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Katherine M. Krage

Practitioner Perspectives on End-of-Life Planning

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PRACTITIONER PERSPECTIVES ON END-OF-LIFE PLANNING

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Submitted in partial fulfillment of
the requirement for the degree of
Master of Social Work

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DEDICATION PAGE

This work is dedicated to my children, Bridget, Patrick and Anne, who supported completion of my Masters degree, even to the point of Bridget coaching mom through the oral presentation on the day of her own graduation ceremony. Also, to my conscious living cohort, wonderful friends who support lifelong learning through wonder. They have always known I would finish, though were wise enough not to place bets on when.

Katherine

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ABSTRACT

PRACTITIONER PERSPECTIVES ON END-OF-LIFE PLANNING

SECONDARY ANALYSIS OF ADVANCED CARE PLANNING AMONG PRACTITIONERS IN A MIDWESTERN COMMUNITY

KATHERINE M. KRAGE

JANUARY 2002

It is becoming more common for practitioners to discuss advance directives, thereby affirming each person's right to participate in directing end-of-life care. However, little attention has been paid to models of end-of-life planning. This study, a secondary analysis of research completed in 18 La Crosse area health care organizations, explores the extent to which practitioners engage patients and surrogates in exploring values and goals while educating patients about advance directives. It also explores the communication process, including retrievability of directives. Despite uniform training throughout the community, the extent to which practitioners discuss treatment options with patients, families, and surrogates varies by setting. This study adds to the scant research in the quality of advance care planning among non-physician practitioners and suggests improvements in social work services in health care organizations. This study also discusses the implications for social work policy and practice.

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CHAPTER 1: INTRODUCTION

"One of the most tragic events of our time is that we know more than ever before the pains and sufferings of the world, and yet are less and less able to respond to them."

Henry J. M. Nouwen

This chapter address several items. After the problem is defined for this study, the chapter describes the purpose of the research and significance of the study. A definition of advance care planning is provided. The research question is stated and a summary of all the chapters is included.

"Advance planning," also referred to in the literature as "advance care planning," is the process of reflection, discussion, and communication of treatment preferences for end-of-life care that precedes and may lead to an advance directive (Miles, Koepp & Weber, 1996). An advance directive is a verbal or written statement which guides healthcare decisions (Hammes & Briggs, 2000). More will be explained about various types of advance directives in the Chapter 2: Literature Review.

Background of the Problem

There has been inconsistent progress in defining and measuring "advance care planning" over the past decade. White, Singer, and Siegler (1993) and Tulsky and Fischer (1998) found continuing problems with patient self-determination in advance planning: those of assisting patients in articulating their desired medical goals. Since organizations must offer this type of planning to satisfy a law on patient's rights, experts speculate that bureaucratic policy focused at honoring the law frequently supercedes a deeper effort of bringing a patient, an appointed surrogate, and caregivers to a clear understanding of the patient's wishes as he/she nears death. According to Colvin, Mhyre, Welch and Hammes (1993), and Miles et al. (1996), it is essential that these discussions include the patient, staff whom the patient deeply trusts, and support persons. Colvin et al. have shown the confidence this mix of planners creates, so that the eventual decision-making is shaped by the patient's expressed preferences. Use or withdrawal of certain technology, medicines, and environmental efforts on the patient's behalf can then follow from the confident discussion between patient, caregivers, and surrogate decision-makers, including family or significant others. According to Silverman (1987), going immediately to medical goal setting, without the support of conversation, leads to a void in knowledge regarding the patient's values and beliefs. Roter, Larson, Fischer, Arnold, and Tulsky (2000) found that typical conversations between physician and patient remarkably lacked narrative. When physicians pursued the subject of advance planning, they asked patients questions about care, such as whether they wanted to be resuscitated if their heart stopped rather than gathering context inclusive of patient's values and beliefs. This was in contrast to physicians who were experts in end-of-life planning, who talked less, engaged patients in discussing their psychological and social conditions, and held more "uplifting" conversations in their efforts to understand patient preferences (Roter et al., 2000).

