision, who should be asked to make a decision on treatment choices? (Rank order on the list below)

a guardian appointed under the Dependent Adults Act with authority to make healthcare decisions on behalf of the patient	_____1
a healthcare agent appointed by the patient	_____2
the patient's spouse or partner	_____3
the patient's children	_____4
the patient's parents	_____5
the patient's siblings	_____6
any other relative of the patient	_____7
the patient's healthcare practitioner	_____8

18. Do you believe a competent person has the right to refuse life-sustaining medical treatment? (Check one)

yes, absolutely	_____1
yes, under most conditions	_____2
undecided	_____3
no, but with some exceptions	_____4
no, absolutely not	_____5

19. Do you think patients should be able to use advance healthcare directives and the appointment of healthcare agents to specify treatment preferences? (Check one)

yes, absolutely	_____1
yes, under most conditions	_____2
undecided	_____3
no, but with some exceptions	_____4
no, absolutely not	_____5

20. Should advance healthcare directives be considered as the admission criteria for people entering long term care facilities? (Check one)

Yes	_____1
No	_____2
Undecided	_____3

21. Do you think nurses should inform patients about advance healthcare directives and the appointment of healthcare agents? (Check one)

yes, absolutely	_____1
yes, under most conditions	_____2
undecided	_____3
no, but with some exceptions	_____4
no, absolutely not	_____5

22. If the answer to question 21 is no, who do you think should provide patients with information about advance healthcare directives and the appointment of healthcare agents?

family	_____1
physicians	_____2
social workers	_____3
religious ministers	_____4
unit clerks	_____5
nurses	_____6
no one	_____7
other (specify)	_____8

23. Should nurses be trained to counsel patients on advance healthcare directives and the appointment of healthcare agents? (Check one)

yes, absolutely	_____1
yes, under most conditions	_____2
undecided	_____3
no, but with some exceptions	_____4
no, absolutely not	_____5

24. When should the counselling on advance healthcare directives and the appointment of healthcare agents be provided to long-term care patients?

on admission	_____1
while patient is competent	_____2
when terminal disease diagnosed	_____3
at a specific age	_____4
never considered it	_____5
other (specify)	_____6

25. What would you do if you did not agree with the patient's and family's choice about life-sustaining treatment? (Check all appropriate choices)

discuss my concerns with the patient	_____1
discuss my concerns with the physicians	_____2
discuss my concerns with my immediate supervisor	_____3
discuss my concerns with the family	_____4
discuss my concerns with the social workers	_____5
do nothing about it	_____6
other (specify)	_____7

26. Should nurses facilitate patients in their decision-making process regarding advance healthcare directives? (Check one)

yes, absolutely	_____1
yes, under most conditions	_____2
undecided	_____3
no, but with some exceptions	_____4
no, absolutely not	_____5

27. Please elaborate on what you believe to be nurses' role and responsibilities in regards to facilitating patients in developing their advance healthcare directives and the appointment of healthcare agents.

_____

_____

_____

_____

_____

_____

_____

Thank you for completing the questionnaire.

Please place your completed questionnaire in the self-addressed, stamped envelope and return it to me through the A.A.R.N. as soon as you can.

Appendix B:

EVALUATION OF SURVEY QUESTIONNAIRE

Please comment on the appearance, content and format of the attached questionnaire. Return the completed evaluation form to Queenie Choo. Your help is much appreciated! Queenie.

1. **Does the questionnaire generally ask the most important and relevant questions regarding nurses' perception and knowledge on advance healthcare directives? (Check one)**
Yes_____ No_____

2. **Are any questions difficult to understand? (Check one)**
Yes_____ No_____

2a. **If the answer to question 2 is yes, which ones, and how these might be improved?**

_____
_____
_____

3. **Are any questions unnecessary? (Check one)**
Yes_____ No_____

3a. **If the answer to question 3 is yes, indicate which ones could be deleted?**

_____
_____
_____

4. **Are any questions missing? (Check one)**
Yes_____ No_____

4a. **If so, what would you suggest could be added?**

_____
_____
_____

5. **How long did it take you to complete the questionnaire?_____**

6. **Is the questionnaire.....(Check one)**
too long _____
too short _____
about the right length _____

7.
comments:_____
_____
_____
_____
_____

Appendix C:
Covering Letter to Subjects

Queenie Choo, RN, BScN.
15512 - 68 Street,
Edmonton, Alberta.
T5Z 2W5.

June 28, 1994.

