

PERCEPTIONS OF NORTH DAKOTA REGISTERED NURSES REGARDING
ADVANCE DIRECTIVES

by

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ABSTRACT

One of the functions of nurses is to assist individuals to achieve a peaceful death. In order to fulfill this role, patient end-of-life wishes must be communicated to family members and health care providers. Since passage of the Patient Self-Determination Act (PSDA) in 1990, advance directives have served as the legal vehicle and communication tool for bringing about an understanding of these wishes, should the patient be unable to competently speak for him/herself. Unfortunately, although the majority of Americans favor the provisions that living wills and health care powers of attorney contain, only a small fraction actually complete advance directives. As one of the largest and most accessible members of the health care team, nurses are in an ideal position to serve as advocates and educators for the facilitation of informed decision-making for patients making choices about end-of-life care. However, a nurse's ability to advocate is greatly affected by a number of essential concepts, such as perception, time, interaction, role, power, status, comfort level, and decision-making.

This was an exploratory descriptive study of nurses registered in and currently working within the state of North Dakota. The purpose of this study was to explore the current perceptions and experiences of North Dakota registered nurses with discussing advance directives with patients and assisting with their implementation.

A self-reported questionnaire was mailed to a random sample of 600 registered nurses in the state of North Dakota who met the study criteria. The

questionnaire elicited participant perceptions and experiences related to advance directives, with a focus on knowledge and comfort levels with discussing advance directives, agreement with the concept of patient autonomy, and barriers to advance directive discussions encountered in practice. Data were analyzed using descriptive and inferential statistics.

More than half of all participants demonstrated actual as well as perceived knowledge on questions relating to the PSDA and possession of sufficient information to discuss advance directives with patients. However, the majority indicated that they would benefit from further education on the topic. Likewise, a little more than half of the participants indicated that they were comfortable with discussing advance directives with patients, and agreed that it was indeed a nursing responsibility to do so. However, social work was predominantly ranked number one over the patient's nurse as the person they would contact if a patient asked for advance directive information. Almost all participants agreed with the concept of patient autonomy in making end-of-life care decisions, yet completion rates of advance directives for themselves reflected the low national averages. Finally, the majority of participants reported encountering multiple barriers to discussing advance directives in their practice, with time constraints ranked number one by a large margin.

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One of the functions of nurses is to assist individuals to achieve a peaceful death. In order to fulfill this role, patient end-of-life wishes must be communicated to family members and health care providers. Since passage of the Patient Self-Determination Act (PSDA) in 1990, advance directives have served as the legal vehicle and communication tool for bringing about an understanding of these wishes, should the patient be unable to competently speak for him/herself. Unfortunately, although the majority of Americans favor the provisions that living wills and health care powers of attorney contain, only a small fraction actually complete advance directives. As one of the largest and most accessible members of the health care team, nurses are in an ideal position to serve as advocates and educators for the facilitation of informed decision-making for patients making choices about end-of-life care. However, a nurse's ability to advocate is greatly affected by a number of essential concepts, such as perception, time, interaction, role, power, status, comfort level, and decision-making.

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CHAPTER I

INTRODUCTION

Dying is a natural process and a fact of life, yet it remains an event that few Americans want to think about and even fewer plan for. Since the advent of antibiotics and improved surgical techniques beginning in the 1930s, death and dying have been increasingly institutionalized in the United States, moving from the home to the hospital and the funeral home. Unfortunately, the result of this shift on how we view death, dying, and end-of-life care has been detrimental socially, culturally, and professionally—we feel stunned and unprepared for the situation, lacking in experience, and see death as a defeat rather than an inevitable culmination of the life cycle.

This discomfort and unfamiliarity can lead to poor communication and planning between patients, family members, and health care providers when end-of-life issues arise, which culminates in decidedly negative outcomes. Nationally, only 25% of deaths occur at home, even though more than 70% of Americans say that is where they would prefer to die (Last Acts, 2002). A recent survey of one thousand people, three-quarters of whom had suffered the loss of a family member or close friend within the past five years, found that 42% rate the health care system as doing only a fair to poor job of involving patients and families in decisions about care. Similarly, they also rate the health care system as doing only a fair to poor job of making sure dying peoples' wishes about their

medical care are followed (Last Acts, 2002). Findings from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (Connors et al., 1995), the largest clinical study ever conducted in the United States with patients near death, demonstrated an alarming mismatch between what dying people wanted and what they received. Despite study interventions designed to improve end-of-care decision-making and reduce prolonged dying, 47% of the time doctors didn't know patients' wishes (Connors et al., 1995). Researchers also reported that 38% of the 608 intervention patients who died spent at least 10 days in intensive care, where aggressive treatment was the norm (Connors et al., 1995).

The idea of advanced care planning gained momentum with the high profile "right-to-die" cases of Karen Quinlan in 1975, and Nancy Cruzan in 1990. In the Nancy Cruzan case, her parents sought to have life-prolonging treatments stopped after a 1983 auto accident left the young woman in a coma. Cruzan's parents testified in court that she had previously verbally expressed a desire not to receive such treatment if she were unable to recover from an illness or accident, however the Missouri Supreme Court deemed that such verbal wishes were not clear and convincing evidence (Maxfield, Pohl, & Colling, 2003). The case highlighted the need for protected self-determination, a concept predicated on the ethical principle of autonomy-an individual's right to self-rule. This belief, that patients have a right to choose their own treatment or lack of treatment, was upheld by the United States Supreme Court in 1991 when it ruled eight to one that every competent patient has a right to refuse medical care, even if that refusal could lead to death (Butler, 1996).

In order for health care providers to assist patients in achieving good living on the way to death, end-of-life choices need to be actively discussed, appropriately communicated, and ultimately followed. Advocated by numerous professional societies, citizens' groups, legislators, and the courts, advance directives represent one way to help ensure that this process takes place. Advance directives are legal documents that convey the health care wishes of a patient should he or she become incapacitated and unable to participate in their medical care. All fifty states and the District of Columbia have legislation that authorizes the use of instructional advance directives, the appointment of a health care agent, or both (Ditto et al., 2001). These state laws are, in turn, reinforced at the federal level by the Patient Self-Determination Act (PSDA).

Despite the fact that the majority of people are familiar with the major elements related to advance directives and agree that advance directives are a good idea (Elpern, Yellen, & Burton, 1993; Nolan & Bruder, 1997), studies since the implementation of the PSDA have consistently demonstrated low rates of advance directive completion varying from 5%-49% (Center for Bioethics, 2001; Douglas & Brown, 2002; Elpern et al., 1993; Gordon & Shade, 1999; Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000). Even more disheartening, of the few individuals who do complete advance directives, only a small number discuss them with their providers or even tell them that the documents exist (Elpern et al., 1993; Gordon & Shade, 1999).

Purpose of the Study

The purpose of this study was to explore the current perceptions and experiences of North Dakota registered nurses with discussing advance directives with patients and

assisting with their implementation. The number of nursing studies as a whole in this area is relatively small in comparison to similar studies involving physicians and patients. Moreover, of the past studies of nursing attitudes and knowledge levels of advance directives that do exist, most have focused on a convenience sample of nurses working within a particular specialty area, and often only included nurses employed within one facility.

Review and Critique of Related Studies

Advance directive documents include living wills and durable powers of attorney for health care (DPOAH) (Maxfield et al., 2003). A living will expresses the health care wishes and life-sustaining treatments that a patient may or may not desire, while the DPOAH formally appoints an advocate to make medical decisions on the patient's behalf.

The PSDA, passed into law as part of the Omnibus Budget Reconciliation Act (OBRA) of 1990 and implemented in 1991, was designed to promote the use of advance directives by increasing public awareness of their medical treatment rights. The law pertains to all health care institutions receiving Medicare or Medicaid funds and requires that every individual receiving health care be informed in writing of the right under state law to make decisions about his or her health care, including the right to refuse medical and surgical care and the right to initiate written advance directives. Institutions must document advance directives in the medical record and ensure compliance with state law regarding advance directives. The PSDA also requires that health care institutions establish mechanisms for disseminating information to patients, designate personnel

responsible for discussing advance directives, maintain pertinent written policies and procedures, and provide staff and community education on advance directives (Mezey, Evans, Golub, Murphy, & White, 1994; OBRA, 1990).

It was hoped that the PSDA would increase the occurrence of timely discussions between patients and their health care providers regarding end-of-life wishes and, in turn, promote completion of advance directives. Unfortunately, that hasn't appeared to be the case. The overall prevalence of advance directive documents remains 15%-20% and, even when completed, these documents often are not readily available to health care providers or completely understood by loved ones (Schwartz et al., 2002). As Elpern et al. (1993) noted at the conclusion of their preliminary investigation of patient opinions and behaviors regarding advance directives:

The impact of this legislation depends on the extent to which hospitals comply with the spirit rather than the letter of the law. We suspect that giving patients forms to sign and literature to read will not have a great impact on knowledge or behaviors regarding use of advance directives (p. 166).

Efforts to better understand the reasons behind the low rates of advance directive completion have focused primarily on the beliefs and practices of patients (primarily the elderly) and health care providers (primarily physicians). Although a number of factors have come to light, a common theme is often times one of communication: who is discussing end-of-life care issues, when is it being discussed, how knowledgeable and comfortable are participants with the discussion, and under what circumstances/setting is the discussion occurring? A 1999 study (n=5117, p=.05) reported that participants who

were asked about their end-of-life plans were nearly three times more likely to have filed an advance directive than those who were not (Gordon & Shade, 1999).

Statements from the American Medical Association (AMA) and the American Nurses Association (ANA) expect that physicians and nurses will advocate for patient participation in end-of-life care planning, and assumes that both groups possess the knowledge and comfort levels necessary to advise patients (AMA, 1997; ANA, 1991; Jarr, Henderson, & Henley, 1998). Studies suggest, however, that this is not always the case. Langerman, Angelo, and Johnston (2000) found in their survey of 417 physicians that, although advance directives are believed to be helpful to patients and physicians (91%), lack of understanding and erroneous beliefs about the appropriateness of advance directives for certain patient groups, lack of knowledge, time constraints, and lack of comfort serve as continuing barriers to the discussion and use of advance directives. These barriers to discussion have also been reported in similar studies by Morrison, Morrison, and Glickman (1994); Tulskey, Fischer, Rose, and Arnold (1998); and Wissow, Belote, Kramer, Compton-Phillips, Kritzer, and Weiner (2004), and likely contribute to the finding that only a little over half of physicians report advance directives as affecting their management of care (Langerman et al., 2000). A recent study that reviewed the charts of patients undergoing high-risk operations at a university teaching hospital between 1996 and 2001 (n=252) found that, although by 2001 20 of 46 patients (43%) had declared having an advanced directive on admission and 6 of 46 patients (13%) had an advance directive in their chart, no attending or resident physician had ever noted the presence of an advance directive in the chart during any of the study years. Additionally,

review of the progress notes revealed no identifiable impact of the presence of an advance directive on the care patients received during their subsequent postoperative hospitalization (Yang et al., 2004).

