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## Home-Care Nurses' Knowledge and Perceived Preparedness to Counsel Patients on Advance Directives

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**HOME-CARE NURSES' KNOWLEDGE  
AND PERCEIVED PREPAREDNESS  
TO COUNSEL PATIENTS ON  
ADVANCE DIRECTIVES**

**By**

**Mary Moran Barr**

**A THESIS**

**Submitted to  
Grand Valley State University  
In partial fulfillment of the requirements for the  
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**HOME CARE NURSES' KNOWLEDGE AND  
PERCEIVED PREPAREDNESS TO COUNSEL  
PATIENTS ON ADVANCE DIRECTIVES**

**MARY MORAN BARR**

**MAY 2002**

## ABSTRACT

### HOME-CARE NURSES' KNOWLEDGE AND PERCEIVED PREPAREDNESS TO COUNSEL PATIENTS ON ADVANCE DIRECTIVES

By

Mary M. Barr

This study examined home-care nurses' knowledge and perceived preparedness to counsel patients on advance directives (ADs). Joyce Fitzpatrick's "life perspective rhythm" model provided the framework for the thesis. Sixty-two registered nurses actively practicing in home-care in West Michigan were surveyed over a 4-week period. Each nurse completed a 16-question survey, which included an 11-question true-false test of knowledge of ADs. Survey results indicated that nurses who feel prepared to counsel patients are more knowledgeable than those who do not feel prepared to counsel ( $t=2.89$ ,  $df=57$ ,  $p<0.05$ ). Overall knowledge was high (87.4%) but only 40 nurses (64%) felt prepared to counsel patients on ADs. The study implies that factors other than knowledge may have an impact on preparedness to counsel. Possibilities for further study include more research on education of health-care providers about ADs, patient education, and the need for mutual discussions on end-of-life care issues in relationship to completing ADs.

## **DEDICATION**

**This thesis is dedicated to my family, Lon, Katherine and Margaret, for without their support and encouragement this accomplishment would still be only a dream.**

## **ACKNOWLEDGEMENTS**

**I would like to acknowledge the inspiration for this work, my patients and colleagues in the critical care unit at St. Mary's Mercy Medical Center, who have taught me the value of an advance directive.**

**I also thank my thesis chair Dr. Phyllis Gendler for her support and encouragement, and my committee members Dr. Emily Bielak and Sandra Davis, J.D., for their interest in this subject matter and their commitment to excellence. Thanks also to Dr. Linda Scott for her assistance with the statistical analysis.**

**I want to recognize and thank home-care nurses, who work tirelessly to promote the health of our community and find the time to counsel on advance directives.**

**Very special appreciation is extended to my friend and editor Ellen Arlinsky, who has been tireless and supportive throughout this process. Her eye for detail and way with words has greatly contributed to the clarity of this work. This paper would not have been completed without her help.**

**Finally, I want to acknowledge those family members whom I have lost during this writing: Jean B. Barr, Philomene L. Moran, Nathan L. Barr, and Nancy DeGregorio Barr, who all died peacefully and with little suffering.**

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## Chapter 1

### Introduction

End-of-life issues are one of the most debated yet most understudied topics in health care today. Uncertainty about what kinds of treatment people want at the end of life is cause for much concern among health-care providers and recipients. An advance directive (AD) is a document that legally designates a spokesperson to articulate a patient's wishes regarding end-of-life care should he or she be deemed unable to do so. This designation is called the durable power of attorney (DPOA) for health-care affairs, and its use through an advance directive document is universally accepted in the United States. A living will, on the other hand, can be an addendum to an advance directive and outlines very specific treatment guidelines. A living will, while not universally recognized in all 50 United States (it is not legally recognized in Michigan) or in Canada, is a tool that the DPOA can use to make informed treatment decisions on behalf of the incompetent patient (Aitken, 1999).

The Patient Self-Determination Act (PSDA) passed by Congress in 1990 made advance directives a matter of federal law. According to the act, all health-care institutions, including hospitals, nursing homes, and home health agencies, that receive federal Medicare/Medicaid funds must inform incoming patients of their right to execute an advance directive and have it followed. Furthermore, to qualify for federal Medicare/Medicaid funding, these institutions must make available patient information documents, health-care provider training, and patient education programs that discuss advance directives (Keigher, 1994).

The PSDA was written in the wake of social and health-care trends that influenced the role of patient decision-making at the end of life (Ersek, 1998). Recommendations for the legislation also came from the Commission for the Study of Ethical Issues in Medicine, appointed by President George Bush in 1990. The highly publicized court decisions involving Nancy Cruzan and Karen Ann Quinlan served as catalysts for addressing end-of-life care through advance directives. Both of these young women were maintained, despite their next of kin's wishes, in a persistent vegetative state after a car accident and an overdose, respectively. These tragic cases brought to light the importance of planning in advance what kinds of care would be considered acceptable at the end of life (Dimond, 1991).

The PSDA is meant to give patients a voice in the decision-making process that occurs at the end of life. Because of increased knowledge and gains in the ability to prolong life artificially, it is virtually possible to keep some patients alive for any length of time regardless of quality of life. Since patients' wishes are often unknown, it is possible that treatment modalities to prolong life may be extended beyond the boundaries of what would have been acceptable to the patient (Freedman, 1994). Conversely, treatment may be discontinued at an inopportune time, before impending death has been acknowledged and accepted by a patient's family. Implementation of an advance directive can avoid much confusion on the part of caregivers and survivors faced with decision-making options for the incapacitated patient (White, 1997). The PSDA is designed to insure that all patients have been made aware of their right to participate in their own end-of-life care or to appoint a proxy should they be unable to express their wishes.

According to a recent survey by the American Association for Retired Persons (AARP) published in the newsletter of The American Nurses Association (ANA), only 25% of respondents indicated they had a durable power of attorney for health-care issues (American Nurse, 1995). The need to comply with the law and the fact that this issue is of such great concern to patients, families, and health-care providers are reasons enough to increase the numbers of patients who complete advance directives (Aitken, 1999).

The provision and execution of advance directives are still not routine practice for all health-care providers. Some clinicians cite lack of time, knowledge, and comfort with the subject as reasons for not pursuing ADs with their patients (Basile, 1998). An admitting clerk or secretary often distributes patient information documents about ADs with no accompanying explanation. Health-care provider training is often sporadic, inconsistent, and poorly documented.

Patient-education programs about advance directives are not well suited to a broad population and vary in the information they provide (Kirmse, 1998). Despite the law, education of staff, nurses, and patients has been sorely lacking in today's fast-paced, productivity-driven health-care environment. This leads to compliance with the letter of the law with little regard to its spirit (Irvin, 1995). Patients are often given the information without explanation and with little encouragement to complete the document.

Publications that address the role of nurses in relation to ADs are mostly in clinically specialized or geographically limited journals. Few articles examine the roles that nurses actually play in implementing and administering ADs and the effectiveness associated with them (Johns, 1996). Nurses can have a lasting impact on the health-care

system by becoming educated themselves and counseling patients about advance directives. Nurses at all educational levels must accept the challenge to enlighten themselves, support staff, physicians, lawmakers, patients and family members (Irvin, 1995). The American Nurses Association maintains that nurses' responsibilities related to the PSDA include an obligation to be informed and able to offer patients information and instructions on completing advance directives (Crego & Lipp, 1998).

Because more than 80% of the United States population will be affected by critical illness sometime in life, most nurses can expect to be asked by patients and their families for information about ADs (Crego & Lipp, 1998). Decisions regarding advance directives should be made before a critical illness occurs so thoughtful consideration of all choices is possible.

This study evaluated nurses' knowledge of advance directives by surveying a population of home-care nurses. This study also evaluated nurses' perceptions of their preparedness to perform their duties to counsel on ADs. Studies have been done in the acute-care setting on nurses who deal with hospitalized patients, but no studies have been done to date on nurses who provide home care. Nurses in the home-care setting often deal with clients of all ages who are either chronically ill or recovering from acute illness. Home-care visits present an ideal opportunity to form a close relationship between nurse and patient. In addition, home-care nurses by job description are required to educate and counsel patients on advance directives.