Empathy in medicine demands that the medical practice avoid dichotomies; clinicians need science and emotion, reason and intuition, and technology and narratives (Spiro, McCrea Curnen, Peschel & St. James, 1993). This thesis reports the results of an exploratory study into the current practices in the La Crosse area among social workers who are trying to help patients develop advanced care plans. It examines discussion, content, and the relationship circle involved when practitioners in La Crosse, WI conduct advance planning interventions.

To understand the need for advance care planning, it is important to review the current backdrop of medical technology, social climate, and medical legal action, leading up to the 1990s and the passage of the Patient Self-Determination Act (PSDA). According to Jonsen, Siegler and Winslade (1998), medical intensive care units were first established in the 1960s, providing technology that required conscious choices be made regarding the application or withholding of aggressive treatment. These decisions were traditionally made by and influenced by physicians (Lo, 1995). However, the use of the new technology stimulated debate, and a presidential commission was established in 1982 to study this area of medicine: the patient's right to choose through informed consent. How and when technology would be applied or withheld were the basis of debate. The commission recommended due consideration of beliefs and values followed by putting in writing choices for medical care in case of incapacity. Lo, Quill and Tulsky (1999) recommend a format for physician/patient discussions on end-of-life issues and documentation of the outcomes. This followed Dr. Linda Emmanuel's format recommendations prior to the 1991 PSDA mandate for advance directive initiatives.

In 1990, Congress passed the Omnibus Reconciliation Legislation. It outlined access and rights to limit treatment related to end-of-life care in the Patient Self-Determination Act (PSDA). This legislation acknowledged the importance of the patient's perspective in developing the context within which treatment decisions will be made during end-of-life care. The PSDA requires health care organizations to (1) inform those admitted for care of their right to express treatment choices; (2) maintain on file a copy of expressed wishes; and (3) educate the public regarding this advance planning procedure. When an individual has an advance directive, it must be incorporated into the medical record. Some written types of directives include (1) a "Living will," which is an advance directive telling caregivers what life-sustaining treatment is to be provided or forgone if the patient is unable to communicate; and (2) "durable power of attorney for health care," which appoints an agent who will speak on behalf of a patient if he/she loses decision-making capacity.

According to Sansone and Phillips (1995) and Ford and Moldenhauer (1998), special problems arise for patients of diverse cultures, the elderly, and patients with limited education. They recommended narrative models for assessment and assistance for these populations, some of whom feel "caught between two worlds" (Ford & Moldenhauer). The importance of partners in end-of-life decision-making, particularly those who have no legal relationship to the ill person, strengthens the need for appointing the chosen surrogate in a legal document. Thus a narrative assessment is key to capturing sensitive issues and incorporating the patient's wishes both for appointing a surrogate and for understanding what quality of life means for the individual patient.

The recommended practice for informing and honoring patients' expressed wishes includes five promises. Healthcare representatives will: (1) initiate conversation about end-of-life care preferences; (2) provide assistance with advance care planning; (3) make sure plans are clear; (4) maintain and retrieve plans; and (5) appropriately follow plans (Hammes & Briggs, 2000).

Problem Statement

Health care organizations responded to the PSDA's mandate to educate patients and honor their choices by providing access to advance directive information upon admission to hospitals, hospices, nursing homes, and home care programs. Yet admission is recognized as a poor time since patients may be in crisis. Thus scholars strongly recommend advance end-of-life treatment planning discussions with motivated patients, such as those who are suffering from chronic or life-threatening illnesses, while in an outpatient setting (Miles, Koepp & Weber, 1996). Research also indicates that a single discipline, e.g., social workers, assigned the bulk of the advance directive practice, may develop too little interaction between patient, surrogate, and direct care providers (Mezy, Mitty, Ramsey & Rappaport, 1997), resulting in poor understanding by caregivers and surrogates of the origin of patient's advance directives. Luptak and Boult (1994) and Colvin et al. (1993) recommend an integrated effort involving a variety of disciplines who see patients for ongoing care. An example would be oncology or renal dialysis staff, who develop relationships with patients and their families over time.