Nurses' attitudes and knowledge levels are integral to their ability and willingness to assume an active role in the discussion and implementation of advance directives. Although the majority of studies concerning perceptions and knowledge levels of advance directives among nurses occurred after enactment of the PSDA in 1991, one survey of Iowa nurses' knowledge of living wills and perceptions of patient autonomy that was initiated prior to implementation of the PSDA provided a preview of some of the recurring themes that would follow in later research. Weiler, Eland, and Buckwalter (1996) noted that the low response rate of 2,697 questionnaires out of 10,000 may have indicated that nurses who were not knowledgeable about the content area chose to ignore the questionnaire, but of those who did respond, 70% were aware of Iowa's living will legislation even though 30% did not gain this information through traditional professional communications. Nursing perceptions of patient autonomy in decision-making were somewhat low, with only 27% agreeing that patients should have complete control in treatment decisions. Although 45% said patients should have as much control and 22% said patients should have more control than health care providers, 4% responded that patients should have either no control or less control in decision-making. At that time, 72% of respondents felt that it was a nursing responsibility to suggest to patients that they talk with family or friends about what care the patient wanted, but fewer felt a responsibility to provide information on living wills (39%) or suggest that patients

actually write a living will (31%), indicating a willingness by nurses to assume a more passive role.

After the PSDA went into effect, the few research studies focusing on professional perceptions concentrated on the themes of patient autonomy, attitudes, role responsibility, and barriers to implementation. The concept of autonomy lies at the heart of advance directives, and is an important indicator of one's willingness to participate in a process designed to give patients control over end-of-life treatment decisions. Nursing attitudes towards patient autonomy have been mixed over the years, with survey studies coming from primarily smaller convenience samples within hospital settings. Wood and DelPapa (1996) found that of 112 hospital nurses surveyed, 38% listed autonomy as the basis for their positive attitude towards advance directives. In a study designed to identify compliance with end-of-life care decision protocols, 93% of the sample of 213 critical care hospital personnel-of which 107 were nurses-reported that they disagreed or strongly disagreed with the statement that all patients have a right to make end-of-life decisions (Stoeckle, Doorley, & McArdle, 1998). A related finding was reported by Davidson, Hackler, Caradine, & McCord (1989) in which physicians believed that their training and experience gave them greater authority than patients to make decisions about withholding heroic treatment. In contrast, a Canadian study by Molloy et al. (1997) found that 97% of the 29 visiting nurses participating in a program to educate patients about advance directives and assist them with completion agreed with the statement that patients need to be more involved in their own health care decisions and that they have a right to refuse or accept medical treatment. A larger and more recent study of Ohio

nurses knowledge, attitudes, and predictors of advance directive discussions (Lipson, Hausman, Higgins, & Burant, 2004) found that respondents ($n=719$) had moderately positive attitudes toward advance directives ($M=3.45$; $SD=1.12$; range of 1 to 5 with 5=strongly agree, 4=agree, 3=undecided, 2=disagree, and 1=strongly disagree), with age positively correlated with this positive attitude ($r=.89$; $p=.02$) while years of nursing experience was not. Respondents disagreed that advance directives represent an unwarranted extension of the law into medicine and that prolonging life is more important than honoring a patient's request to forego life-sustaining treatment ($M=1.41$).

It could be argued that perhaps the low completion rates for advance directives among the American public is an indication that patients do not rate autonomy in treatment decisions highly. Studies have indicated that, in general, patients believe they should be given choices about the care they receive at the end-of-life. A study of attitudes about advance directives among a sample of 30 inpatients by Douglas and Brown (2002), reported that all thirty participants believed they would be given such choices, while 29 said that, if they were unable to make such choices, their family members would be given the opportunity. In a 2000 study of 1,016 randomly drawn patients from four tertiary hospitals, the most frequently cited reason respondents gave for having a directive was "wanting to make up your own mind" (92%) (Mezey et al., 2000). In comparing signers versus nonsigners of advance directives, Medvene et al. (2003) noted that the motivations for those who completed an advance directive (36%, $n=248$) included "reducing family burden" and "need for individual control and autonomy". Conversely, a qualitative study of housebound patients averaging 86 years

old (Carrese, Mullen, Faden, & Finucane, 2002) illustrates the point that patient agreement with the principle of autonomy is not always a given. Most of the twenty participants (n=19) indicated that they consider what happens at the end of life to be God's domain, and that it was not the individual's role to be concerned about or actively plan for such matters.

Nurses tend to have a positive attitude about advance directives, yet ironically this does not translate into higher completion rates of these documents for themselves. Studies have reported a positive or strongly positive attitude of 93% (n=104) (Wood & DelPapa, 1996), or a generally favorable attitude (Blondeau, Valois, Keyserlingk, Hebert, & Lavoie, 1998; Lipson et al., 2004; Silverman, Fry, & Armistead, 1994) towards advance directives or involvement in an advance directive program, while at the same time reporting only 16% (n=18) (Wood & DelPapa, 1996), 11.4% (n=39) (Blondeau et al., 1998), and 36% (n=258) (Lipson et al., 2004) completion rates for advance directives among respondents. Crego and Lipp (1998) reported that 86% of 339 acute care registered nurses had no advance directives for themselves, yet these same respondents indicated that it was important for patients to complete advance directives. Similar results were reported among 214 surveyed school nurses, with 78% stating that they did not have an advance directive for themselves, even though 77% indicated that they wouldn't want to have cardiopulmonary resuscitation if they were terminally ill (Schultz-Grant, Young-Cureton, & Kataoka-Yahiro, 1998). These researchers also reported that affirmative life experiences and education level were not significant factors as to whether or not a nurse had an advance directive completed.

These results mirror the low rates of completion among the American public, however studies have not addressed why this might be the case, or whether significant differences exist between health care professionals and patient populations. Schultz-Grant et al. (1998) speculated that possible reasons for the low completion rates among nurses might include a conflict regarding acceptance of death, their personal mortality, not thinking about establishing the documents for themselves, or the nursing profession's strong emphasis on preservation of life. Another possible reason could be a perception of ineffectiveness. Neuman and Wade (1999) noted that 63% of health care providers they surveyed in Michigan indicated that, in their experience, advance directives only occasionally or rarely assured compliance with a patient's wishes. Of the 116 participants, 25% were nurses. Disappointing results from the SUPPORT study (Connors et al., 1995), in which intensive, costly interventions intended to facilitate prognosis accuracy, advance care planning, and communication between physicians and seriously ill patients and their families failed to improve end-of-life care or patient outcomes, as well as questions regarding the effectiveness of advance directives to change care at the end of life (Hanson, Tulsky, & Danis, 1997) or accurately convey patient wishes to physicians (Coppola, Ditto, Danks, & Smucker, 2001; Maxfield et al., 2003) or to designated surrogates (Ditto et al., 2001) further heighten this perception and may negatively affect completion rates among health care providers.

However, a more recent study of opinions and use of advance directives among 417 hospital physicians (Langerman et al., 2000) painted a more positive picture, with 91% of participants reporting that they felt advance directives were beneficial to them

and 55% reporting at least one instance where an advance directive changed their management of a particular patient's care. Additionally, a 2003 study by Ahrens, Yancey, and Kollef to evaluate the use of a dedicated physician-clinical nurse specialist team to improve communication between health care professionals and patients near the end of life in intensive care units and their families reported reduced ICU lengths of stay (9.5 days for the control group [n=108] versus 6.1 for the intervention group [n=43]), mean hospital length of stay (16.4 days versus 11.3), and resource utilization (\$24,080 versus \$15,559 for direct costs and \$8035 versus \$5087 for indirect). Interestingly, these savings occurred even though the mortality rate was lower in the intervention group (74%) than in the control group (93%) for reasons that were not clear. Unlike the SUPPORT study, which focused on providing predictive information to enhance care, this study highlighted the need for more effective communication strategies that were provided early, frequently, and consistently by members of the health care team.

Whatever else they may or may not accomplish, advance directives do appear to give patients a feeling of having some control over their life-sustaining treatments, as well as relieving family of the responsibility of having to make such decisions. Studies have found that advance directives reduce stress levels among family members of hospitalized patients (Tilden, Tolle, Nelson, & Fields, 2001) and that discussions of treatment interventions improve perceived surrogate understanding and comfort (Ditto et al., 2001). A 1997 study of patients' attitudes found that 67% of subjects (n=34) felt advance directives would prevent them from receiving treatment that they did not want, while 85% agreed that it would ensure they would receive the treatment they did want

(Nolan & Bruder, 1997). Most of these patients also indicated a belief that advance directives would positively impact their families, with 82% indicating their families would want them to have them, 74% indicating an advance directive would keep family from disagreeing over the patient's treatment, 78% feeling it would prevent guilt over treatment decisions, and 74% believing that an advance directive would prevent costly medical expenses for their families (Nolan & Bruder, 1997).

Although the early years of the PSDA left some nurses feeling unsure about their professional responsibility in discussing advance directives with patients, more recent studies have shown that they are taking an increasingly active role despite the presence of significant barriers. Haynor's 1996 study of chief nurse executives (CNEs), conducted over a four year period beginning in 1992, noted that half of the 17 CNEs surveyed were continuing to report reluctance to discuss advance directives and resistance to that role responsibility among their nursing staff and physicians, even though by the fourth year of the study 75% (n=13) of the institutions the respondents were employed at had designated nurses to perform advance directive activities and charting. In a study of 107 hospital nurses from 13 different patient care units conducted by Jarr et al.(1998), nurses ranked themselves third behind admitting and social work among personnel they would call if a patient desired advance directive information. Only two out of five respondents from the study agreed that it should be a nursing responsibility to assist the patient to acquire such information, while one out of five nurses surveyed were unsure of their responsibility. Poupolo and colleagues (1997) noted in their study of communication between nurses and patients (n=1,427) about preferences for cardiopulmonary

resuscitation (CPR) that direct discussion of patient preferences occurred in only 13% (n=191) of cases. This study also found that a well-established philosophy exists (even in large teaching hospitals) that discussing resuscitation is medical decision-making and not within the realm of nursing practice to initiate. Such beliefs run contrary to the American Nurses Association's 1991 position statement, which specifically states, "It is the responsibility of nurses to facilitate informed decision-making for patients making choices about end-of-life care" (p. 1).