## **Purpose**

**The purpose of this study was to determine whether home-care nurses have adequate knowledge of advance directives and feel they are adequately prepared to counsel patients on advance directives, and also to determine if there is a relationship between preparedness and knowledge.**



## Chapter 2

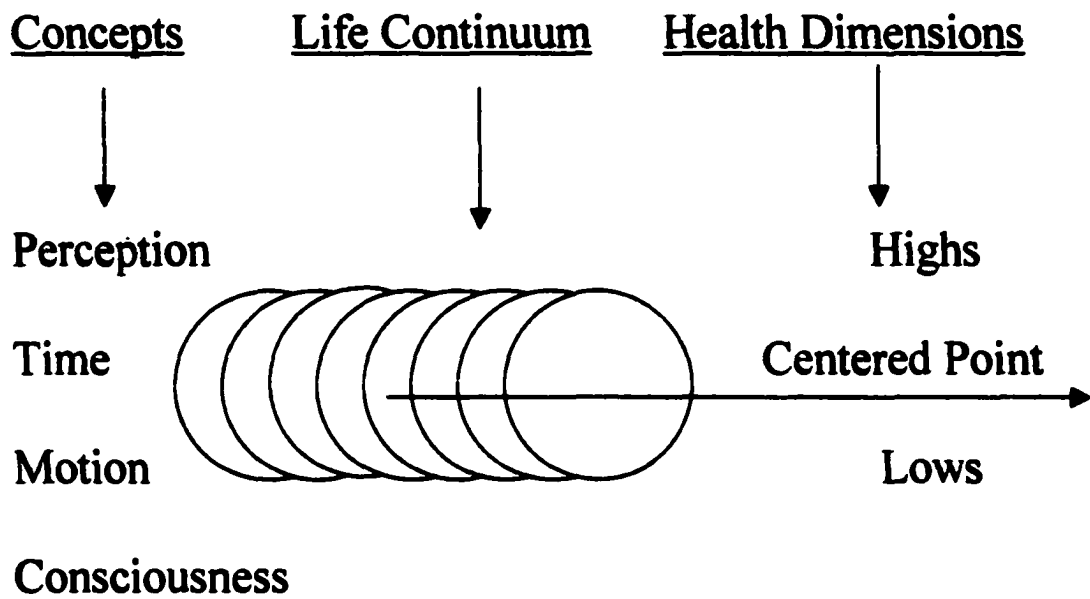
### Conceptual Framework and Literature Review

#### Conceptual Framework

The conceptual framework for this thesis was Joyce Fitzpatrick's rhythm model, which is derived from her own research on individuals' abilities to integrate crisis situations into their life perspectives. It is this integration that builds the experience base for the professional nurse. The concepts of Fitzpatrick's framework as shown in Figure 1 include the rhythms of "time, motion, consciousness, and perception." These rhythms help nurses and patients focus awareness on the meaning of life as a dimension of health, and death as an inevitable consequence of birth. The goal in life is to balance these rhythms by weathering through both highs and lows and trying to maintain a "centered point." According to Fitzpatrick, these concepts are rhythms that suffuse human development and create personal meaning for each individual. Her model was inspired by a professional interest in how nurses can help people live through and move through life's experiences. She examined "how a consideration of rhythmic methodologies might develop nursing knowledge pertaining to nursing diagnoses and personal knowledge in nursing" (Fitzpatrick, p. 310, 1996).

Fitzpatrick states that "life is a continuum" that involves many ups and downs, but always returns to a centered point (George, 1995). Crises in health are the "lows," with triumph over illness considered a "high." Nurses who integrate new knowledge into their nursing practice are developing tools that can better prepare them to help patients return to a centered point in life's continuum through better nursing practice.

**Figure 1. Conceptualization of  
Fitzpatrick's Rhythm Model**



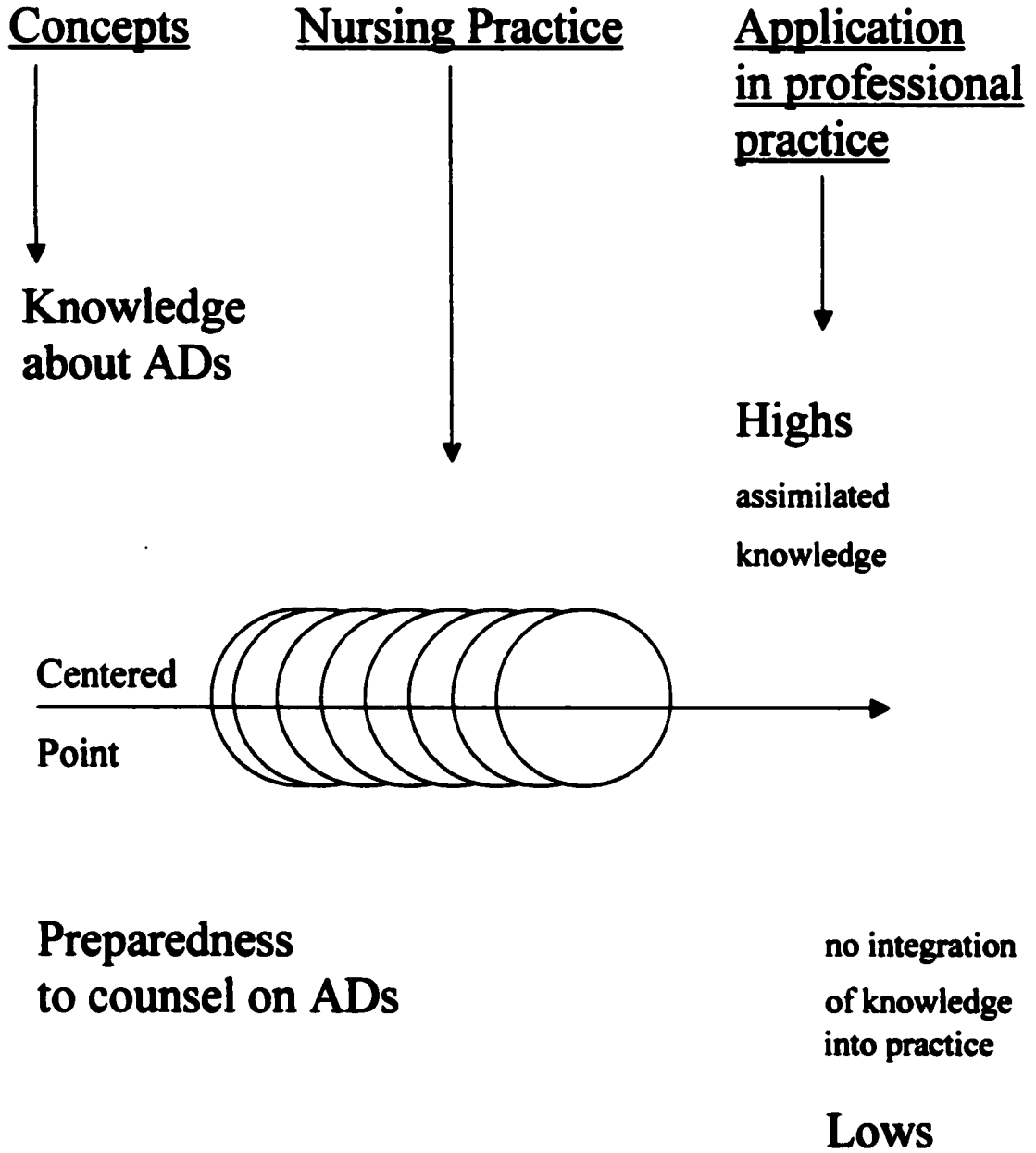
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Fitzpatrick, J.J., & Whall, A.L. (1996). Conceptual models of nursing analysis and application (3<sup>rd</sup> ed.). Stamford, CT: Appleton & Lange.

**This framework also resembles what nurses experience when they attain new knowledge and are better prepared to meet patient needs, as shown in Figure 2. Nurses who integrate new knowledge and feel prepared can feel “centered” in their approach to nursing care. They have experienced both highs (gaining new knowledge and feeling prepared) and lows (not possessing knowledge and feeling unprepared) and need to come to a centered point to feel competent and comfortable in delivering quality nursing care. According to the Fitzpatrick model, nurses either choose to integrate new knowledge into their personal database for easy retrieval, or file it away as reference material (George, 1995). If a nurse does not plan to use this knowledge, it is not likely he or she will commit it to long-term memory. New knowledge can be considered peripheral to a nurse’s practice if he/she does not intend to use it. By choosing to incorporate new knowledge into nursing practice, the nurse is maintaining an open mind and acquiring information that may be helpful to both nurse and patient. Nurses use their knowledge of and experience with ADs to help patients understand issues that can affect their life and health and maintain their autonomy.**

**Nurses possess a variety of characteristics that affect patient interactions. They have values, morals, and ethics that they abide by when caring for patients. Their knowledge and experience contribute greatly to patient encounters. Nurses also have a unique body of knowledge that changes and expands as dictated by changes in nursing roles and practice.**