Dear Colleague:

I am a candidate for a Master's in Nursing degree at the University of Alberta and I am undertaking a research project to determine the knowledge and perceptions towards advance healthcare directives and appointment of healthcare agents among Alberta nurses. Your name has been randomly selected from the membership of the Alberta Association of Registered Nurses. I would appreciate if you could take 10 to 15 minutes to complete the attached questionnaire on advance healthcare directives and return your completed questionnaire in the prepaid envelope as soon as possible.

This study is my research project and is being conducted at my expense. Although the AARN has allowed me to use its mailing service, this does not constitute endorsement by the AARN of this research. Since your participation in this survey is completely voluntary, you are under no obligation to return the questionnaire. There will be no direct benefits to you if you take part in this study, nor will there be any repercussions if you decide not to participate. But your responses are very important to this study.

Since not much is known about nurses' perception of and feelings about their role in the discussion of advance healthcare directives, research results of this research will provide baseline data for future research in the area of advance healthcare directives and could be used for designing education programs for clients/family and healthcare professionals to implement advance healthcare directives within the healthcare setting.

Your consent to take part in this study will be assumed once the completed questionnaire has been received by me. The data collected in this study will be retained in a secure location for seven years. The only persons to see the completed questionnaire will be my thesis supervisor, Dr Janet Ross Kerr, my research committee members (2) and myself. Your responses will be completely confidential and anonymous. I will have no way of identifying individuals from any completed questionnaires, and all information will be reported as group data only. At no time the information will be possible to identify any individual participant.

If you have any questions, please telephone me at 430-9110 in Edmonton. My supervisor on this research project is Janet Ross Kerr, RN, PhD, Professor in the Faculty of Nursing and Division of Bioethics, University of Alberta, and she may be contacted at 492-6253. We can be contacted between 0900 and 1600 hours Monday to Friday.

Should you wish to access the results of this study, a copy of my thesis will be placed at the J.W. Scott Health Sciences Library and the AARN Library upon

completion of this research. Thank you very much for your time and interest in our fellow nurses in Alberta. I look forward to receiving your completed questionnaire.

Sincerely,

Queenie Choo, RN
Master's in Nursing Candidate

Appendix D:
Reminder Letter to Subjects

Queenie Choo, RN, BScN
15512-68 Street,
Edmonton, Alberta.
T5Z 2W5
Tel: (403) 430 - 9110

August 2, 1994

Dear Colleague:

Approximately three weeks ago, I have sent you a survey questionnaire on advance healthcare directives and appointment of healthcare agents. Since your response to this survey questionnaire is very important to my research project, I really appreciate your time and effort in completing the questionnaire as soon as possible and returning it in the pre-stamped envelope provided in the package.

If you have already returned your questionnaire, I would like to take this opportunity to thank you for your keen interest in our fellow Alberta nurses by participating in this research project and please ignore this reminder. If you have not yet responded to the questionnaire, please take 10 - 15 minutes to complete the questionnaire. Your response is very much appreciated!

Should you require another copy of the survey questionnaire, please contact the Graduate Education Office at the Faculty of Nursing, University of Alberta at (403) 492-6251. This procedure will ensure your responses are completely anonymous.

Thanks again!

Sincerely,

Queenie Choo, RN
Master's in Nursing Candidate

Appendix E

QUESTIONNAIRE:
FACTOR ANALYSIS WITH EIGHT FACTORS GENERATED

	FACTOR							
VAR	1	2	3	4	5	6	7	8
1	0.17	0.83	0.22	0.23	0.36	0.17	0.09	-0.05
2	0.26	0.37	0.02	0.35	0.76	0.17	0.09	-0.05
3	0.10	0.35	0.84	0.11	-0.07	-0.23	0.03	0.07
4	0.24	0.14	-0.22	0.49	-0.07	-0.02	0.33	-0.69
5	0.30	0.89	0.07	0.09	-0.08	-0.19	0.03	0.16
6	0.56	0.28	0.66	0.19	0.04	0.05	0.14	0.11
7	0.68	0.05	-0.06	-0.02	0.53	0.28	0.23	-0.08
8	0.11	-0.06	0.09	0.26	0.15	0.89	-0.21	0.11
9	0.17	0.83	0.22	0.23	0.37	0.17	0.09	-0.05
10	-0.01	0.12	-0.09	0.11	-0.02	-0.07	0.05	0.96
11	0.77	0.06	0.41	0.11	0.22	0.19	-0.16	-0.34
12	0.37	0.27	0.40	0.57	0.08	0.40	0.20	-0.03
13	0.80	0.15	0.45	0.09	-0.03	0.15	-0.08	-0.15
14	0.90	0.08	0.00	0.25	0.06	0.05	0.18	0.16
15	0.51	0.24	0.03	0.71	-0.21	0.20	-0.01	-0.15
16	0.92	0.26	0.13	0.02	-0.01	-0.07	-0.10	0.19
17	-0.02	-0.16	0.53	-0.57	-0.28	-0.07	0.45	-0.14
18	0.06	0.22	0.09	0.16	0.83	0.37	0.20	-0.03
19	0.42	-0.36	0.37	-0.09	0.30	-0.05	0.64	0.07
20	0.00	-0.01	0.35	0.74	0.22	0.21	0.13	0.24
21	0.69	0.30	0.48	0.35	0.08	0.04	-0.03	-0.12
22	0.87	0.13	0.08	-0.05	0.15	-0.03	0.21	-0.24
23	0.36	0.05	0.80	0.03	0.22	-0.01	0.21	-0.11
24	0.02	0.18	0.01	0.77	0.23	-0.15	-0.02	-0.10
25	0.01	0.27	0.00	0.12	0.16	0.10	0.92	-0.05
26	0.44	0.47	0.32	0.04	0.24	0.08	0.09	0.01
27	-0.07	-0.1	0.14	0.14	-0.03	-0.82	-0.35	0.22