Discussions about advance directives, which are expressed patient choices of treatment for end-of-life care, often fail to meet their stated goals (Roter, Larson, Fischer, Arnold & Tulsky, 2000). Therefore, specific models wherein health care professionals assist with decision-making, thereby decreasing misperceptions of patients' intent are presented in Chapter 2 and developed further in Chapter 3.

In summary, two problems are noted. First, no legal standard exists for discussing advance directives during non-crisis care, only for the introduction of the topic on admission to health care; second, observational studies suggest that discussions about directives often fail to meet goals (Miles, Koepp & Weber, 1996). These failed goals include the clear and expressed preferences and values of the patient, proper documentation of these wishes in the patient's record, and communication to family, and surrogates, as well as direct caregivers.

Purpose of Research

This secondary analysis will explore the "failed goals" (Miles et al., 1996). Health care organizations and their multiple professionals involved in advance care planning have a complex mission. They must deliver high-quality care and are heavily regulated by government agencies due to receiving funds from Medicare and Medicaid. At the same time, they must assure that patients receive only the care they agree to, document that discussion, and ensure that informed consent precedes care and treatment. In the absence of a patient's directive, all available care befitting "reasonable medical practice" must be applied. Doctors are generally hesitant to discontinue life support without the clear mandate of patient's wishes (Jonsen et al., 1998). The patient's surrogate, as well as primary physician, must be assured that choices in care come out of the patient's beliefs and values. It is possible to tailor treatments such as antibiotics, intubation/ventilation, nutrition and hydration, and cardio-pulmonary resuscitation efforts, even hospitalization and quality-of-life factors to the patient's expressed wishes (Hammes & Rooney, 1998). This study explored the extent to which practitioners may be facilitating planning that supports this tailoring. This study is a secondary analysis of results of an earlier study (Krage, 1996, unpublished) and focuses on the following three points.

(1) Were surrogates involved in developing the patient's plan? In particular, were they included in discussions of patient beliefs and values, which form the context for advance directives?

(2) Which treatment options do practitioners report when they discuss advance directives?

(3) Were patients' directives sufficiently documented to assure they could be followed?

Significance of the study

A study by Hammes and Rooney (1998) indicates that 85% of those who died in the care of La Crosse area health care organizations in 1995 had an advance directive in place. Generally, they found physicians were honoring these directives. A related study (Krage, 1996) was conducted concurrently with Hammes and Rooney's. It found that advance care planning varied among practitioners at 18 La Crosse area health care organizations where Hammes and Rooney had done their research, and these findings form the basis of this exploratory study. It is hoped that on analysis of this research will reveal implications for social work practice, since social workers are often called upon to facilitate advance care planning. "If practitioners align themselves with the interests of consumers, including consumer input and control, the result will be greater self-determination among clients and less ethical discord regarding paternalism within the helping professions" (Tower, 1994). This study will show the depth of end-of-life planning discussions (consumer input and control) and frequency of social work involvement (practitioners aligning with consumer interests). This study uses data gathered in 1996, and applies it to a current literature review using a theoretical framework.

Research Question

The research question of this study asks, "What is the relationship between La Crosse area advance care planning practices and recommended practices to assure patient self-determination?" This question will be addressed by focusing on advance care planning in five types of health care organizations, including outpatient and inpatient programs. The study focuses on key elements of a quality process, largely provided by social workers, and examines how practitioners influence validity and usability of advance directives.

Definition of Advance Care Planning

Advance care planning (ACP) is the process of reflection, discussion, and communication of treatment preferences for end-of-life care that precedes and may lead to an advance directive (Colvin, Myhre, Welch & Hammes, 1993 and Miles, Koepp &

Weber, 1996). According to Gibson (1990), advance directives, at their best, are a way of "articulating one's values and beliefs based on a present situation so that decisions in the future will reflect these values. The challenge lies in assisting patients and families to participate in this value identification" (Colvin et al., 1993, p. 566). Supporting and maintaining self-determination are appropriate goals of ACP, reflecting a shift from paternalistic practices to patient choice, which Beauchamp (1994) states has occurred since the 1960s. One consequence of this type of planning is the influence the patient has over decisions previously in the realm of a physician's control. With the support of medical social workers and pastoral care personnel, attorneys, and others who join physicians and nurses in ACP, diverse and complex issues may be investigated. Conversations with patients or their surrogate decision-makers regarding whether or when to discontinue treatment may include ethical, spiritual, medical, and legal perspectives, or they may not.