**Figure 2. Adaptation of Fitzpatrick's Rhythm Model**



**A nurse's responsibility is to help people maintain their maximum level of wellness throughout their lifespan (George, 1995). Patients rely on nurses as trusted providers to care for them and teach them in many ways how best to care for themselves. Nurses are "trusted authority figures" with unique patient and family relationships (Johns, 1996). It is because they have these unique relationships that they are in a position to be trusted when they broach difficult topics related to end-of-life care, such as a review of the patient's values, and informing, instructing, and counseling the patient about an advance directive.**

**With the advancement of modern medical technology, phenomenal things to preserve life or forestall death can be achieved. Because of their experience in dealing with these issues, nurses can be of great assistance in helping patients, co-workers, and the general public to understand the value of an advance directive. An AD provides the opportunity to discuss patient values and educate patients about end-of-life-care options. Ditillo (1999) felt that initiating and participating in ongoing discussions about death and dying will help to change care at the end of life. She also stated that ongoing discussions are imperative because as patients' lives and states of health evolve, so may their thoughts regarding treatment preferences. It is this evolution and constant change in levels of health that demonstrate Fitzpatrick's framework as does the evolution of nursing knowledge. Nurses have the opportunity through experience and education to support patient autonomy and the decision-making process. These concepts are key to fostering an understanding of the nursing role in advance directives. Nurses' knowledge about ADs can influence their interaction with patients.**

## **Review of Literature**

Very few published studies of nursing knowledge and nursing experience in counseling patients about advance directives exist in current literature. A comprehensive literature review revealed only six studies that addressed the role of nurses in relation to advance directives. Most articles appeared in clinically specialized or geographically limited journals and related primarily to ethical issues and educating nurses in specialty areas (Johns, 1996). A small number addressed the potential roles for nurses. The primary conclusion of the existing literature was that most nurses have some knowledge of advance directives, but do very little to share that knowledge with their patients.

Barta and Neighbors (1993) studied nurses' knowledge and their role in patients' end-of-life decision-making with an 18-question survey that focused on four major categories. The survey examined (a) experience with advance directives [6 questions], (b) knowledge of state law regarding ADs [4 questions], (c) confidence in providing information about ADs [3 questions], and (d) incorporating questions about ADs into their patient admission interview [5 questions]. A panel of experts knowledgeable about advance directives developed the survey, and the questions were reviewed for validity. A pilot test was given to a group of nurses, and minor changes were made based upon their recommendations. A random sample of 1% of the registered nurses in Arkansas (n=175) was invited to participate in the survey. Fifty-five questionnaires were returned for a response rate of 31%.

Highlights from the results are as follows: with regard to experience, 84% (n=46) of nurses had seen an AD, and 82% (n=45) would be interested in learning more about advance directives. Only 31% (n=17) had been a witness for an AD, and only 20%

(n=11) had executed one for themselves. Based on knowledge of Arkansas law, 98% (n=54) knew that an AD might be revoked or changed at any time by the patient. However, only 42% (n=23) knew that the health-care proxy does not have the authority to make all decisions regarding the withholding of treatment. Fewer than 33% (n=20) of nurses initiated conversations about ADs in their nursing assessment; only 18% (n=10) said they were confident answering patient questions about ADs and living wills; and 49% (n=27) were not at all confident in presenting all or part of a community-education program on advance directives and living wills (Barta & Neighbors, 1993).

Based upon the results of the study, Barta and Neighbors (1993) felt that it might be beneficial for all institutions of higher learning to provide educational programs on advance directives for student nurses and practicing nurses. Highlights would include information about state and federal legislation regarding ADs, appropriate ways to counsel patients on ADs, and development of institutional policy and procedures for handling ADs. The authors felt that nurses can gain better understanding of the process by filling out their own ADs and in doing so learn how to resolve some of the questions that this type of document brings to mind.

One of the limitations of this study was that the authors randomly sampled 1% of the registered nurses in Arkansas (n=175). They did not assure themselves that the potential participants were all practicing registered nurses. Of the 55 questionnaires returned (response rate 31%), only 55% (n=30) were employed in a hospital setting and only 51% (n=15) were in staff nurse positions. The study also did not indicate what the other 45% of the nurses (n=25) were doing, or what their employment status was. Barta and Neighbors (1993) did differentiate the respondents according to educational level, but

did not report any statistics correlating knowledge of ADs with educational level. In their summary they indicated that the best time and place to prepare an advance directive is still in question. They suggested that upon admission to the hospital is probably not the best time or place to construct an advance directive, but this does not seem to be based on any measurable research. What this study did point out, however, is that nurses lack knowledge and confidence in counseling patients on advance directives.

Wood and DelPapa (1996), also in Arkansas, examined nurses' attitudes and knowledge of the law concerning advance directives. They conducted a small, descriptive, correlational study using a framework of deontology and utilitarianism, both ethical principles nurses use when confronting ethical dilemmas. The researchers developed and used a tool called the Wood Advance Directives Survey (WADS). The survey consisted of three parts: Part I contained demographic information; Part II examined nurses' attitudes; and Part III tested nurses' knowledge. A panel of registered nurses determined face validity and content validity of the attitude and knowledge items. The test-retest method at a 2-week interval was used on 15 graduate-student nurses to evaluate the tool's reliability. In a pilot survey administered to the 15 students, alphas of .64 for Part II and .88 for Part III were obtained. Minor changes were made in the tool based on the recommendations of the panel. Thirteen true-false statements were used to assess knowledge and 20 attitude statements were scored using 1 for a positive response and 0 for a negative response.

For the final survey Wood and DelPapa (1996) used a convenience sample of 112 nurses (77% RNs and 23% LPNs) who worked in a variety of areas in one general hospital. The five research questions were: (a) What are the attitudes nurses have



towards advance directives? (b) What are the ethical reasons nurses give for their attitudes towards advance directives? (c) How knowledgeable are nurses about Arkansas and federal laws on advance directives? (d) What is the relationship between nurses' attitudes towards advance directives and their demographic data? and (e) What is the relationship between nurses' knowledge of the law about advance directives and their demographic data?

Prior to administering the survey, the authors defined an acceptable level of knowledge as a minimum of 10 out of 13 possible correct answers (77%) on Part III of the survey. In fact, despite overwhelmingly positive attitudes, acceptable levels of knowledge occurred in only 24% (n=27) of the subjects. The authors established a statistically significant relationship between nurses' knowledge of the law and experience with advance directives ( $r = .2424$ ;  $p = .005$ ), and knowledge of the law and education regarding advance directives ( $r = .3492$ ;  $p = .000$ ).

It is not clear from this work how the statistical correlation was established, nor did the authors indicate a directional relationship. In Wood's 1993 master's thesis, on which the abstract publication was based, 71.4% (n=80) of the nurses had experience dealing with patients with advance directives. Only 37.5% (n=42) had attended conferences or in-services about advance directives. The study did not indicate whether the 27 nurses with acceptable levels of knowledge about advance directives were in the same group as those who had attended conferences or had experience with advance directives.

In examining attitudes, Wood and DelPapa (1996) reported that 93% of the nurses (n=105) had a strongly positive attitude toward advance directives regardless of their educational levels and other demographic characteristics. This positive attitude was

determined by responses to 20 statements scored on an interval scale with a choice of reasons for the attitude and space for individual comments. The ethical principle of autonomy was cited as the most frequent reason for their positive attitude (38%, n=43). Other reasons were divided among the principles of “beneficence, nonmaleficence, justice, and veracity.”

Weiler, Eland, and Buckwalter (1996) studied nurses' knowledge of living wills and perceptions of patient autonomy. Their research, done before the passage of the federal Patient Self-Determination Act in 1990, was conducted in Iowa, which, in 1985, was one of the first states to enact living will legislation. Iowa also recognized the durable power of attorney for health care in April 1991, nearly nine months before the PSDA took effect.

Believing that nurses and other health-care providers have an ethical responsibility as well as a legal obligation to be aware of the Patient Self-Determination Act, the authors sent questionnaires to 10,000 actively licensed RNs and LPNs in Iowa in March of 1991. Although the 27% response rate (2,161 RNs and 512 LPNs) was low, the authors believed that the respondents were similar enough to the state nursing population in terms of demographic characteristics to accept the generalizability of the findings. The majority of respondents were employed (95%, n=2,053 RNs, and 96%, n=492 LPNs) in a variety of positions. Sixty percent (n=1,231) of the respondents were staff nurses, 19% (n=234) were in administrative positions, 14% (n=287) were in other nursing positions such as patient education, office management or utilization review. Advance practice nurses comprised 5% (n=108) of the survey respondents, and 2% (n= 43) did not indicate their practice role (Weiler et al., 1996).