In contrast to these findings, Silverman et al. (1994) found that most of the 20 nurses they interviewed felt not only that they were qualified to meet the requirements of their facility's advance directive program, but that they should have more responsibility in PSDA implementation (n=11). They described this as a perceived "duty" or "moral obligation" (p. 34) to provide patients with detailed information and promote meaningful discussions. The researchers noted that this tension between the desire to perform an obligation, and the lack of resources to fulfill it created a conflict for these nurses. In a replication of the Jarr et al. (1998) study, Ryan, Santucci, Gattuso, Czurylo, O'Brien, and Stark (2001) found that the 133 community hospital nurses they surveyed felt more responsibility towards providing patients with advance directive information. Seventy-nine of these nurses ranked themselves number one among personnel to call if a patient requested information, and 55% (n=69) agreed that assisting patients to obtain advance directive information was their responsibility.

The one common thread tying virtually all nursing studies of advance directive perceptions together are the barriers to implementation of the PSDA that are repeatedly

identified. Lack of knowledge, both perceived and actual, hinders the nurse's ability to competently discuss advance directives with patients or assist them with executing the documents. Despite the PSDA requirement that institutions provide staff education, many nurses report a lack of knowledge regarding advance directives and the provisions of the PSDA. Wood and DelPapa (1996) reported 76% (n=85) of nurses had an unacceptable knowledge of laws about advance directives, with knowledge found to be significantly correlated with experience ($r=.2424$; $p=.005$) and education levels ($r=.3492$; $p=.000$). Mean scores for the knowledge test given by Crego and Lipp (1998) were 78%, with a wide range of scores (range=40%-95%) indicating significant deficits for some nurses. Fifty-five percent of nurses in that study (n=339) felt that they didn't have a good understanding of advance directives and nearly all of them (92%) thought that they would benefit from additional education, yet only 37% of nurses had attended some form of class on advance directives. Knowledge test scores reported by Schultz-Grant et al. (1998) had a mean of 2.9 out of 5 advance directive questions answered correctly, with masters prepared nurses scoring significantly higher than those with a bachelor's degree ($F(1,211)=6.63$, $MS=8.60$, $p=.01$). Both Jarr et al. (1998) (n=107) and Ryan et al. (2001) (n=133) reported a number of nurses in their studies felt they lacked sufficient knowledge to discuss advance directives (56% and 31% respectively, with an additional 17% in the Ryan et al. study indicating they were unsure). These continuing findings through the years are disturbing, considering that nurses are not only responsible for having this knowledge but also are often asked by patients and their families for input related to advance directives. These findings also cast doubts on the quality and effectiveness of

current nursing and institution education programs. Stoeckle et al.(1998) found that 85.4% (n=182) of healthcare providers surveyed felt that the educational preparation they received did not enable them to discuss end-of-life care decisions.

The most recently identified nursing study to address knowledge and attitudes (Lipson et al., 2004) found that respondents (n=719) scored better on the knowledge questions, with 88.1% of questions answered correctly. However, respondents recalled only minimal exposure to advance directive information during nursing school and reported that they were not adequately prepared to discuss advance directives without proper education on the subject. The researchers noted that the minimal exposure finding may have been influenced by the mean age of respondents (51) and by their attending nursing school prior to the enactment of any advance directive legislation. However, this lack of knowledge may also be due in part to the scarcity of advance directive content in formal nursing education. Ferrell, Virani, and Grant (1999) analyzed end-of-life content in nursing textbooks and found that only 2% of the content and 1.4% of the chapters within the examined 50 major textbooks used in nursing education addressed end-of-life issues. It's important to note that the Lipson et al. (2004) study found a statistically significant difference ($p=.000$) in reported levels of advance directive discussions with patients among those respondents with exposure to advance directive information both during nursing school ($M=2.3$) and outside of formal education ($M=2.0$), while higher age ($r= -.12$; $p=.002$), greater years of nursing experience ($r= -.15$; $p=.000$), and higher level of education ($r= -.09$; $p=.020$) correlated negatively.

A related barrier to PSDA implementation is nurses' comfort level regarding advance directives. Discussing, educating, and assisting patients with advance directives is a complex task requiring determination of competency, understanding of medical technology, and sensitivity to emotional factors (Molloy et al., 1997). Nurses who do report being comfortable with discussing advance directives also tend to report having sufficient information to do so. All twenty nurses in Silverman et al. (1994) reported feeling both comfortable with, as well as qualified to participate in their institution's advance directive program. Jarr et al. (1998) (n=107) reported that the only nurses who responded to their question, "I am comfortable talking with patients about advance directives" (p. 31) were those who had answered in the prior question that they felt they had sufficient information to discuss advance directives (28%). In their replication study, Ryan et al. (2001) reported similar results, with 53% (n=70) of nurses agreeing they had sufficient information and 55% (n=73) agreeing that they were comfortable discussing advance directives with patients. Lipson et al. (2004) found that 61% (n=397) of nurses felt moderately confident to very confident in their advance directive discussion skills, while 36% (n=255) felt only slightly confident or not at all confident. Increased confidence in their advance directive discussion skills was found to be a significant predictor of actual advance directive discussions (OR=3.0, CI=2.3 to 3.8). Comfort level among nurses can also be affected by a perceived pressure to "know everything" pertaining to advance directives. During their development of a participatory educational program in faith communities designed to increase discussion and signing of advance directives, Medvene et al. (2003) found that the parish nurses who were implementing the

program were more comfortable with their role when the emphasis was shifted to a model in which they functioned as facilitators of personal change versus advance directive experts.

This connection of comfort level with knowledge level is important, but clearly is not the only factor involved. Studies have also raised the issues of advance directive discussions causing anxiety and/or suspicion among patients (Silverman et al., 1994) and of a majority of health care providers (78.9%; n=168) feeling uncomfortable even using words such as death and dying with patients and families (Stoeckle et al., 1998). Although one study was found in which lack of trust that health care professionals would implement advance directives in ways that were in their best interests was noted by some participants in an advance directives education program as a motivation for not completing the document (Medevane et al., 2003), from the patients' standpoint these worries appear for the most part to be unfounded. Elpern et al. (1993) found that of the 46 inpatients and 50 outpatients interviewed, 83% said they were either comfortable or very comfortable discussing advance directives. Furthermore, the respondents reported that they felt more comfortable discussing advance directives with an attending physician (94%) or nurse (78%), versus other hospital personnel (39%). Douglas and Brown (2002) found that of their sample of thirty hospital patients, only 18% of the seventeen who didn't complete advance directives listed "discomfort with making decisions about life support" as a reason (p. 64). Although a study of 55 adults aged 50 years or older by Inman (2002) did find a degree of patient discomfort with discussing advance directives with statements such as "it's too morbid" and "I can't cope with the thought of death"

(p. 44), these reasons fell behind less emotional ones such as “haven’t gotten around to it” and “not ready” (p. 44) and were taken from a minority 22% who had not discussed end-of-life wishes with someone. As noted by Silverman et al. (1994), nurses who reported initial patient responses of anxiety and/or suspicion to advance directive discussions found that further explanation resolved these anxieties for most patients.

A third major barrier to advance directive discussions involves time constraints. Primarily studied in the past from an inpatient viewpoint, health care providers have raised concerns regarding insufficient time to adequately address the subject of advance directives with patients, as well as patient and family inability to retain the information and make decisions in the more crisis-oriented, information overloaded environments of admission, serious illness, and short hospital stays. Lack of time for meaningful end-of-life discussions and/or a need for other health care personnel to assist has been identified by participants as an issue in many of the nursing studies discussed previously (Molloy et al., 1997; Neuman & Wade, 1999; Ryan et al., 2001; Silverman et al., 1994). Physicians have also noted time constraints as a concern (Morrison et al., 1994; Wissow et al., 2004).

Along with inadequate amounts of time for advance directive discussions, the timing of such discussions in terms of when and how they are conducted is also an important issue. The study by Elpern et al. (1993) (n=96) found that patients prefer to be given advance directive information either before (51%), or at the time of (31%) admission. Interviews of 329 adult outpatients (mean age=50.9) performed by Johnston, Pfeifer, and McNutt (1995) also indicate that they want to receive such information while

they are well (80% to 84%). The 1995 study by Johnston et al. specifically looked at patient versus physician opinions regarding when and how advance directive discussions should be conducted. Multiple discrepancies were found between the two groups, with patients indicating discussions should occur earlier than the physicians did, at an earlier age, earlier in the natural history of disease, and earlier in the patient-physician relationship. Although many articles promote initiation of these discussions in the outpatient setting when patients are healthy or well (Crego & Lipp, 1998; Elpern et al., 1993; Inman, 2002; Maxfield et al., 2003; Neuman & Wade, 1999; Wissow et al., 2004), few studies have addressed the perceptions and knowledge levels of nurses employed in such settings.

In their study to develop and evaluate an instrument to measure barriers to implementation of advance directives, Stiller, Molloy, Russo, Dubois, Kavsak, and Bedard (2001) identified seven domains for barriers among 41 health care personnel (61% of whom were nurses) working in various settings in Ontario, Canada. These domains, listed from highest to lowest intraclass correlation coefficient score (ICC), included demographics (e.g. culture, gender, age, status) (ICC=0.85), education (ICC=0.78), lack of privacy (ICC=0.77), health care facilitator attitudes (ICC=0.76), time constraints (ICC=0.73), difficulty of patients to grasp the concept (ICC=0.71), and family influence (ICC=0.68). The researchers noted that health care providers were more likely to rate higher system-level barriers such as time constraints, health care facilitator attitudes, lack of privacy, and lack of education over individual-level barriers like religion, culture, or procrastination. Nurses were found to be more likely to rate

demographics, education, health care facilitator attitudes, and difficulty of patients to grasp the concept as barriers to implementation.

The majority of research on nursing perspectives of advance directives and the PSDA have focused on the issues of patient autonomy, attitudes, role responsibility, and barriers to implementation. Along with being few in number and primarily occurring within the later half of the 1990s, many of these studies are also limited due to the fact that they were conducted using smaller convenience samples of nurses working within one institution and/or specialty area, making generalization difficult. Despite these shortcomings, these studies have suggested that nurses, although less conflicted over their perceived responsibility towards patients than in the past with regards to discussion of advance directives, tend to demonstrate significant deficiencies in their knowledge of these documents, which in turn can lead to more individuals experiencing decreased levels of comfort in discussing them with patients. For those who are knowledgeable and comfortable with this role, other barriers to implementation such as time constraints and the attitudes of other health care providers remain. Generally positive in their attitudes towards advance directives and supportive of their execution by patients, nurses nonetheless often fail to implement the documents for themselves for largely unknown reasons. The degree of autonomy that a patient should be afforded in end-of-life decision-making, as well as the ability of advance directives to affect treatment decisions may also be significant issues for some.