Summary

Chapter 1 introduced to this study, defining the problem and purpose of such research. A historical overview of the development of patient's rights in response to increasing medical technology was presented, as well as the significance of this study in the field of health care. Chapter 2 reviews past and current literature on advance care planning, focusing on important aspects of planning, theoretical frameworks, inconsistencies in research and gaps in the literature. Chapter 3 specifically describes theory and model related to autonomy, in relation to the research findings. Chapter 4 addresses methodology, including the research design, population, sample data collection and analysis, and the protection of subjects. Chapter 5 presents the findings of the study, while Chapter 6 discusses the implications of this research.

CHAPTER 2: LITERATURE REVIEW

"Informed advance planning and support of patient and family decisions remains the fundamental objective of all of our educational efforts."

Ren Davis (1992)

Introduction

Previous studies tell us what we know about coaching patients in advance planning and how well we know it. This chapter summarizes these important factors: consideration, recording, and communication of choices related to end-of-life care described by Miles et al., (1996). Success in these factors correlate with successful patient self-determination and autonomy (Hammes & Rooney, 1998).

Studies were found by focusing on those published between 1991 and 2001. This period was influenced by the 1983 President's Commission report on forgoing life-sustaining treatment, the 1990 Supreme Court Cruzan decision, and the widespread legal recognition of advance directives (Miles et al., 1996).

Empirical studies

Miles et al., (1996) found the research between 1985 and 1995 failed to develop a single research question regarding the worth of advance planning. When they viewed the entire body of research, they found a broad, impressionistic overview of the value of advance directives. Limitations to this body of work include the small, uncontrolled, descriptive, single-institution, and retrospective samples that lead to misleading, unrepresentative, or nongeneralizable results. Observational studies, non-experimental, descriptive studies of practitioner/patient discussion, and surveys and clinical trials (Rubin, Strull, Flalkow, Weiss, and Lo, 1994) account for the methods commonly used in advance care planning research. Empirical studies since 1996 are limited to communities with committed teams of scholars interested in Teno, Nelson and Lynns' (1994) finding that improving end-of-life care requires more than completing a form; instead, it requires sustained, in-depth conversations about end-of-life preferences, and is seen as a process, not an event. Few studies look at this from a community perspective. The La Crosse, WI team of Hammes and Rooney (1998), following Colvin et al., (1993), and including Krage (1996) did explore the process versus the event.

Exploratory, Descriptive and quasi-experimental studies

Several categories make up the studies. Many studies were done to determine the percentage of persons who completed advance directives, what motivated them, and whether the directives were followed. These are evidenced-based studies. The work of Hammes and Rooney (1998) was qualitative and quantitative in data analysis, as they recorded whether patients had directives and whether the directives were honored; it also included after-death studies of how families perceived the role of the advance planning process. Their research shows that discussions between patient and clinicians are generally descriptive and exploratory. Studies of models of applied efforts such as scripts and formats for advance care planning (Lo, Emmanuel) and models of discussions by interdisciplinary members of the health care team (Luptak and Boult; Colvin et al.,) are quasi-experimental. The clearest example is the incremental, episodic, interdisciplinary research of Luptak and Boult, applying certain efforts, repeated over time, and supported by social work, physicians, and trained volunteers.