Included in this survey were two knowledge-based questions and one practice-based question focusing on perceptions of nurses' roles involving living wills. The two knowledge-based questions were: (a) Does Iowa have living will legislation? and (b) What were nurses' sources of information to learn about living wills? The practice-based question was: What is the nurse's role in discussions regarding the patient's living will? Regarding knowledge, 70% of nurses (n=1,897) responded that they knew Iowa had living will legislation. Another 17% (n=454) were uncertain if Iowa had living will legislation, and 7% (n=189) did not know that Iowa had living will legislation. Six percent (n=162) of nurses did not answer the question (Weiler et al., 1996).

The sources of information nurses used most often were professional journals, 16% (n=444); the media, 15% (n=391); and continuing education, 13% (n=363). At least 30% (n=809) did not obtain information from any traditional forms of continuing education. The need for uniformity and consistency in disseminating information was highlighted by the results of this research (Weiler et al., 1996).

The results indicated that nurses are willing to play a role in helping patients maintain autonomy in health-care decision-making. Seventy-two percent (n=1,942) agreed it was a nursing responsibility to suggest that patients talk to family and friends about their health-care options. Another 39% (n=1,052) said that it was a nursing responsibility to provide information to patients about living wills. Only 31% (n=836) felt it was the nurses' role to suggest that patients write a living will (Weiler et al., 1996).

The implications of this study were that nurses are not sufficiently knowledgeable about Iowa's living will statute, that there is a lack of consistent quality information in

the form of in-service education for nurses, and that nurses need to become more comfortable in an assertive advocacy role. When the PSDA took effect on December 1, 1991, it became incumbent upon every nurse who delivered health care to be prepared to support patient autonomy and practice nursing according to the nurses' code of ethics. The authors suggested that there needs to be much more research conducted nationally to determine the current level of knowledge and implications for nursing practice in the area of advance directives (Weiler et al., 1996).

The Jarr, Henderson, and Henley (1998) study of registered nurses' perceptions about advance directives concluded that nurses may feel uncertain about legal, moral, and ethical obligations surrounding their participation in end-of-life treatment decisions. The authors also felt that nurses are in a position to facilitate patient autonomy and to assist in the quest for self-determination, but nurses have difficulty advocating for the patient in end-of-life decisions because they do not have the understanding necessary to perform this task. The authors sought to answer three questions: (a) How knowledgeable are nurses about the essential message of the PSDA? (b) How well do nurses at one institution understand the policy and procedures of that institution regarding the execution of advance directives? and (c) To what extent do nurses feel comfortable in the discussion of advance directives with patients to whom they provide care?

Jarr et al. (1998) used an exploratory, descriptive design with a 10-item, self-reported questionnaire developed for the study. A panel of experts reviewed the questionnaire for content validity. A convenience sample of 411 registered nurses in 13 active patient-care units was surveyed. There were 127 questionnaires returned, with 20 excluded due to incompleteness, for a total sample of 107 registered nurses (26% return rate).

When asked what they thought was the essential message of the PSDA, 98% (n=105) of the sample answered correctly. Compared with other studies that reported approximately 40-70% of nurses as knowledgeable, this percentage seems unusually high. In fact, the correct answer as originally determined by the authors was chosen by 39% of the sample (n=42), but because of ambiguity in the multiple-choice questions, a second response was considered acceptable as well. This accounts for the high percentage of correct responses. It is unusual that so many nurses answered correctly, and this certainly can be considered a limitation in this study. This also presents a problem in comparing results from study to study when so many different instruments and methods are used (Jarr et al., 1998).

As to the statement, "It should be a nursing responsibility to facilitate a patient's getting advance directive information," 41% (n=44) strongly agreed or agreed; 38% (n=41) disagreed or strongly disagreed; and 21% (n=22) were unsure. As to another statement, "I have sufficient information to discuss advance directives with my patients," 56% (n=60) disagreed or strongly disagreed; 15% (n=16) were unsure; and 28% (n=31) agreed or strongly agreed. In response to "I am comfortable talking about advance directives with my patients," only 28% (n= 31) agreed. Of those who agreed they had sufficient information, 100% agreed that they were comfortable in talking with their patients (Jarr et al., 1998).

The notable limitations of the study as cited by the authors are two. The first is that the sample was convenience and surveyed nurses at only one hospital. Thus, results cannot be easily generalized. Second, the low response rate may mean that attitudes

**expressed about the PSDA are not representative of the entire nursing department at the hospital complex (Jarr et al., 1998).**

**The authors concluded that nurses at this particular institution are unprepared for the function of educating patients and families about advance directives. Jarr et al. (1998) believe that nurses must support their patients in self-determination and decision-making and have identified education about PSDA and advance directives as primary needs among nurses. “Nurses can play a key role in educating patients and families about end-of-life choices if they have received the necessary education to be knowledgeable and comfortable in this area” (p. 35).**

**Canadian researchers Downe-Wamboldt, Butler, and Coughlan (1998) studied nurses’ knowledge, experiences, and attitudes concerning living wills in order to identify and describe registered nurses’ awareness and understanding of legislation on substitute decision makers and living wills. They also examined nurses’ experiences, roles, and attitudes as well as perspectives on barriers to and resources for using living wills. The authors conducted an exploratory, descriptive study using a 12-page survey questionnaire that was assessed for content validity and clarity by a panel of experts external to the research team.**

**Selecting from the members of the Registered Nurses Association of Nova Scotia (RNANS), the authors randomly sampled 974 nurses. The response rate was 16% for a total sample of 157. The unusually low response rate was, the authors felt, significant. They speculated that many nurses, even those with higher levels of nursing education, were unwilling to participate because they lacked familiarity with the issue. This low**

response rate and the sample profile, in terms of education, limits the generalizability of the study's results (Downe-Wamboldt et al., 1998).

A variety of questions assessed nursing knowledge. First, nurses were asked if they were aware of options for people in Nova Scotia to use living wills. On a Likert scale with 1= very aware and 10= not at all aware, subjects rated themselves a mean of 7.4 (closer to not aware) with a standard deviation of 2.62. When asked about specific legislation, 65% (n=103) were not aware of the Medical Consent Act (1989); 75% (n=118) were not aware of the Hospitals Act (1989); and 60% (n=95) were not aware of the Powers of Attorney Act (1989).

In spite of the lack of knowledge about the specific legislation on the part of the majority, 85% (n=133) were aware of the meaning of durable power of attorney (DPOA) for health care. Only 44% (n=69), however, knew that an "instructional directive" provides specific instruction for the kinds of treatment a person wishes to receive. Only 25% (n=40) of the respondents knew that a designated proxy is legally recognized in Nova Scotia. Forty-four percent (n=69) knew that under the Medical Consent Act (1989), one could designate an individual to make decisions about one's medical care. Under this same act, any competent person can write a living will, but no more than 40% (n=64) of nurses knew this to be true. Under the Hospitals Act (1989), a patient's spouse was legally designated next-of-kin for the purpose of treatment, and 32% (n=50) knew this (Downe-Wamboldt et al., 1998).

In broader terms, between 31% (n=50) and 42% (n=66) of those surveyed had varying degrees of confusion about both the Hospitals Act (1989) and the Medical Consent Act (1989). Most incorrect beliefs were attributed to not knowing specifically

which act covers what circumstance. A majority of respondents, 82% (n=128), incorrectly believed that the living will should be followed in a situation in which the designated proxy for an incompetent patient disagreed with the living will (Downe-Wambolt et al., 1998).

Downe-Wambolt et al., (1998) used students' t-tests and Fisher's exact test to profile the most knowledgeable respondents. Comparing nurses at the diploma level to those with higher nursing education, they found no statistically significant difference regarding awareness of legislation. Diploma-prepared nurses, however, had greater knowledge of the extent to which a designated proxy could express an individual's preference for care ( $t = -2.51, p = 0.028$ ). Diploma-prepared nurses also knew more about instructional directives (living wills) ( $p = 0.028$ ) and designated proxy ( $p = 0.021$ ) than those with more formal education.

Seventy-two percent (n=113) of nurses surveyed had no experience with instructional directives (living wills), and 76% (n=120) had no experience with designated proxies. The 37 nurses who had experience with living wills used a checklist to describe their various roles: advocate 76% (n=28); facilitator 14% (n=5); educator 5% (n=2); and combination of roles 30% (n=11). Five respondents did not believe they had a role in relation to living wills, stating, "Not my place," "It's a private matter," and "We were not permitted to follow the terms of her living will as her doctor would not honor it." Those who had experience with living wills said, "Being aware of a patient's and family's wishes makes nursing that person much easier" (Downe-Wambolt et al., 1998).