Significance of the Study

The United States population is growing older. From 1950 to 2000, the total resident population of the United States increased from 150 million to 281 million, representing an annual growth rate of 1%, while the elderly population (65 years of age and over) grew twice as rapidly during the same time period, increasing from 12 to 35 million persons (National Center for Health Statistics [NCHS], 2003). It is projected that growth in the elderly population will be particularly rapid as the “baby boom” generation turns 65 years of age beginning in 2011, and by 2050 it is projected that one in five Americans will be elderly (NCHS, 2003). A number of factors, including advances in technology and medical science, have contributed to increased life expectancy and reduced mortality and morbidity associated with many chronic diseases and conditions, but such advances have come at a cost. Chronic diseases cause major limitations in daily living for more than one of every ten Americans (25 million people), are responsible for 1.7 million deaths each year, and account for more than 70% of the one trillion spent on health care each year in the United States (U.S. Department of Health and Human Services, 2004).

The aging of the population will continue to provide unique challenges and carry important consequences for the health care system, and issues surrounding end-of-life care and patient autonomy in making treatment decisions will only intensify as more people become seriously ill. The failure to offer patients and their families a full range of end-of-life care options, services, and settings will cost dearly in terms of quality of life and utilization of appropriate resources. The National Institute of Nursing Research

(2003) acknowledges this fact, supporting research that optimizes the interactions between the patient, the family, and the health care provider regarding decisions about advance directives and other concerns as part of its efforts to enhance the end-of-life experience for patients and their families-one of five themes the agency has identified to meet the health needs of our society. The PSDA and advance directives provide a legal mechanism to encourage and support end-of-life care discussions. As the ANA emphasized in its 1991 position statement, nurses should play a primary role in implementation of the PSDA as their role in education, research, patient care, and advocacy is critical to its success within all health care settings.

Nurses make up the largest number of health care providers in the United States (Bureau of Labor Statistics, 2003), and are in the unique position of having relationships with patients that are often frequent, sustained, and intimate. Thus, they can play a key role in educating and advocating for patients with respect to end-of-life treatment decisions and advance directives. In order to fulfill this legal, ethical, and moral obligation, however, nurses must possess adequate knowledge about advance directives. When nurses are well informed, they are more actively engaged and comfortable with this role.

By law, patients are required to be educated on advance directives and afforded the opportunity to execute these documents. Moreover, studies have indicated that most patients believe they should have control over end-of-life decisions, that they are comfortable discussing advance directives, want these discussions initiated by their health care providers, and prefer that these discussions take place while they are well and

before they are hospitalized. Further research is needed to obtain a broader picture of nursing perspectives and knowledge levels across the continuum of care from a variety of work settings. Such knowledge will assist with efforts to assess the profession's current strengths and identify where further education and support is needed to ensure nurses are able to successfully educate and advocate for appropriate end-of-life decision-making and advance directive execution.

Research Questions

This research study focused on answering four key questions regarding advance directives perceptions among North Dakota registered nurses:

1. How knowledgeable are registered nurses in the state of North Dakota about the PSDA and advance directives?
2. What is the comfort level of North Dakota registered nurses with discussing advance directives with patients?
3. Do North Dakota registered nurses agree with the concept of patient autonomy in making end-of-life decisions?
4. What barriers (if any) do North Dakota registered nurses feel are keeping them from assisting patients to make informed decisions about advance directives?

Theoretical Framework

The theoretical framework for this study was the Advance Directive Decision-Making Model (ADDM), adapted from Imogene King's conceptual system, transaction process, and theory of goal attainment by Goodwin, Kiehl, and Peterson (2002). This model assists in achieving mutual goal attainment resulting in both increased client

autonomy and PSDA compliance. The model outlines the interacting role of the registered nurse and the client, and sheds light on the essential concepts that affect a nurse's ability to educate and advocate for their clients in the areas of self-determination and end-of-life care.

The ADDM model incorporates seven components from King's original conceptual systems framework (Goodwin, Kiehl, & Peterson, 2002). The personal system contributes the concepts of perception and time. Perception is holistic, with both the registered nurse and the client autonomous with rights of self-determination. Both must first determine to enter into the interaction, with the registered nurse perceiving when education is appropriate and sufficient while the client determines what (if any) decision to make, when to make it, and to whom to make it known. Time is a continuous linear flow from the present to the future. Time is also pertinent as discussions and decision-making for advance directives should not be limited to the elderly but are appropriate at any stage of life-most preferably prior to actual need.

The interpersonal system contributes the concepts of interaction and role to the process. Interaction is a two-way communication with nonverbal cues considered and confidentiality maintained, and it involves not only the exchange of information, but also the processing of that information as well. Both the nurse and the client bring individual perceptions as they interact. The initial goals of the registered nurse are to determine the client's level of advance directive knowledge, to add any essential information, and potentially to advocate for the informed choices the client selects. The client will then make the decision to either take action or inaction. Role is assumed by both the

registered nurse and the client. The nurse assumes the role of facilitator, while the client fills the role of active, mutual partner for goal attainment.

The social system contributes three additional concepts of power, status, and decision-making. Power is recognized as client controlled and directed, utilizing the knowledge, skill, and expertise of the registered nurse to support the client. Status is recognized as ability and authority to make decisions. The registered nurse is stratified as competent, assistive, and knowledgeable. Decision-making is a process in which the client selects one action from alternatives. Decision-making is also active from the registered nurse's vantage as deciding if education is appropriate (time), effective (cognitive), and sufficient (adequate).

Registered nurses must be comfortable with the issues of death and dying which are primary to discussing and advocating for compliance with advance directives (Goodwin, Kiehl, & Peterson, 2002). In addition, there must exist the time, education, resources, and institutional support necessary to appropriately assist nurses in fulfilling their role as educator and facilitator (Jarr et al., 1998; Ryan et al., 2001). The achievement of education and autonomy, which in turn equals decision-making by the client (the intent and goal of the PSDA) is hindered when the registered nurse is confused, floundering, unprepared, or experiencing personal conflicts that may inhibit their ability to teach and advocate. A closer look at the current knowledge and comfort levels of advance directives among registered nurses is needed to determine how willing and prepared they are to serve in the role of educator and advocator. Identification of

barriers to completion of this role is also needed in order to facilitate changes within the workplace to better support registered nurses and enhance compliance with the PSDA.

Definitions

Advance directive is an umbrella term for several legal documents that convey the health care wishes of a patient should he/she become incapacitated and unable to participate in his/her medical care (Maxfield et al., 2003). For this study, advance directives include living wills and durable powers of attorney for health care documents.

Autonomy is an ethical principle that addresses personal freedom and self-determination-the right of an individual to choose what will happen to his or her own person (Guido, 2001). This study focuses on the patient's right to make decisions affecting care and treatment at the end of life, as well as the health care provider's respect for that patient's right, even if they do not agree with the decisions made.

Patient Self-Determination Act of 1990 is part of the Omnibus Budget Reconciliation Act of 1990 that was enacted into law in November 1991. The act requires that all health care institutions that receive Medicare/Medicaid funds have patient information documents, health care provider training, and community and patient education programs that discuss advance directives (Haynor, 1996). It is intended to educate adults regarding their right to make medical treatment decisions and to encourage them to complete written advance directives.

Registered nurse refers to an individual who holds a current license to practice in a particular state as a registered nurse. The results of this study will be based on the responses of registered nurses in the state of North Dakota.

Assumptions

1. Participants will be honest in their responses.
2. Participants can read and write English.
3. Participants will be willing to take the time to fill out and return a mailed questionnaire.

Limitations

The sample size for this study was relatively small due to Air Force policy restrictions regarding outside funding for this researcher. However, it nonetheless provided pertinent information as to the current knowledge levels and attitudes of North Dakota registered nurses regarding advance directives, along with barriers encountered in discussing advance directives. As North Dakota is a rural state in which greater than 90% of the population is white, generalization of study results to larger, more industrialized and/or more ethnically diverse settings may not be appropriate.

CHAPTER II

METHODOLOGY

Introduction

Nursing theorists such as Virginia Henderson and Jean Watson suggest that one of the functions of nursing is to assist individuals to achieve a peaceful death (Tomey & Alligood, 2002; Watson, 1979). In order to fulfill this role, a patient's end-of-life wishes must be communicated to family members and health care providers. Since passage of the Patient Self-Determination Act (OBRA, 1990), advance directives have served as the legal vehicle and communication tool for bringing about an understanding of these wishes, in the event that the patient is unable to competently speak for him/herself. As one of the largest and most accessible members of the health care team, nurses are in an ideal position to serve as advocates and educators for the facilitation of informed decision-making for patients making choices about end-of-life care. The purpose of this descriptive study was to explore the current perceptions and experiences of a random sample of North Dakota registered nurses regarding the discussion and implementation of advanced directives in their practice.

Population

The target population for this study consisted of all registered nurses in the state of North Dakota who held an active license with the North Dakota State Board of Nursing (NDBON) and were employed in nursing within the state of North Dakota. As

of July 2004, 8,520 individuals held active licenses as registered nurses. Participants needed to be able to read and write English and have their current address available through the NDBON.

Sample

A systematic random sample of 600 potential participants was obtained from a listing of all actively licensed nurses registered in North Dakota, and living within the states of North Dakota (ND), South Dakota (SD), Montana (MT), and Minnesota (MN) (8,250 total individuals) that was available on request for a fee from the NDBON. The list was delivered, ordered via zip code, and each eligible individual had an equal chance of being in the sample. From a random starting point of three, as determined from a table of random numbers, every 13th individual on the list was included in the sample. Returned questionnaires reporting that an individual was either not employed, employed outside of nursing, or employed outside of the state of North Dakota were excluded from the study.

Study Design

This was an exploratory descriptive study design in which a quantitative approach was used. Sample registered nurses were contacted by mail and asked to participate in the study by completing and returning an advance directives questionnaire.

Data Collection Methods/Procedures

Data was collected between the months of October 2004 and December 2004. As described previously, a sample of 600 registered nurses licensed through the NDBON and living within the states of ND, SD, MT, and MN were identified for participation,

and were mailed a packet containing a cover letter explaining the purpose of the study and requesting their participation (see Appendix A), a copy of the questionnaire for completion (see Appendix B), and a stamped, self-addressed envelope for the questionnaire's return. As an incentive to return the questionnaires, 50 cents was donated to the American Nurses Foundation for every completed and returned questionnaire.