APPENDIX F

LIST OF EIGENVALUES FOR THE FACTOR ANALYSIS OF THE QUESTIONNAIRE

FACTOR	EIGENVALUE	PCT OF VAR	CUM PCT
1	10.41	38.5	38.5
2	3.24	12.0	50.5
3	2.60	9.6	60.2
4	2.19	8.1	68.3

APPENDIX G

LIST OF VARIABLES ON THE QUESTIONNAIRE RELATED TO EACH FACTOR

FACTOR	VAR	QUESTIONNAIRE ITEM	FACTOR LOADING
1	7	23	0.68
1	11	10b	0.77
1	13	10c	0.80
1	14	14b	0.90
1	16	14a	0.92
1	21	10	0.70
1	22	10a	0.87
2	1	15	0.83
2	5	13a	0.89
2	9	16	0.83
2	29	24	0.47
3	3	20	0.84
3	6	12a	0.66
3	17	22	0.53
3	23	12	0.79
4	4	11	0.49
4	5	14	0.71
4	20	8	0.74
4	24	18	0.77

APPENDIX H
MULTIPLE REGRESSION

Dependent Variable: Familiarity with Advance Healthcare Directives

Variables in Regression Equation: Age, Types of Nursing, Experience, Information on AD, Academic Education, Inservice Education, Size of Facility, and Location of Facility.

Variable(s) Entered on Step Number 1: Inservice Education

Multiple R	0.40
R Square	0.16
Adjusted R Square	0.15
Standard Error	1.25

Analysis of Variance

	DF	Sum of Square	Mean Square
Regression	1	36.38	36.38
Residual	120	1188.61	1.57
F = 23.15	Signif F = 0.00		

.....Variables in the Equation.....

Variable	B	SE B	Beta	T	Sig T
Inservice Education	1.02	0.21	0.40	4.81	0.00
(Constant)	1.21	0.39		3.14	0.00

.....Variables not in the Equation.....

Variable	Beta In	Partial	Min Toler	T	Sig T
Age	-0.17	-0.18	0.98	-2.05	0.04
Types of Nursing	-0.01	0.10	0.99	-0.10	0.92
Information on AD	0.16	0.17	0.96	1.88	0.06
Academic Education	-0.13	-0.14	1.00	-1.52	0.13
Location of Facility	0.01	0.01	0.98	0.16	0.87
Experience	-0.07	-0.08	0.96	-0.87	0.39
Size	-0.04	-0.05	0.99	-0.51	0.61

APPENDIX I

MULTIPLE REGRESSION

Dependent Variable: Familiarity with Advance Healthcare Directives

Variable(s) Entered on Step Number 2: Age

Multiple R	0.44
R Square	0.19
Adjusted R Square	0.18
Standard Error	1.24

Analysis of Variance

	DF	Sum of Squares	Mean Square
Regression	2	42.80	21.40
Residual	119	182.20	1.53
F = 13.98	Signif F = 0.00		

.....Variables in the Equation.....

Variable	B	SE B	Beta	T	Sig T
Age	-0.11	0.05	-0.17	-2.05	0.04
(Constant)	1.97	0.53		3.72	0.00

.....Variables not in the Equation.....

Variable	Beta In	Partial	Min Toler	T	Sig T
Types of Nursing	-0.01	-0.01	0.97	-0.11	0.91
Information on AD	0.16	0.17	0.94	1.91	0.06
Academic Education	-0.14	-0.15	0.97	-1.69	0.09
Experience	-0.01	-0.01	0.84	-0.14	0.89
Location	0.01	0.01	0.96	0.09	0.93
Size	-0.06	-0.07	0.97	-0.71	0.48