Crego and Lipp (1998), using a descriptive correlational design, studied nurses' knowledge of advance directives and its relationship to demographic characteristics. Of



the 900 acute-care nurses invited to participate, 37% (n=399) replied. The sample size of approximately 400 was estimated to detect a medium relationship between study variables at a .05 significance level with a power of 0.96%. A pilot test was done to determine clarity and readability of the items in the questionnaire. To test readability, 5 graduate students and 5 RNs verified the questionnaire was easy to read and understand. Nurses and faculty with expertise in advance directives established content validity for the knowledge questionnaire.

Demographic information included age, sex, religious preference, ethnicity, marital status, education, number of years as an RN, area of practice, number of years in specialty, and personal experience with advance directives. Of 339 nurses surveyed, 86% (n=292) had not completed ADs for themselves, and in 61% (n=207) of the cases neither had most of their family members. Only 37% (n=125) had ever attended a class, workshop, or seminar on ADs (Crego & Lipp, 1998).

To assess nurses' knowledge, a 44-item, true-false questionnaire was administered. The 34 items left blank from all questionnaires (14,916 possible answers) were scored as incorrect responses. The mean score was 78% correct with a range of 40-95%, and scores evenly distributed with a median of 77% and mode of 75%. Analysis of variance (ANOVA) was used to define relationships between demographic information and knowledge (Crego & Lipp, 1998).

The only statistically significant relationship was between ethnicity and knowledge ( $f=5.47$ ;  $p=.02$ ). The non-white group, 3.45% (n=12), had significantly less knowledge about ADs. However, there were some other findings of interest. With 86% (n=291) not completing ADs for themselves, the authors felt this suggested the subjects had not

contemplated the significance of end-of-life decisions. Regarding understanding of ADs, 87% (n=295) did not think patients had a good understanding of ADs. Fifty-five percent (n=186) thought they, themselves, did not have a good understanding of ADs. Sixty-seven percent (n=277) indicated that the bedside nurse is more likely than other health-care providers to initiate discussion about ADs. Fifty-one percent (n=173) felt the nurse is the best person to address the subject, while 86% (n=290) believed the physician was not best suited to discuss ADs with patients. Ninety-two percent (n=311) thought they would benefit from additional education, but only 37% (n=124) had attended a class on advance directives. Additionally, the wide range of scores on the knowledge portion (40-95%) shows a need for knowledge for some nurses (Crego & Lipp, 1998).

#### **Summary and Implications for Study**

Through review of the current literature and particularly the six studies that were conducted in various states and settings, it is evident there is a gap in nurses' knowledge with regard to advance directives. This gap exists regardless of educational level or work setting. Inconsistency in the way knowledge of advance directives is acquired is a problem for nurses and most health-care professionals. Most studies indicate that there is interest on the part of nurses in gaining more knowledge, but less interest in taking an active role in informing patients and securing advance directives from them. Gaps and limitations in the current literature include studies that have little generalizability, and a lack of consistency using valid and reliable instruments. This is because the studies have been conducted on special populations that do not necessarily reflect the nursing population as a whole. There are also no studies published to date that survey the home-care nursing population.

## **Research Questions**

This research measured home-care nurses' knowledge and perception of preparedness to counsel patients on advance directives as part of their job requirement. The questions asked were:

1. Are home-care nurses knowledgeable about advance directives?
2. Do they feel prepared to counsel patients on advance directives?
3. Is there a difference in knowledge scores between those who feel prepared and those who do not?

## **Definitions**

**Advance Directive or AD.** A document that appoints a person as durable power of attorney for health-care affairs (DPOA) should the patient become unable to speak for himself/herself. An AD can include a values-assessment survey and/or a living will.

**Counsel.** Answering basic questions and supplying information about advanced directives.

**Home-care Nurse.** Nurse with a license to practice in Michigan as an LPN or RN and who care for patients in their homes under the auspices of a home-care agency or organization.

**Knowledge.** Familiarity with the terms, rights, and laws concerning advance directives at the federal level, as well as implications for and appropriate use of advance directives. A 75% survey score was considered knowledgeable.

**Perceived Preparedness.** A sense of competency when performing an expected task.

## **Chapter 3**

### **Methods**

#### **Design**

The purpose of this study was to explore home-care nurses' knowledge of advance directives and their perception of their preparedness to counsel patients on ADs. Approval for the study was granted by the Human Research Review Committee of Grand Valley State University (Appendix A). Permission was granted by three home-care agencies to allow surveys to be distributed to their nurse-employees (Appendix B). A letter of introduction (Appendix C) and the surveys (Appendix D) were distributed to 98 nurses actively working for the agencies and making home-care visits. Permission to use the survey tool was received from authors Crego and Lipp (Appendix E). A non-experimental, descriptive design was used to address the research questions. Selected demographic data were solicited as well in order to describe the population and their exposure to advance directives through continuing education. Data collection was completed as described in the procedure section of this chapter

#### **Setting and Sample**

The population surveyed were nurses licensed in Michigan and actively engaged in the practice of home-care nursing at three West Michigan home-care agencies. The sample was obtained according to the following criteria:

1. RNs or LPNs licensed to practice in the state of Michigan
2. RNs or LPNs working in the home-care environment
3. RNs or LPNs who voluntarily agreed to participate in the study

All of the nurses who returned the surveys were RNs, 10 of whom had previously been LPNs. All of the nurses on the home-care agencies' employment rosters were RNs, and no LPNs were available to answer the survey.

Of the 98 surveys distributed, 62 completed surveys were returned: 30 out of 38 were from Home Health Services of Holland Community Hospital, and according to the director, 7 of the 38 were hospice nurses; 11 of 25 were returned from In Home Care Services, North Ottawa Community Hospital; and 21 out of 35 were from Home Health Care Agency of Holland Home.

The study took place in the home-care nurses' office settings. These are office headquarters where the home-care nurses receive assignments, maintain files, and perform clerical tasks. The administrator makes a mailbox system for office communication available to each home-care nurse. It was through the mailbox system that nurses received the cover letter requesting their participation, and the survey.

#### **Protection of Human Rights**

Approval of this study was obtained from Grand Valley State University's Human Research Review Committee (Appendix A). Anonymity of subjects was maintained through the use of code numbers, and no names were used. Permission from each home-care agency to survey its employees was obtained prior to distribution of surveys (Appendix B). An introductory letter (Appendix C) accompanied all surveys (Appendix D) and indicated the purpose of the study, the guarantee of anonymity throughout the study, and the availability of a member of the Human Research Review Committee at Grand Valley State University to field any issues of subjects' rights regarding participation in the study. Voluntary completion

of the survey constituted informed consent. There was no risk to participants involved as surveys were anonymous, and it was emphasized that participation was completely voluntary.

### Instruments

The instrument used in this study measured knowledge of ADs, preparedness to counsel on ADs, and demographic data (Appendix D). Permission was granted by researchers Crego and Lipp (1998), (Appendix E), to use 10 of the true-false questions from their 44-question knowledge survey conducted in 1998, the only instrument in the literature up to that point that specifically studied knowledge of ADs. The researcher selected these particular 10 questions because Crego and Lipp cited them as especially salient to nurses' understanding and defining of advance directives. The researcher also added one true-false question (question 9) intended to test respondents specifically about Michigan law. A pilot test of the survey was given to 14 critical-care nurses, and their responses were consistent with those of the nurses surveyed in the Crego and Lipp study.

The 11 true-false questions (numbers 6-16 on the survey) (Appendix D) were used to test nurses' knowledge of advanced directives. Knowledge was measured by the number of correct responses to the true-false questions. Nurses' perception of their preparedness for counseling patients on ADs was answered with a yes or no response to question 5. An internal consistency reliability coefficient was calculated using the Kuder-Richardson 20 (KR-20) method. According to Polit and Hungler (1995), for most purposes, reliability coefficients above .70 are considered satisfactory. The true-false survey was calculated to have a reliability coefficient of

false survey was calculated to have a reliability coefficient of 0.13. Instrument reliability studies for the original work done by Crego and Lipp were not available.

### Procedure

After approval from the home-care-agency administrators to distribute the survey at their facilities, subjects were recruited through a letter from the researcher inviting their voluntary participation (Appendix C). The letter detailed all data-collection procedures. The survey was attached to the letter of introduction and placed in each nurse's in-house mailbox at his/her place of employment. There were no consequences if nurses chose not to complete a survey, and they were not asked to return the survey if it was left blank. Volunteers who chose to participate were asked to read the directions, complete the survey, and deposit it in an enclosed box left at their nursing agency headquarters. They were asked to keep the cover letter, which gave the researcher's telephone number as well as directions for reaching the Human Research Review Committee at Grand Valley State University.