The researcher used a twenty-two item, self-reported questionnaire consisting of multiple choice, yes/no, and Likert scale questions that required approximately 5-15 minutes to complete. The instrument used was adapted with permission from Jarr et al. (1998). The questionnaire contained ten questions that related to demographic information, followed by twelve questions related to participants' perceptions and experiences with advance directives. In order to provide additional context and to accommodate a greatly expanded variety of possible participants, the demographics information collected was expanded from the original instrument to include items such as gender, employment status and setting, nursing position, practice area, and whether or not the participant and/or members of the participant's family have completed an advance directive. Of the original ten items from the Jarr et al. (1998) instrument, nine were included in the questionnaire for this study. The original open-ended question, number ten, which asked participants how their particular facility could facilitate patients' understanding and execution of advance directives, was deleted because the sample for this study was drawn from a wide variety of anonymous work settings. In the original Jarr et al. (1998) study, the researchers felt use of the wording "essential message" in question number one of their questionnaire regarding the patient self-determination act

led respondents to answer the question incorrectly. To avoid a recurrence of this problem, the corresponding question in the adapted questionnaire for this study, number twelve, was revised. Minor revisions to the remaining questions, such as replacing the words “the hospital” with “your work setting”, were employed (where necessary) to reflect the variety of potential characteristics of this study’s sample.

Three questions not found in the original study instrument were added to the questionnaire by this researcher. The first addition, question number eleven, asked participants to identify their primary sources of information about advance directives. The second addition, question number sixteen, asked participants to rate the degree to which they agreed or disagreed with the statement that all patients have a right to make end-of-life care decisions. This question was inspired by the Stoeckle et al. (1998) study in which, surprisingly, 93% of participants-nearly half of which were nurses working with critically or terminally ill patients-disagreed or strongly disagreed with a similar statement. In that the principle of patient autonomy lies at the heart of the PSDA, and the issue of both the quality and quantity of ethics education afforded to health care professionals continues to be a hot topic, the researcher felt this area deserved further attention. The third addition, question number twenty-two, was added to assist with identifying possible barriers to advance directive discussions encountered by nurses. Multiple choice items were taken from the domains identified by Stiller et al. (2001) in their development of an instrument to measure barriers to implementing advance directives, and a write-in response was also available to capture any additional barriers perceived.

Instrument Reliability and Validity

The original instrument constructed by Jarr et al. (1998) was reviewed for content validity by a panel of experts including a physician and a professor of nursing. Because this researcher made additions and adaptations to that original questionnaire, a second review by two professors of nursing specializing in the areas of geriatrics and research methods, and one professor of psychology was conducted for content validity of the questionnaire used in this study. Additionally, a small-scale pilot study was performed in August 2004, with ten graduate nursing students as subjects, to identify any necessary corrections needed to minimize variations in participants' understanding of the instructions and/or questions, determine if any parts of the questionnaire might be perceived as offensive or objectionable to the participants, and improve the quality of data available for analysis. No adjustments were found to be necessary.

Because this survey was not designed to serve as an index, contained a relatively small amount of questions that varied broadly in content, and elicited answers based predominantly on the personal experiences, perceptions, and opinions of the respondents, reliability testing was not considered applicable to this study.

Proposal Data Analysis

For analysis and quantification of the questionnaire's demographics information, and responses to each question, descriptive statistics were applied. Inferential statistics were employed to further explore significant relationships and mean differences based on research questions one through three. Qualitative techniques were used, as indicated, for grouping of write-in responses into consistent themes. Although not a proposed research

question for this study, analysis of differences in response means between participants working in an inpatient setting versus an outpatient setting were also performed.

Protection of Human Subjects

The institutional Review Board of the University of North Dakota approved this study. Confidentiality was maintained and assured within the cover letter, and return of the completed questionnaire served as consent to participate.

Possible risks to the participants of this study were minimal. The identities of those who chose to return their questionnaires were not maintained or coded in any manner, and all participants were able to easily and anonymously withdraw from the study at any time by not completing or returning the questionnaire. It is possible that the study matter of advance directives might have been uncomfortable for some since it relates to the concepts of death and dying, and the notion that individuals can plan for and/or control aspects of their end-of-life experience. However, as all participants were engaged in a profession that traditionally provides education on and/or involvement with these concepts, and the fact that this profession has, in effect, been charged by the federal government on legal grounds as well as by the American Nurses Association on ethical and moral grounds to engage and educate patients on the subject of advance directives, it was not expected that any potential discomfort would not be overwhelming or stressful. As noted previously, the cover letter informed participants about the nature of the study questions, and so they were able to choose not to participate anonymously at that time without reviewing the contents of the questionnaire. No difficulties in this regard were identified by participants in the pilot study.

Possible benefits to the participants were derived from the information that the study results generated for the profession of nursing in particular and health care organizations in general with regards to its current ability and comfort level with discussing and implementing advance directives. Such information helped to identify areas of concern for further study, education, and correction. On a personal level, participation in this study might have also assisted respondents in the evaluation of their own practice and/or their facility's policies in this regard, and perhaps led to further education, interest, or activism on their part within the areas of end-of-life care and advance directives.

CHAPTER III

RESULTS

The purpose of this study was to explore the current perceptions and experiences of North Dakota registered nurses regarding discussing advance directives with patients and assisting with their implementation. This chapter will describe the demographics of the study sample, descriptive statistics for each study question, and data analyzed in relation to the following research questions:

1. How knowledgeable are registered nursing in the state of North Dakota about the PSDA and advance directives?
2. What is the comfort level of North Dakota registered nurses with discussing advance directives with patients?
3. Do North Dakota registered nurses agree with the concept of patient autonomy in making end-of-life decisions?
4. What barriers (if any) do North Dakota registered nurses feel are keeping them from assisting patients to make informed decisions about advance directives?

Quantitative data were analyzed with descriptive and inferential statistics. Qualitative data were analyzed as appropriate. Although the overall sample size was 268, variations in sample size are reported within the results due to missing data as some respondents either did not answer every question in the survey or answered a question incorrectly (e.g. marking multiple answers where only one was asked for).

Demographics Description

The study participants were predominantly female (n=255, 95.9%), with only 11 male participants (4.1%). Participants ranged in age from 22 to 79 (n=263) with a mean age of 45.0 (SD=11.43). When divided into 12 categories, the largest category contained those aged between 45-49 years (n=50, 19%), and together the three largest age categories of 40-44 years (n=40, 15.2%), 45-49 years, and 50-54 years (n=46, 17.5%) represented 51.7% of returned surveys. All participants were employed in nursing within the state of North Dakota in either a full-time (n=174, 64.9%) or part-time (n=94, 35.1%) capacity.

A little over half of all participants (n=251) indicated that they were employed in a hospital setting (n=134, 53.4%). Nursing home (n=37, 14.7%) and office (n=22, 8.8%) settings ranked second and third out of 13 possible categories. The "other" category (n=27, 10.8%) included a variety of write-in responses such as research, dialysis, hospice, community health center, consulting, ambulatory surgery clinic, and insurance.

Participants (n=257) were most likely to be employed in the position of staff nurse (n=155, 60.3%), with the write-in "other" category (n=51, 19.8%) and manager (n=21, 8.2%) coming in at a more distant second and third out of 8 total categories. Again, there were a wide variety of write-in responses (e.g. clinical/care coordinator, staff development, supervisor, advance practice nurse, triage, case manager, insurance examiner, medicare resource).

Practice areas of participants (n=236) varied widely, and the large number of individuals who either marked multiple settings despite instructions not to do so (n=32) or chose to write in an area under "other" (n=40, 16.9%) rather than using one of the 19

categories provided on the survey made generalizations more difficult. The “other” category represented the most common response, with practice areas such as employee health, pain management, research, nursing home, physicals, risk management, and a number of specific departments such as gastroenterology, respiratory, and cardiology indicated. The second and third most commonly reported practice areas included geriatrics (n=36, 15.3%) and perioperative (n=31, 13.1%) respectively.

The majority of respondents held a bachelor degree in nursing (n=145, 54.1%), followed by those with diplomas (n=61, 22.8%) and associate degrees (n=36, 13.4%). Those with masters (n=25, 9.3%) or doctorate (n=1, 0.4%) level education made up the smallest portion of participants.

The number of years of nursing experience responses (n=266) ranged from less than 1 to 56, with a mean years of experience of 20.6 (SD=12.45). Those who indicated that they had 20-24 years of nursing experience (n=42, 15.8%) made up the largest group, followed by those with 25-29 years of experience (n=40, 15%), and 30-34 years of experience (n=34, 12.8%). Together, those possessing between 20 and 34 years of nursing experience represented almost half (43.6%) of the total participants.

Only 57 (21.4%) of 266 total participants who answered the question reported having completed an advance directive for themselves. In contrast, 130 (48.9%) reported having family members who had done so. All demographic data is listed in Table 1.

Primary Sources of Advance Directive Information

Survey question #11 asked participants to identify their primary sources of information about advance directives by checking however many of 9 listed choices applied.

Among those who answered the question (n=265), employer programs/in-services received the most marks (n=153, 57.1%), followed by continuing education courses (n=83, 31%), and professional journals (n=76, 28.7%). A write-in "other" column was available for answers (n=44, 16.4%), and a wide variety of responses were given, such as family members, educational materials, government departments, particular health institutions or departments within a health institution (e.g. pastoral care, admissions, case managers, ethics committee), churches, state or institution policies/regulations, the internet, and past experience.

Table 1. Demographic Data of Study Participants (N=268).

Variable	Value	n	%
Gender (n=266)	Female	255	95.9
	Male	11	4.1
Age (n=263)	20-24	8	3.0
	25-29	21	8.0
	30-34	27	10.3
	35-39	21	8.0
	40-44	40	15.2
	45-49	50	19.0
	50-54	46	17.5
	55-59	26	9.9
	60-64	16	6.1
	65-79	8	3.0
Employment (n=268) status	Full-time	174	64.9
	Part-time	94	35.1
Employment (n=251) setting	Hospital	134	53.4
	Nursing home	37	14.7
	Other	27	10.8
	Office	22	8.8
	Home health	12	4.8
	Public health	7	2.8

Table #1 cont.