The researcher delivered the surveys to each agency personally and secretarial staff then placed them into the individual employee mailboxes. The researcher also attached a small bag of M&M candies as an inducement to fill out the survey. The researcher did not recruit participants face to face, thereby avoiding potential risks for biasing individuals who did not wish to volunteer, but may have felt pressured by the researcher's presence. After a 14-day time period the enclosed boxes in which the completed surveys had been deposited were collected. Each survey was numbered for ease of tracking and data analysis. Voluntary participation implied informed consent for this study.

## Chapter 4

### Results

The purpose of this study was to evaluate the knowledge of home-care nurses about advance directives (ADs) and their perceived preparedness to counsel patients on ADs, as their jobs require. Three specific questions were addressed: Are home-care nurses knowledgeable about ADs? Do they feel prepared to counsel patients about ADs? Is there a relationship between knowledge and preparedness? Additional information sought from subjects included the length of time they held an RN and/or license, and if and how they had received education on advanced directives. That data helped define the sample and offered additional findings of interest in this study. Statistical Package for the Social Sciences (SPSS) was the program used to analyze the data. Frequencies and t-tests were used to analyze the data and test the difference in knowledge scores between those who feel prepared and those who do not. The level of significance was set at  $p < 0.05$ .

Of the 98 who fit the sample criteria in three home-care agencies, 62 registered nurses actively practicing in West Michigan completed the surveys. To this researcher's knowledge, none of the nurses practicing with the home-care agencies were LPNs, although 10 of the RNs previously held LPN licenses. As can be seen in Table 1, the nurses were licensed from 1 to 38 years ( $M=19.43$  years,  $SD= 8.86$  years). Most RNs in the sample have held a nursing license more than 10 years.

Fifty percent of the nurses surveyed had continuing education (CE) about advance directives in the last 3-5 years from various sources. The types of CE are listed in Table 1. Two nurses had more than one method of continuing education. Of



the 5 nurses who indicated “other” for method of continuing education, 2 nurses reported having informal conversations with social workers, whom the respondents felt were, on the whole, more knowledgeable than themselves about advance directives; one named the hospital as a source of education; and 2 respondents did not indicate what their “other” source of information was.

**Table 1**  
**Demographic information (N=62)**

<b>Variables</b>	<b>n</b>
<b><u>Years of RN license</u></b>	
1-10	9
11-20	22
21-38	27
<b><u>Education on ADs</u></b>	
Last 3-5 years	31
None	31
<b><u>Types of CE</u></b>	
Journal	1
Inservice	26
Lecture	1
Course	0
Other	5

Table 2 summarizes the responses to the question of preparedness to counsel patients on ADs. The results of this question divided the study group into two: prepared and unprepared. Those who left the question unanswered were not included in either of the two groups.

**Table 2**  
**Preparedness to counsel (N=62)**

<b>Variable</b>	<b>n</b>
Feel prepared	40
Do not feel prepared	19
No answer	3

Table 3 shows the number and percent of subjects correctly answering each question. The questions are numbered as they are on the survey. (Appendix D) Scores on the knowledge questionnaire ranged from 6-11 correct out of a possible range of 0-11 (M=9, SD=1). Fifty-five of the 62 subjects scored 87.4% and above.

**Table 3****Knowledge (N=62)**

<u>Question</u>	<u>TRUE</u>	<u>FALSE</u>	<u>CORRECT</u>
* correct answer	n	n	%
6. DPOA for health care defined as one who is named to speak on patient's behalf	62*	0	100
7. After DPOA document is signed patient cannot change mind	0	62*	100
8. Legally competent adults have right to make decision even if leads to death	62*	0	100
9. In Michigan a pregnant woman may make wishes known even if leads to death	37*	17	60
10. PSDA is federal law giving patient right to accept or refuse treatment	58*	1	94
11. Term "AD" describes living will and DPOA for health-care affairs	48*	13	77
12. Must have DPOA before end-of-life decisions will be honored	16	45*	73
13. Witness for DPOA may not be caregiver, physician or administrator	54*	8	87
14. DPOA must be notarized	11	50*	81
15. DPOA for health means no power over real estate or financial affairs	61*	1	98
16. DPOA document may only be processed by an attorney	5	57*	92

The 2-tailed t-test was used to compare knowledge levels between nurses who said they felt prepared to counsel patients on ADs (n=40) and those who said they did not feel prepared (n=19). Those who did not answer the question (n=3) were not included in either group. The mean knowledge score (as a percentage) for the 40 nurses who felt prepared was 89.3 and the mean percentage for the 19 nurses who did not feel prepared was 81.8, ( $t=2.89$ ,  $df=57$ ,  $p=.005$ ). Although knowledge scores were high in general, and certainly adequate, the nurses who said they felt prepared were statistically more knowledgeable as evidenced by higher average scores. Four of the 7 nurses who scored below 75% said they did not feel prepared to counsel patients on advance directives. Three of the 7, however, did say they felt prepared.

Other additional findings of interest were that six nurses (9.7%) who had received formal education on advance directives perceived that they were not prepared to counsel patients on advance directives. The knowledge scores of those who had received education in the last 3-5 years (n=31, M 87.9) were not significantly different than those who had not received education (n=31, M 86.8), ( $t=.462$ ,  $df=60$ ,  $p=.646$ ). Also of interest was the absence of a difference between knowledge and years of practice as a nurse. There was no significant difference in the knowledge scores between those who had been in practice 1-19 years (M=87.6) and those in practice 20-38 years (M=87.3) ( $t=.148$ ,  $df=56$ ,  $p=.883$ ).

In summary, nurses who feel prepared to counsel patients about advance directives are more knowledgeable about advance directives than those who do not feel prepared. Nurses who do not feel prepared to counsel patients on advance directives are knowledgeable, but to a lesser degree statistically. Most nurses working

**in home care do feel prepared and have a good working knowledge of advance directives.**

## Chapter 5

### Discussion and Implications

#### Summary of Results

This study was designed to investigate home-care nurses' knowledge of advance directives (ADs) and their perceived preparedness to counsel patients on ADs. In this study there was a statistically significant difference in knowledge between those who felt prepared to counsel patients on ADs and those who indicated they did not feel prepared. At the same time there seemed to be no relationship between knowledge and number of years as a nurse or knowledge and recent education on advance directives. The mean knowledge score of all participants was 87.4%. Knowledge scores of those who said they felt prepared to counsel was 89.3%, and those who felt unprepared scored 81.8%.

At 87.4%, the participants' mean knowledge in this study was higher than expected and likewise higher than earlier studies assessing knowledge. The 6 other surveys of this type analyzed in Chapter 2 showed a range of between 40-95% correct on the instruments used to study knowledge of ADs. Tests with a similar instrument used by Crego and Lipp (1998) showed a lower mean knowledge score of 77%. Areas in other studies where knowledge was weak included the basic content of the PSDA and, in Canada, exactly which laws governed specific situations involving decision-making and care at the end of life.

This study showed that most nurses were very knowledgeable about advance directives, more so than indicated by previous studies. In their study of Arkansas nurses, Barta and Neighbors (1993) found that while 98% of nurses knew ADs might be changed

at any time, few knew many more details and most were not confident answering patient questions about ADs. Poor overall scores on a 13-question knowledge survey led Wood and DelPapa (1996) to conclude that institutions were more interested in informing patients about advance directives than educating nurses. The work of Weiler, Eland, and Buckwalter (1996) in Iowa in 1991 implied that nurses are not sufficiently knowledgeable, nor do they have consistent quality information about advance directives. Jarr, Henderson, and Henley (1998) determined that nurses knew the essential message of the Patient Self-Determination Act (PSDA), but many felt they did not have enough information to discuss advance directives with their patients. In the Downe-Wambolt, Butler, and Coughlan study (1998), 85% of nurses knew what a DPOA was, but only 25-44% answered knowledgeably about more specific questions. Most nurses had little experience with ADs at all. Crego and Lipp (1998) determined 78% of nurses surveyed were knowledgeable about ADs and 37% had received education about ADs. Fifty-five percent thought they did not have a good understanding of ADs, and 51% felt the nurse is the best person to address the subject of ADs.

One of the reasons for the current high knowledge scores may be that nurses are more aware that there are choices to be made about end-of-life care. Perhaps this awareness has contributed to increased knowledge about the specifics of ADs. Also, it has been 3 years since a survey has been published testing nurses' knowledge, and since that time there has been much media coverage of end-of-life issues, including ADs. This could contribute to both awareness and knowledge increases. Additionally, it is a job requirement of those nurses who work in home care to ask if their patients have an

**advance directive. If not, then it is the nurse's responsibility to see that information is provided.**

**The relatively high knowledge scores may also indicate that survey respondents have sought to increase their knowledge because of job requirements. Knowledge, however, does not guarantee feelings of preparedness to counsel patients on ADs as demonstrated by the fact that nearly a third of the respondents, although knowledgeable as defined by scores higher than 75%, did not feel prepared to counsel patients on ADs.**

### **Relationship to Theoretical Framework**

**Joyce Fitzpatrick's life perspective rhythm model helps us to understand how many factors may influence counseling patients on ADs (Fitzpatrick, 1996). Knowledge and feeling prepared are just two elements that a nurse may consider when counseling patients. In her theoretical model of nursing, Fitzpatrick views life as a continuum, with ups and downs moving forward in a spiral motion. The goal of nursing is to help patients maintain a "centered point." Her theories were inspired by her professional interest in how nurses help people live and move through life's experiences. Nurses improve their practice for the good of their patients by incorporating Fitzpatrick's principles of accumulating knowledge and life's experiences for their continued growth and development. The nurse maintains a "centered point" in practice and can achieve an even balance when delivering nursing care. This integration of knowledge and experience allows for more holistic nursing care and improved outcomes for patients and their families.**



### **Implications for Practice**

**Patient education is a central part of good nursing practice, and patients rely on nurses' knowledge and expertise to keep informed. Nurses can often reassure and reinforce care the primary provider has rendered. This would include counseling about end-of-life issues and advance directives.**

**Most of the previous studies dealing with nurses' knowledge of advance directives were conducted on nurses who work in the hospital setting. Yet it seems as though, optimally, ADs should be considered well before a hospital admission (Ditillo, 1999). Usually, medical or surgical admission to a hospital is a very serious matter and often constitutes a health crisis of some sort. This is not considered the ideal time to be discussing advance directives. Outside the hospital setting, many other ancillary support personnel come in contact with patients. Nurses are less prevalent in the primary-care setting and can often be found in the home-care setting or the hospital. With fewer nurses in primary care settings, this leaves the task to perhaps lesser-educated ancillary personnel or the busy provider with little time to discuss important details of ADs and end-of-life care.**

**If nurses are less prevalent in the primary-care setting, another place to reach and educate patients is the home-care setting. Many severely ill patients who are discharged from hospitals receive home-nursing care for a period of time. A home-care nurse is in an excellent position to help a homebound client deal with the issues of an advance directive. Any apprehensions, concerns, or burdens could be addressed over time, and patients could thoughtfully reflect on decisions they and their families make (Freedman, 1994).**

Nurses in the home-care setting, therefore, need to answer basic questions about ADs. Judging from their knowledge scores on this researcher's survey, most home-care nurses would adequately be able to perform those duties. However, the definition of "counsel patients on ADs" may imply to the nurses more than just providing the "legal" information. Perhaps "counsel" implies that a nurse may be asked to "help make choices" about what kinds of care a patient might want at the end of life. This is the living will portion of the AD and would certainly be important for a person appointed as an advocate or proxy to understand. Perhaps nurses are not going to be totally comfortable with the role of counseling patients on ADs. (Nineteen of the home-care nurses surveyed did not feel prepared. This could be for a variety of reasons, not the least of which could be comfort with the subject matter as well as confidence in the knowledge they do possess.)

Even with variations from state to state with regard to the acceptance of living wills and advance directives, the PSDA gives all Americans the right to be counseled on the existence of the AD and patient choices with regard to end-of-life care (Keigher, 1994). However, with a wide range in understanding what advance directives are, and what they are designed to achieve, a universal format for the education of nurses and other health-care practitioners seems ideal and probably necessary (Downe-Wambolt, Butler, & Coughlan, 1998). Similarly, Barta and Neighbors (1993) concluded that institutions of higher learning should provide educational programs on advance directives for student nurses and practicing nurses. Crego and Lipp (1998) felt that with so many gaps in knowledge, more education on ADs for nurses was indicated. Downe-Wambolt, Butler and Coughlan, (1998) felt that further efforts toward education and collaboration were necessary and that educating nurses and the general public was good policy.

Today, home-care nurses are in perhaps the best position to counsel on advance directives. Home-care nurses are trusted health providers and confidants. Their place and privilege allow them access to many intimacies of their patients' lives (Johns, 1996). When nurses discuss the issue of advance directives with their patients, they must feel as prepared as they do to answer a basic question about blood pressure, for example, or any other health issue. If home-care nurses are to be trusted providers of health-care information, then why not be able to provide the basic facts about ADs? In the 5 years since many of the previous studies were completed, much has appeared in the general media about advance directives and end-of-life issues. As the public becomes more educated and more aware, trusted health professionals must be well informed and professionally educated about the issues of ADs and end-of-life-care choices.

As this researcher's study indicated, home-care nurses are knowledgeable about advance directives, and some do indeed feel prepared to counsel patients. Every effort must be made to provide the education and other means that will increase nursing involvement with counseling patients and their families toward a good understanding of ADs and end-of-life choices.

### Limitations of Study

Limitations of this study included small sample size, instrument reliability, and conceptual meaning of terms. The sample size was small due to constraints on resources of the researcher. This significantly decreases any generalizability of the study results to the general population of nurses practicing in the home-care setting. The reliability of the instrument used is questionable. Crego and Lipp (1998) relied on a panel of experts who reviewed their 44-question survey for content validity. No psychometric assessment of

the instrument was available to ensure validity and reliability. Reliability of the instrument used in this study was calculated using the Kuder-Richardson (KR-20) formula for calculating an internal reliability coefficient. A reliability coefficient of 0.13 was reported. Additionally, the question designed to reflect Michigan law could have contributed to the very low reliability of the 11-question instrument this researcher used. The question was ambiguous in that the answer was intended to be false, but in truth, if the question is read as written (with no implications) the correct answer was true. Most nurses (n=37) answered true and (n=17) answered false. Nine nurses did not answer the question and were scored with an incorrect answer. The question did not contribute to the understanding of Michigan law. Many nurses who answered true, however, added comments in the margin of the page indicating they were indeed familiar with and understood Michigan law.

Another limitation was the researcher's assumption study subjects would all have the same concept of "to counsel." To counsel, however, could have many interpretations. Nurses who said they did not feel prepared to "counsel" patients on ADs may have read a deeper meaning into the word "counsel" than was intended. Also the term "prepared" could be quantified. "Prepared" can be considered a relative term to some people and an absolute term to others. Some may consider themselves prepared with little knowledge. Others who are very knowledgeable may never feel prepared. These terms will have to be clarified if used in future research.

### **Future Research**

Future research should explore knowledge, education, attitudes, and practices of nurses in the home-care setting with regard to advance directives. Other studies should be

considered in the various settings where nurses practice and are in contact with the same patients on a regular basis. Any setting where a nurse has a chance to establish an ongoing, familiar, and professional relationship with patients would lend itself well to further study of advance directives. A study of issues that influence a nurse to educate patients on ADs and follow through to the subsequent completion of the AD document by the patient would be fruitful research. The ultimate goal is to have the patient complete the AD and be confident in the fact that it has been done correctly and with full knowledge and understanding of all that an advance directive document implies.

### Summary

While this study indicated that obtaining continuing education in the last 3-5 years regarding advance directives was not related to knowledge of ADs, continuing education also was not associated with preparedness to counsel on ADs. Length of time in practice as a nurse was not a factor associated with knowledge scores either.

Feeling prepared to perform an expected task, especially one as difficult as answering questions about advance directives, necessitates preparation and commitment on the part of the nurse. Preparation comes from education, integration of knowledge into nursing practice, and experience discussing advance directives. Commitment to quality patient care integrates knowledge and experience into everyday nursing practice. Patients deserve the best care from nurses and this includes counseling about ADs. By becoming knowledgeable and comfortable with ADs and feeling prepared to inform patients of their choices in end-of-life-care, nurses are able to make a valuable contribution to the continuum of patient care across the life span.

## APPENDICES

## APPENDIX A



**GRAND VALLEY  
STATE UNIVERSITY**

APPENDIX A

1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

November 2, 2001

Mary Moran Barr  
2150 Robinson Rd. SE  
Grand Rapids, MI 49506

RE: Proposal #02-79-H

Dear Mary:

Your proposed project entitled **Home-Care Nurses' Knowledge and Perceived Preparedness to Counsel Patients on Advance Directives** has been reviewed. It has been approved as a study, which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

[REDACTED]

Paul A. Huizenga, Chair  
Human Research Review Committee



## **APPENDIX B**

# Home Health Services

653 Michigan Avenue, Holland, Michigan 49423-4995 (616) 394-3346 FAX (616) 394-3629



**Holland  
Community  
Hospital**

## APPENDIX B

October 25, 2001

To Whom it Concerns,

Mary M. Barr has my permission to survey the employees at Holland  
Community Hospital Home Health Services.