Variable	Value	n	%
Employment setting	Nursing education	4	1.6
	Self-employed	2	0.8
	Government	2	0.8
	Church	1	0.4
	Occupational health	1	0.4
	Social services	1	0.4
	School	1	0.4
Nursing position (n=257)	Staff	155	2.7
	Other	51	19.8
	Manager	21	8.2
	Office	13	5.1
	Administrator	7	2.7
	Educator	4	1.6
	Consultant	3	1.2
Practice area (n=236)	Faculty	3	1.2
	Other	40	16.9
	Geriatrics	36	15.3
	Perioperative	31	13.1
	Medical/surgical	22	9.3
	Critical care	17	7.2
	Home health	11	4.7
	Mental health	10	4.2
	Family practice	8	3.4
	Public health	8	3.4
	Emergency services	8	3.4
	Maternal/child	8	3.4
	Oncology	7	3.0
	Pediatrics	7	3.0
	Rehabilitative services	7	3.0
	Nursing administration	6	2.5
	Quality assurance	3	1.3
	School	2	0.8
	Chemical dependency	2	0.8
	Neonatal	2	0.8
	Parish	1	0.4

Table #1 cont.

Variable	Value	n	%
Nursing (n=268) setting	Associate degree	36	13.4
	Diploma	61	22.8
	Bachelor's degree	145	54.1
	Master's degree	25	9.3
	Doctorate	1	0.4
Years in nursing (n=266)	<1-4	36	13.5
	5-9	29	10.9
	10-14	29	10.9
	15-19	22	8.3
	20-24	42	15.8
	25-29	40	15.0
	30-34	34	12.8
	35-39	13	4.9
	40-44	13	4.9
Advance directive (n=266) completed for self	No	209	78.6
	Yes	57	21.4
Advance directive (n=266) completed for family member	No	136	51.1
	Yes	130	48.9

Knowledge of the Patient Self-Determination Act

Question #12 of the survey asked respondents to identify which of four multiple choice answers demonstrated compliance with the Patient Self-Determination Act (see Table 3). Answer b, "on admission, all patients 18 years or older are asked if they have advance directives and are given advance directives information" was considered the right answer. More than half of the participants who answered the question (n=250) chose the correct answer (n=172, 68.8%).

Table 2. Primary Sources of Information About Advance Directives (n=265).

Value	n	%
Employer programs/in-services	153	57.1
Continuing education courses	83	31.0
Professional journals	76	28.7
Other nurses	68	25.4
Formal nursing courses	47	17.5
Other	44	16.4
Physician	31	11.6
Attorney	37	13.8
Media	27	10.1

Advance Directives Available at the Work Place

The next survey question, #13, instructed respondents to check the types of advance directives available to patients at their work setting from a list of four options. Two hundred and twenty-one (83.4%) out of 265 participants who answered reported that living wills were available at their work place, while 197 (73.5%) indicated health care powers of attorney were available to patients. Although a do not resuscitate order is not an advance directive, but rather a medical order based on an advance directive (Staten, 2000), 190 (70.9%) respondents marked it as such. Nineteen participants (7.1%) indicated that no advance directives were available for patients where they worked.

Nurse Involvement in the Advance Directive Process

Survey question #14 asked participants if they had ever worked in a hospital or other setting in which nurses were involved in the advance directive process. Of the 267 respondents who answered this question, 164 (61.4%) reported they had. Seventy-two (27%) had not worked in a past setting where nurses were involved, and 31 (11.6%) didn't know.

Table 3. Compliance with the Patient Self-Determination Act (n=250).

Answer	n	%
Patient determines treatment	67	26.8
On admission, all patients 18 years or older are asked if they have advance directives and are given information	172	68.8
Having an advance directive means do not resuscitate	2	0.8
Families decide treatment direction if patient is unable	9	3.6

Contacts for Patient Information on Advance Directives

For survey question #15, respondents were asked to rank order (1-7) who they would contact if a patient desired information on advance directives. Social work (n=113, 42.2%), the patient's nurse (n=69, 25.7%), and the patient's doctor (n=31, 11.6%) were the top three options ranked #1 by the 264 respondents who answered the question, and these same three options, in varying order, also constituted the top three options for the #2 and #3 ranking as well. A write-in option of "other" was also available, with seven participants (2.6%) ranking it as their number one contact person. Among the range of answers given under "other" were patient representative, attorney, the manager, the director of nursing, the patient's family, hospice staff, the house supervisor, and internet sites.

Patients' Right to Make End-Of-Life Decisions

Participants were asked in question #16 to declare their degree of agreement or disagreement with the following statement: "All patients have a right to make end-of-life

care decisions". The overwhelming majority of the 267 respondents who answered the question either strongly agreed or agreed with this statement (n=258, 96.7%). Four respondents (1.5%) were unsure, and 5 (1.8%) disagreed or strongly disagreed. Table 5 provides the mean scores and standard deviations for questions 16-21. Ranges for these questions were 1 to 5 with 5=strongly agree, 4= agree, 3=unsure, 2=disagree, and 1=strongly disagree.

Table 4. Rank Order (1-3) of Contacts if a Patient Asked for Advance Directive Information (n=264).

Value	Ranked #1		Ranked #2		Ranked #3	
	n	%	n	%	n	%
Social Work	113	42.2	61	22.8	40	14.9
Patient's nurse	69	25.7	46	17.2	43	16.0
Patient's doctor	31	11.6	50	18.7	54	20.1
Admitting	19	7.2	18	6.8	16	6.1
Chaplain	14	5.2	31	11.6	23	8.6
Patient relations	11	4.1	34	12.7	40	14.9
Other	7	2.6	9	3.4	4	1.5

Advance Directive Information in the Work Place

Survey question #17 stated "At my work setting patients are provided with sufficient information about advance directives to execute these documents". Again, a majority of the 260 respondents who answered this question agreed or strongly agreed with this statement (n=185, 71.2%). Forty (15.4%) were not sure, and 35 (13.5%) disagreed or strongly disagreed.

Responsibility for the Facilitation of Advance Directive Information

Participant reactions to the statement, "It should be a nursing responsibility to facilitate a patient's getting advance directive information" (question #18) were mixed. Two hundred sixty-seven respondents answered this question, with 155 (58.1%) indicating agreement or strong agreement. Fifty-three (19.9%) were unsure if this should be a nursing responsibility, while 59 (22.1%) disagreed or strongly disagreed that nurses should be responsible for helping patients get advance directive information.

Perceived Information Level to Discuss Advance Directives

Survey question #19 read, "I have sufficient information to discuss advance directives with my patients". Only about half of the 266 answering respondents (n=135, 51.4%) agreed or strongly agreed that they had enough information. Ninety-four (22.1%) disagreed or strongly disagreed that they had sufficient information for such a discussion, while 37 (13.9%) were unsure.

Perceived Comfort Level with Discussing Advance Directives

In response to the statement, "I am comfortable talking with my patients about advance directives" presented in question #20, the majority of the 266 participants who answered the question agreed or strongly agreed (n=171, 64.3%), this despite the fact that a lesser number of them (n=155) had reported having sufficient information to do so as noted above. Fifty-one respondents reported that they did not feel comfortable talking with patients (19.2%), and 44 participants were unsure (16.5%).

Perceived Need for an Educational Program

The final Likert-style question (#21), "An educational program would increase my knowledge and comfort in the advance directive area", was supported by the majority of the 267 respondents, with 227 (85%) agreeing or strongly agreeing. Fifteen participants (5.6%) did not think an education program would assist them in this area, while 25 (9.4%) were unsure.

Table 5. Mean Scores and Standard Deviations for Questions 16-21.

Question #	n	Mean	Standard Deviation
16	267	4.70	0.633
17	260	3.80	1.03
18	267	3.46	1.02
19	266	3.23	1.189
20	266	3.66	1.067
21	267	4.07	0.826

Perceived Barriers to Discussing Advance Directives

The last survey question, #22, asked respondents to rank order (1-8) any barriers to discussing advance directives that they had encountered in their work setting for however many applied (see Table 6). They were further instructed that, if they encountered no barriers in their work setting, they were to leave the question blank. Two hundred sixteen (81%) of 268 total survey respondents answered the question. Time constraints (n=84, 38.9%), conflicting opinions between patients and family members (n=35, 16.2%), and lack of patient education (n=28, 13%) were the top three options ranked #1 by participants. Lack of patient education and patient/family conflicts were also top contenders

for being ranked # 2 or #3, with differences in attitudes and values about life and death replacing time constraints in these rankings. Fifteen respondents (6.9%) utilized the "other" category to write in additional options to those already listed as their number one encountered barrier. As with prior questions, these write-ins were wide ranging, and included such responses as not applicable in my setting (e.g. no patient contact, little contact with seriously ill patients, job description), negative patient reaction (e.g. don't believe it's important, no interest, get offended), lack of knowledge/initiative (e.g. forget to ask, staff unsure of policy, too new to nursing/still learning, should be done by social work), patient confusion/need to frequently review options, and differences in rules.

Additional Analysis Related to Research Questions

Pearson correlations were performed to determine if significant relationships between age or years of nursing experience and respondents' level of agreement with patient autonomy in end-of-life decisions (question 16), nursing responsibility in discussing advance directives (question 18), and perceptions of knowledge (question 19), and comfort (question 20) level existed. Both age ($r=-.162$; $p=.01$) and years of nursing experience ($r=-.139$; $p=.05$) were negatively correlated with the degree of agreement with patient autonomy at the end of life. Conversely, age ($r=.164$; $p=.01$) and years of nursing experience ($r=.144$; $p=.05$) were positively correlated with respondents' reported comfort levels in discussing advance directives with patients.

The idea that one's level of knowledge is related to their level of comfort in discussing advance directives, which was suggested by Jarr et al. (1998), was also further explored with this study's sample using Spearman correlation. A strong positive relationship

was found to exist between the two factors ($r_s=.685$; $p=.01$), and Cronbach's alpha for the two questions was .8065.

Table 6. Rank Order (1-3) of Barriers to Discussing Advance Directives (n=216).

Value	Ranked #1		Ranked #2		Ranked #3	
	n	%	n	%	n	%
Time constraints	84	38.9	23	10.6	15	6.9
Conflicting opinions between patients and family members	35	16.2	37	17.1	26	12.0
Lack of patient education	28	13.0	55	25.5	41	19.0
Difference in attitudes and values about life and death	23	10.6	30	13.9	26	12.0
Concept too difficult for patients to grasp	23	10.6	21	9.7	22	10.2
Other	15	6.9	2	0.9	2	0.9
Lack of support from other health care providers	7	3.2	11	5.1	21	9.7
Lack of privacy	1	0.5	11	5.1	10	4.6

One-way ANOVA testing was used to determine if a statistically significant difference existed between one's level of nursing education and their responses to questions 16, 18, 19, and 20. Because the doctorate level category had only one respondent, it was not

included in the analysis. No significant differences were found between the diploma, associate degree, bachelor degree, and master degree categories, suggesting that education level was not a prominent factor in how respondents answered these questions regarding patient autonomy, nursing responsibility, or perceived knowledge or comfort level with discussing advance directives.