Jan Langland

Holland Community Hospital

Home Health Services



# In-Home Care Services

An Affiliate of North Ottawa Community Health System

November 5, 2001

To Whom it concerns:

APPENDIX B

Mary Moran Barr has my permission to

Survey the employees of our agency for her study.



Nora Boiten,  
Director

In Home Care Services  
North Ottawa Health Services

## **In-Home Care Information**

(616) 847-9090  
800 968-3888

## **Nursing Services**

1500 S. Despelder  
Grand Haven, MI 49417  
Telephone  
(616) 847-9090  
Fax  
(616) 847-9166

## **Infusion Therapy**

1309 Sheldon Road  
Grand Haven, MI 49417  
Telephone  
(616) 847-5504  
Fax  
(616) 842-7746

## **Home Medical Equipment**

403 Taylor Avenue  
Grand Haven, MI 49417  
Telephone  
(616) 846-0360  
Fax  
(616) 846-6643

## **Hospice**

1515 S. Despelder  
Grand Haven, MI 49417  
Telephone  
(616) 846-2015  
Fax  
(616) 846-7227

Established 1892



# HOLLAND HOME

**Central Admissions**

1000 Main Street, Suite 1000  
Holland, Michigan 49423

**Corporate Office**

2000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Bretton Manor**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Bretton Woods**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Brown Manor**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Fulton Manor**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Raybrook Manor**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Raybrook Estates I & II**

**Raybrook Homes**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**HomeCare of Holland Home**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Hospice of Holland Home**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

**Rehab Dimensions**

1000 Main Street, Suite 1000  
Holland, Michigan 49423  
Phone: (616) 835-1000  
Fax: (616) 835-1000

November 5, 2001

APPENDIX B

To Whom it concerns:

Mary Moran Barr has my permission to survey the employees of our agency for her study.



Jo Kellogg

Administrator

Home Health Care Agency

Of Holland Home

## APPENDIX C

## ADVANCE DIRECTIVES SURVEY

October 29, 2001

Dear Home-Care Nurse,

My name is Mary Barr and I am an MSN student at Grand Valley State University's Kirkhof School of Nursing. I am examining nurses' knowledge of advance directives, and their perceived preparedness to counsel patients on advance directives, and I hope you will volunteer for this project. It should take you no more than 10-20 minutes to fill out the attached survey. You may complete it at your leisure in any location you choose. There is no risk to you as this survey is **completely anonymous**. The only "payment" you will receive for your time is the attached package of M & M's! I plan to keep the data I collect for a period of one year in a secure location in my home, and my statistics consultant and I will be the only persons to see these surveys. Please know that your individual responses will not be shared with your employer and are totally anonymous. I plan to share only a summary of the data with your employer. If my data proves worthy, I plan to publish it in a professional journal. The benefit to you might be an improved knowledge of advance directives. **If you choose to complete the survey, please read on.** Completion of the survey implies your consent to be a study subject.

**DIRECTIONS**

**Please follow directions on the survey and answer questions on the three pages that are attached to this letter.**

**Do NOT put your name anywhere on the survey. It is voluntary and anonymous and will only be numbered later for data analysis.**

**When you have completed the survey please place it in the box labeled "AD surveys" where you receive your mail at work, and retain this letter in case you have questions later. I plan to retrieve the survey box 4 weeks from the date at the top of this letter.**

**“You are free to decide not to participate in this study or to withdraw at any time without adversely affecting your relationship with me or Grand Valley State University. Your decision will not result in any loss of benefits to which you are otherwise entitled.”**

**If you have any questions regarding this survey please feel free to contact me at any time by phone, e-mail or mail. Also, Paul Huizenga of the Human Subjects Review Committee at Grand Valley State University is available to field any issues regarding your rights while participating in this survey. He may be reached through Grand Valley State University at 895-2472.**

**Thank You Again,**

**Mary M. Barr**

**Mary M. Barr, barrmary@aol.com, (616) 774-2894  
2150 Robinson Rd. SE, Grand Rapids, MI 49506**

## **APPENDIX D**



## APPENDIX D

**NURSING SURVEY**  
**Advance Directives Knowledge Questionnaire**

1. Please indicate your professional status                      LPN \_\_\_\_\_ RN \_\_\_\_\_

2. Year of your first nursing license                              LPN \_\_\_\_\_ RN \_\_\_\_\_

**Please answer yes or no to the following questions:**

(circle your answer)

3. Have you had formal education about advance directives in the last 3-5 years ?

YES

NO

4. If YES, how did you learn about advance directives?

Journal

Inservice

Lecture

Course

Other \_\_\_\_\_

5. Do you feel prepared to counsel patients about advance directives?

YES

NO

**Comment (optional):**

**Please answer the following true-false questions.**

**APPENDIX D**

**Circle your choice.**

- |  |             |              |
|--|-------------|--------------|
| <p><b>6. A durable power of attorney for health-care formally names an individual (proxy) to make medical decisions on your behalf when you can no longer decide for yourself.</b></p>   | <b>TRUE</b> | <b>FALSE</b> |
| <p><b>7. After a living will or durable power of attorney for health-care has been signed, patients cannot change their minds.</b></p>   | <b>TRUE</b> | <b>FALSE</b> |
| <p><b>8. Legally competent adult patients have the right to make their end-of-life care wishes known to their health-care providers even if their decision may lead to death.</b></p>  | <b>TRUE</b> | <b>FALSE</b> |
| <p><b>9. In Michigan, a pregnant woman may make her end-of-life care wishes known to her healthcare providers even if her decision may lead to her death.</b></p>  | <b>TRUE</b> | <b>FALSE</b> |
| <p><b>10. The Patient Self-Determination Act is a federal law that states that all federally reimbursed facilities must have a mechanism to advise patients of their legal rights and options for refusing or accepting treatment if they are or become incapacitated.</b></p> | <b>TRUE</b> | <b>FALSE</b> |

## APPENDIX D

<b>11. Advance directive is a term used to describe living wills and durable powers of attorney for health-care.</b>	<b>TRUE</b>	<b>FALSE</b>
<b>12. Patients must have a living will and durable power of attorney for health-care before end-of-life decisions are honored.</b>	<b>TRUE</b>	<b>FALSE</b>
<b>13. Living wills and durable powers of attorney cannot be witnessed by the attending physician or administrator of a nursing facility where the patient is receiving care.</b>	<b>TRUE</b>	<b>FALSE</b>
<b>14. Living wills and durable powers of attorney for health-care must always be notarized.</b>	<b>TRUE</b>	<b>FALSE</b>
<b>15. A durable power of attorney for health-care does not give the designated agent power over financial or real estate transactions</b>	<b>TRUE</b>	<b>FALSE</b>
<b>16. Living wills and durable powers of attorney can only be processed by an attorney.</b>	<b>TRUE</b>	<b>FALSE</b>

**Thank You**

**Adapted from a survey by Crego& Lipp, (1998).**

**Critical care nurses knowledge about advance directives. American Journal of Critical Care, 7,  
218-233.**

## APPENDIX E

Subj: Graduate Student Master's Thesis  
Date: Monday, January 11, ~~1994 2:44:28 AM~~  
To: elizabeth.lipp@wright.edu

phone # receipt e

APPENDIX E

Dear Dr. Lipp,

I am a graduate student in the Kirkhof school of nursing, Grand Valley State University, Allendale (Grand Rapids) Michigan. The subject of my thesis is the nursing role in advance directives. I was hoping you would consider allowing me to use your Knowledge and Experience questionnaire as published in American Journal of Critical Care, May 1998. Also I'd be interested in your validity and reliability statistics for the questionnaire. I greatly appreciate your time and any consideration you may give to me. I am also going to try and contact your co-author Patti J. Crego. Thank you for your consideration.

Mary Moran Barr, RN, BSN, CCRN, MSNc

2150 Robinson Rd. SE

Grand Rapids, MI 49506

Phone 616-7742894

e-mail BarrMary@aol.com

Subj: Advance Directives  
Date: Tuesday, February 15, 2000 2:51:18 PM  
From: CREGOP@ohiohealth.com  
To: barrmary@aol.com

Mary--Thank you for your interest in the advance directive article

I will attach the letter I usually send. You can review and get back with me.

Good Luck

(See attached file: advdir request 10.doc)

</XMP>

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