The study participants were recoded into “inpatient” and “outpatient” categories based on the employment setting demographic to again determine if a statistically significant difference existed between them with regards to their responses to questions 16, 18, 19, and 20. Hospital and nursing home/extended care responses (n=171, 68%) were considered “inpatient” type settings where a patient is admitted to an institution, whereas the other categories available in the employment setting demographic (e.g. home health, physician’s office, school health services) were considered “outpatient” settings (n=53, 21%). Because of the variety of responses of questionable setting or, in some cases, no specification of a setting made in the “other” category of the employment setting demographic, respondents in the “other” category (n=27, 11%) were not included. Neither one-way ANOVA nor t-test analysis produced any statistically significant differences between the mean scores of the inpatient and outpatient groups to these questions, thus employment setting also didn’t appear to be a factor in how respondents perceived a patient’s right to make end-of-life decisions, their responsibility towards assisting patients with advance directives, or their knowledge and comfort level with discussing advance directives with patients.

CHAPTER IV

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

Discussion

The study sample consisted of a group of North Dakota registered nurses who were predominantly female, had an average age of 45 years, and possessed an average of 20 years of nursing experience. These demographics were similar to those reported for the North Dakota nursing population by the Center for Rural Health in 2004, in which 91% of all nurses (registered and licensed practical nurses combined) were female and the average age of registered nurses was 45 years.

Study results culminated in an illuminating snapshot of participants' views on a number of issues related to the research questions posed. Knowledge, according to the ADDM model (the framework for this study), is necessary in order for the registered nurse to support the client during the interactive process intended to increase client autonomy and PSDA compliance. Although more than half of the participants in this study were able to correctly identify what constituted compliance with the PSDA, this number, 68.8%, was lower than the PSDA question results from the original Jarr et al. study (1998) as well as the replication study by Ryan et al. (2001), in which 98% and 83% respectively were considered to have answered correctly. Although the PSDA question for this study was altered from the Jarr et al. (1998) study in an attempt to avoid the problem of having more than one potentially correct answer that occurred with the

original survey, it could nonetheless be argued that, while answer b of question #12 for this study was technically the only correct answer in a legal sense, answer a embodied the intent of the PSDA, and so could also have been deemed as “compliance” by participants. If either answer a or b were accepted as correct answers for this study, then the number of correct responses would rise to 95.6%. However, one has to keep in mind that, unlike the other two studies, this one included participants who were employed in a wide range of outpatient settings in addition to inpatient settings, where exposure to the PSDA requirements might be more limited.

The number of respondents from this study who felt they had sufficient information to discuss advance directives with patients (51.4%) was similar to the 53% reported in Ryan et al. (2001), and thus no further increases were noted between this study and that one versus the 25% increase seen between the time of the Jarr et al. study (1998) and Ryan et al. The reported sources of information about advance directives varied widely, with employers providing the majority of education in this area while formal nursing education was only listed as a source of information by 17.5% of respondents. This low number would appear to support concerns in the literature regarding a lack of sufficient end-of-life content in nursing courses, and perhaps plays some role in the positive relationship that was found in this study between respondents’ age and their level of comfort with discussing advance directives if employers are providing the bulk of education in this area. Almost all respondents (85%) indicated that they would like more education on advance directives to increase their knowledge and comfort level, suggesting high interest and relevance for this topic in their practice.

The ADDM model discusses the concept of role in the process of discussing advance directives. The nurse assumes the role of facilitator, an action that will likely only occur if the nurse is comfortable with, and agrees to engage in, the interaction. Social work was ranked number one by 42% of the participants in this study as the individual they would call if a patient desired information on advance directives, with the patient's nurse coming in a more distant second at 25.7%. This contrasted with both the Ryan et al. (2001) and Jarr et al. (1998) studies, in which the patient's nurse and admitting were, respectively, ranked number one. Although the ANA considers advising patients on advance directives a nursing role, workplace policy, culture, and staff ratios may not always support the role of nurses as facilitators in this area, a point perhaps reflected by the fact that only 61% of respondents reported having worked in a setting where nurses were involved in the advance directive process. These issues, outside of a respondents' personal viewpoint, may account for the lower ranking of the patient's nurse as a contact person for this question. However, the fact that only 58% of respondents agreed that assisting patients to get advance directive information was a nursing responsibility speaks to a reluctance by many to embrace this role, if not outright disagreement with the ANA policy statement, suggesting at the very least a need for further education and promotion on the need to incorporate this aspect of nursing care into practice. Jarr et al. (1998) and Ryan et al. (2001) also reported similar split opinions on nursing's responsibility in this regard.

Not surprisingly, the number of respondents who felt comfortable talking with patients about advance directives (64.3%) was similar to both the number who felt it was

a nursing responsibility to do so (58%) and the number who felt they had enough information to do so (51%), and reflects the positive relationship that was found between perceived knowledge level and comfort level. It also, once again, highlights the importance of education to the process of advance directive facilitation by nurses.

Patient autonomy in end-of-life decision-making was one subject on which almost all respondents (96.7%) agreed, in sharp contrast to the 93% of critical care hospital personnel who reported disagreeing with the same statement that all patients have a right to make end-of-life decisions in the Stoeckle et al.(1998) study. Education and advocacy for clients in the areas of self-determination and end-of-life care are the goals of the ADDM model, and an individual's ability to assist in this endeavor is questionable if one does not agree with the overall concept of patient autonomy. However, autonomy is not always a clear-cut issue, and hesitancy on the part of some nurses to agree with such a blanket statement is understandable to a degree. A number of surveys that were returned contained unsolicited comments next to certain questions, and although they were not analyzed due to potential bias, a sense of controversy seemed to exist for some with respect to certain patient populations or conditions in regards to this issue. Although it is beyond the scope of this paper to address the ethical issues surrounding end-of-life decision-making in particular situations such as the operating room, pediatric, or psychiatric settings, the following statement from an article on a related topic is presented for consideration:

As advocates for the human condition, health care providers can and must assist the patient to find meaning and/or purpose in living or dying. This meaning must

be whatever the patient wants it to be. We must then respect those meanings and the decisions made in concert with them (Smith, 2000, p. 525).

Barriers to discussing advance directives were reported by a large majority of study respondents (81%), with time constraints identified by far as the number one barrier. Although 19% of respondents did not answer the question, it is not completely clear if this was because they were not encountering any barriers (as the instructions indicated) or because they simply did not discuss advance directives in their practice, an oversight that would need correcting in any future research. Acknowledging the fact that the interactive process of determining a client's level of advance directive knowledge, adding any essential information needed, and potentially advocating for the informed choices the client selects (as described by the ADDM model) is a complex one, time is a major factor in the success of any such endeavor. Although nurses have the potential to be proactive leaders in this area due to their large numbers and unique relationships with patients, that potential can not be realized without sufficient time to go beyond merely asking patients if they have advance directives at admission to educating and advocating for them on their rights and options with respect to end-of-life care decisions regardless of setting, age, or medical condition. Institutional support of nursings' role in the advance directive process is likely a prominent factor as to whether or not such encounters can take place. Without such policy, staffing, and community education funding support, the odds that nurses will be able to take an active role in the advance directive process on a large scale, as the ANA endorses in its position statement, may be slim no matter what their knowledge or comfort level with such discussions are.

Conclusions

The study sample consisted of a randomly chosen group of North Dakota registered nurses who were currently employed in a variety of practice settings and areas on either a full or part-time basis within the state, were predominantly female, and averaged 45 years of age with an average of 20 years of nursing experience. Survey questions elicited participant perceptions and experiences related to advance directives, with a focus on knowledge and comfort levels with discussing advance directives, agreement with the concept of patient autonomy, and barriers to advance directive discussions encountered in practice.

According to the Advance Directive Decision-Making Model, the achievement of mutual goal attainment resulting in both increased client autonomy and Patient Self-Determination Act (PSDA) compliance is assisted through an interacting role of the registered nurse and the client, for which concepts such as perception, time, role (comfort), and power (knowledge) affect a nurse's ability to educate and advocate for clients in the areas of self-determination and end-of-life care. More than half of all participants demonstrated actual as well as perceived knowledge on questions relating to the PSDA and possession of sufficient information to discuss advance directives with patients. However, a large portion indicated that they would benefit from further education on the subject. Likewise, a little more than half of the participants indicated that they were comfortable with discussing advance directives with patients and agreed that it was indeed a nursing responsibility to do so. However, social work was predominantly ranked number one over the patient's nurse as the person they would

contact if a patient asked for advance directive information. Almost all participants agreed with the concept of patient autonomy in making end-of-life care decisions, yet completion rates of advance directives for themselves were consistent with the low rates reported among the American public. Finally, the majority of participants reported encountering multiple barriers in their practice to discussing advance directives, with time constraints ranked number one by a large margin.

Recommendations

Nurses make up the largest number of health care providers in the United States and have relationships with patients that are often frequent, sustained, and intimate. This position provides an ideal opportunity for the profession to play a key role in education and advocacy for patients with respect to end-of-life decision-making and advance directives. However, in order for nurses to successfully engage in this role, they must be knowledgeable and comfortable with the advance directive process, be allowed the time and support to perform these actions, and ideally agree with the concept of patient autonomy that lies at the heart of advance directives.

On a professional level, the results of this exploratory inquiry suggest a number of potential areas for focus and improvement if the goals of the ADDM and position statements such as the ANA's are to be realized. First and foremost, nurses want and need additional information on advance directives and end-of-life care. This need for further education crosses all levels and types of practice, and should begin with a larger amount of end-of-life content in nursing schools. With the large number of respondents who indicated that they needed additional information in order to discuss advance

directives with patients, education programs or workshops for nurses designed to fulfill this need and provide a safe forum for role-playing and addressing ethical or cultural concerns with advance directives and issues related to death and dying should be considered.

Further education and promotion may also be needed to help those nurses who do not feel discussing advance directives should be a part of their practice to understand the value and importance of this role. Like questions about sexuality, inquiries into a patient's end-of-life wishes and plans can be an uncomfortable subject for some. The best way to overcome this reaction is to make such assessments a routine part of nursing care. Institutional support for the nursing role in advance directive discussions, as well as support for much needed community education programs on the purpose and process of advance directives, is most likely lagging at the current time. This situation will probably not be corrected until nurses acknowledge the gravity of this deficiency and take a proactive role in correcting it. This is especially true for those nurses who are working outside of areas traditionally considered the "appropriate" settings for advance directive discussions, as they are the ones with the best opportunity to have advance directive discussions with the well and healthy who should ideally and, according to past studies, want to be making these decisions before illness or accident strikes.

Although the literature suggests that nurses feel advance directives are important for patients to obtain, the low rate of nurses from this study who had completed advance directives for themselves reflected findings from past studies of completion rates for both health care providers and the general public. It seems that if our profession does indeed

believe in patient autonomy and finds value in these discussions and documents, then we should take the time to lead by example and take care of ourselves the way we do our patients and family members. The process of completing these documents for oneself would also provide further insight and information on the process and state laws that could assist with later professional discussions with patients.

Lastly, for those who possess the knowledge and experience to comfortably take part in advance directive discussions, it's important to reach out to those who do not, especially younger novice nurses, and act as mentors for this process. Other health care providers and administrators would also likely benefit from the expertise of these individuals, who could lead the way in highlighting this issue and ensuring it is adequately addressed by both staff and institution policy makers.

This study suggests a myriad of further research opportunities and questions related to advance directives and the nursing role. A larger and more focused study on nursing attitudes and knowledge is needed for this population, as this study only briefly touched on a wide range of issues with one or two questions rather than incorporating more detailed indexes of common entities.

A number of questions arose from the study results, such as (a) what specific factors affect a nurse's comfort and knowledge levels with discussing advance directives? (b) what are the specific issues that led some nurses to disagree with the idea of patients having a right to make end-of-life decisions? (c) are there any unique aspects or experiences within certain practice areas or settings (e.g. intensive care, pediatrics, operating room, mental health) that affect the attitudes of those nurses towards end-of-life

care, advance directives, and/or their role, differently? (d) are nurses aware of position statements such as the ANA's regarding their role in patient self-determination, do they agree or disagree with it, and why? (e) why aren't health care providers in general, and nurses in particular, completing advance directives for themselves? (f) what are the perceptions and experiences of nurses with regards to the effectiveness or ineffectiveness of advance directives? (g) are there professional issues or attitudes unique to outpatient settings that would make conducting advance directive discussions easier or more difficult to accomplish? Answers to these types of questions are essential to the development of successful promotion and education programs for nurses and to clarify the ability of nurses to realistically fulfill their obligations to the advance directive process. It is this researcher's opinion that these questions would lend themselves best to the rich, holistic understanding of subjective dimensions beyond numbers that a qualitative approach would provide.

Other research areas suggested by this study include inquiries into the amounts and types of end-of-life content currently being taught in the state's nursing programs, whether or not support for the nursing role in advance directive discussions is present within the state's health care institutions, and identification of strategies to overcome barriers to advance directive discussions that are being encountered in the workplace.

As our country's population continues to age and advances in technology and medical science increase life expectancy and reduce mortality and morbidity associated with many diseases and conditions, issues surrounding end-of-life care and patient autonomy will become more and more critical for the health care system to address

effectively. Nurses, with our rich tradition of patient education and advocacy and our image among the American public as one of the most trustworthy of professions, can and should seize the opportunity to take the lead in ensuring that patients' end-of-life decisions are discussed, and subsequently met. As a nursing PhD recently stated in an article discussing helping patient's achieve a good death: "Nurses have already reformed the way babies come into the world. Now it's time for us to help reform the way people depart this world" (Dobbins, 2005, p. 45).

APPENDICES

APPENDIX A
COVER LETTER

October 20th, 2004

Dear Sir/Ma'am:

I am a graduate student in the Department of Nursing at The University of North Dakota. I am conducting a study on nurses and their experiences with advance directives. Your name was randomly selected through the North Dakota Board of Nursing to be included in this survey. Even if you do not readily discuss advance directives in your nursing practice, this subject matter is important to all aspects of health care. Your participation is very important because the information you provide may aid in developing future education for nurses on this topic.

The questionnaire takes approximately 5-15 minutes to complete. The questionnaire will not ask you to identify yourself, and your individual responses will be held confidential. The results of the research study may be published, but your individual responses will not be identified, as the data will only be reported in aggregate form. Only the researcher, the advisor, and people who audit IRB procedures will have access to the data. The completed surveys will be kept in a locked file cabinet at the researcher's residence for three years, and then shredded. Your participation in this study is voluntary. If you choose not to participate or stop completing the questionnaire at anytime, there will be no penalty. Your completion and return of the questionnaire indicates you have been informed and will be considered your consent to participate in the study.

For every questionnaire returned, fifty cents will be donated to the American Nurses Foundation, the research, education, and charitable affiliate of the American Nurses Association. There is a potential for a total of \$300.00 to be donated to the American Nurses Foundation if all questionnaires are returned.

Please return the completed questionnaire as soon as possible. A prepaid envelope is enclosed for your convenience. If you have any questions concerning this questionnaire, you can contact me at (701) 594-3414 or my thesis chair, Dr. Marcia Gragert, at (701) 777-4549. If you have any concerns about your rights in this study you may contact The Office of Research and Program Development on The University of North Dakota campus at (701) 777-4278. Thank you in advance for taking the time to complete the questionnaire.

Sincerely,

Nichole A. Fritel, RN, BSN, OCN
Graduate Student, Nursing Therapeutics
University of North Dakota

ADVANCE DIRECTIVES QUESTIONNAIRE

6. Practice area:
- | | |
|--|--|
| ☐ School | ☐ Chemical dependency |
| ☐ Critical care | ☐ Emergency services |
| ☐ Family practice | ☐ Geriatrics |
| ☐ Home health | ☐ Maternal/child |
| ☐ Med/Surg | ☐ Mental health |
| ☐ Neonatology | ☐ Nursing administration |
| ☐ Oncology | ☐ Perioperative |
| ☐ Pediatrics | ☐ Quality Assurance |
| ☐ Public health | ☐ Rehabilitative services |
| ☐ Parish | ☐ Other (please specify) |

7. Nursing education: ☐ Diploma
☐ Associate degree
☐ Bachelor's degree
☐ Master's degree
☐ Doctorate
8. Number of years in nursing: _____
9. Have you completed an advance directive for yourself? Yes ☐ No ☐
10. Have any of your family members completed an advance directive? Yes ☐ No ☐
11. What are your primary sources of information about advance directives (check all that apply):

- | | |
|--|--|
| ☐ Professional journals | ☐ Other nurses |
| ☐ Formal nursing courses (i.e. college) | ☐ Personal attorney |
| ☐ Media | ☐ Physician |
| ☐ Continuing education courses | ☐ Employer programs/in-services |
| ☐ Other (please specify) _____ | |

12. Which of the following demonstrates compliance with the Patient-Self Determination Act? (Circle one)

- a. Patient determines treatment
- b. On admission, all patients 18yrs or older are asked if they have advance directives and are given advance directives information
- c. Having an advance directive means do not resuscitate
- d. Families decide treatment direction if patient is unable

13. From the following list, check the type(s) of advance directives available to patients at your work setting (if not currently employed in nursing, please answer questions based on your last nursing experience):

- ☐ a. Living will
- ☐ b. Health care power of attorney
- ☐ c. Do not resuscitate
- ☐ d. None of the above

14. Have you ever worked in a hospital or other setting in which nurses were involved in the advance directives process?

- ☐ Yes
- ☐ No
- ☐ Don't know

15. Please place in rank order who you would contact if a patient desires information on advance directives, using a 1 to indicate the person you would contact first, 2 for second, etc.:

<u> </u> Admitting	<u> </u> Patient's doctor
<u> </u> Social work	<u> </u> Patient's nurse
<u> </u> Chaplaincy	<u> </u> Other (please specify) _____
<u> </u> Patient relations	

Directions: For questions 16 to 21, please circle your choice.

16. All patients have a right to make end-of-life care decisions.

Strongly agree Agree Unsure Disagree Strongly disagree

17. At my work setting patients are provided with sufficient information about advance directives to execute these documents.

Strongly agree Agree Unsure Disagree Strongly disagree

18. It should be a nursing responsibility to facilitate a patient's getting advance directive information.

Strongly agree Agree Unsure Disagree Strongly disagree

19. I have sufficient information to discuss advance directives with my patients.

Strongly agree Agree Unsure Disagree Strongly disagree

20. I am comfortable talking with my patients about advance directives.

Strongly agree Agree Unsure Disagree Strongly disagree

21. An educational program would increase my knowledge and comfort in the advance directive area.

Strongly agree Agree Unsure Disagree Strongly disagree

22. Please place in rank order any barriers to discussing advance directives that you encounter in your work setting, using 1 for the most frequently encountered, 2 for the second most frequent, etc. for however many apply. If you have encountered no barriers in your work setting, leave this question blank.

- ☐ Differences in attitudes and values about life and death
- ☐ Time constraints
- ☐ Lack of patient education
- ☐ Conflicting opinions between patients and family members
- ☐ Lack of support from other health care providers
- ☐ Lack of privacy
- ☐ Concept too difficult for patients to grasp
- ☐ Other (please specify) _____

This is the end of the questionnaire. Thank you for your participation in this study.

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This was an exploratory descriptive study of nurses registered in and currently working within the state of North Dakota. The purpose of this study was to explore the current perceptions and experiences of North Dakota registered nurses with discussing advance directives with patients and assisting with their implementation.

A self-reported questionnaire was mailed to a random sample of 600 registered nurses in the state of North Dakota who met the study criteria. The

questionnaire elicited participant perceptions and experiences related to advance directives, with a focus on knowledge and comfort levels with discussing advance directives, agreement with the concept of patient autonomy, and barriers to advance directive discussions encountered in practice. Data were analyzed using descriptive and inferential statistics.

More than half of all participants demonstrated actual as well as perceived knowledge on questions relating to the PSDA and possession of sufficient information to discuss advance directives with patients. However, the majority indicated that they would benefit from further education on the topic. Likewise, a little more than half of the participants indicated that they were comfortable with discussing advance directives with patients, and agreed that it was indeed a nursing responsibility to do so. However, social work was predominantly ranked number one over the patient's nurse as the person they would contact if a patient asked for advance directive information. Almost all participants agreed with the concept of patient autonomy in making end-of-life care decisions, yet completion rates of advance directives for themselves reflected the low national averages. Finally, the majority of participants reported encountering multiple barriers to discussing advance directives in their practice, with time constraints ranked number one by a large margin.

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