Key Aspects of Advance Care Planning

Many studies have attempted to identify quality indicators of advance planning for end-of-life care. Researchers have struggled to answer these questions: What constitutes helpful planning for end-of-life care? What about planning with patients who have chronic, debilitating disease; are theirs the only scenarios that can be predicted and thought through? What do patients want to know about their prognosis and how early in their disease process do they begin to seek outcome information? How satisfied are they with the conversations they have with their medical providers? Which conversations prove to be helpful to surrogates and direct caregivers (a good basis for decision-making) in cases where patients are no longer able to speak for themselves? Are the plans made during these conversations recorded and passed along to a continuum of health care organizations who may serve the patient over time? Researchers have studied many variables in determining the effectiveness of advance directives. The following discussion addresses those that appear frequently throughout the literature.

Research of advance care planning models that span the disciplines of physician, social work, and others are limited to single-institution studies (Luptak & Boult, 1994, Mezy et al.,1997). Problems that Mezy found were "no uniform procedures for placing directives in the medical record of residents or for their timely review; bureaucratic procedures excluding 'primary caregivers-nurses and physicians' from playing a prominent role in the process" (Ackerman, 1997, p. 114). In the Mezy study, social workers facilitated advance planning with patients, without direct caregiver or patient-family interaction. Such practice isolates patient decision-making, leaving proxies without a clear picture of patients' choices for care. Mezy suggests this facilitation reduces the resulting directive's effectiveness.

In addition to inadequate involvement of the patients' relationship circle, there are failures in the availability of documents completed by patients. Several studies have demonstrated that advance directives that are completed in the ambulatory setting are rarely available and recognized when patients are admitted to the acute-care hospital

(Meier et al., 1996). Others find this is not a problem (Hammes & Rooney, 1998).

The timing of discussions (whether prior to crisis), and the willingness of physicians and other medical professionals to enter into planning early in a chronic debilitative disease, particularly as listeners, as opposed to questioners, are frequently mentioned needs of patients (Emanuel et al., 1995 and Lynn, 1997). Typically physicians tend to delay discussion later than the patients wish, focus on goals rather than the patients' values, and talk more than the patient (Roter et al., 2000). Because they rarely explore patients' values in detail, physicians are less comprehensive in getting to the root of patients' choices (Tulsky & Fischer, 1998). Patients tend to want earlier discussion, respond well to trusted caregivers in general rather than just physicians, and are interested in outcomes (Emanuel, L. et al.,1991; Colvin et al., 1993; Pugh & West 1994-95; Fried, Rosenberg & Lipsitz, 1995; Pfiefer et al., 1994).

Fear enters into advance planning, as patient perceptions impact whether practitioners will be allowed to open the subject of death and dying. Some cultures, specifically American Indians (B. J. Hammes, personal communication, April 18, 2001) believe that discussing a phenomena (such as death) may bring it about. Therefore, the issue of culture-specific planning is important. A social worker stated it took eight months from the first referral until she was able to actually convene a Hmong patient, family, interpreter, physician, and other hospital staff for a discussion of preferences in end-of-life care. This ethnic group favored family-centered decision-making. According to Ford and Moldenhauer (1998), cultural sensitivity requires an awareness of clan or community decision-making; Hmong, traditional Native Americans, and Amish are ethnic cultures that favor group process of decision-making. Individualized planning for these groups involves determining whom the individual assigns to make end-of-life decisions. Patients may say they prefer not to be kept alive with aggressive treatment, but still leave the actual decision up to the group. Dr. B.J. Hammes (personal communication, April 18, 2001) notes that traditionals of Native American tribes have declined to even speak of death in the first person. Instead, traditionals speak of "what one would want or might prefer if one were chronically or terminally ill."

Seniors, and anyone experiencing the vulnerability of medical distress, should be assessed as to their preferences in support (who will be present during completion of advance directives). If they must proceed with planning while out of their normal environment, many seniors appreciate the support of adult family members or others whom they have come to rely on (Bailly & DePoy, 1995). While all persons should have support and approaches that respect their preferences, gay, lesbian, and bisexual persons may need the most advocacy with hospital staff who are unfamiliar with their customs, beliefs, or feelings of vulnerability.

"Policy should facilitate ease of use among all peoples, not just among the advantaged" (High, 1993, p. 348). Suspicions about the motivation for advance care planning, fears that having a directive means all care might be withheld, or that rationing of care will fall more heavily on some income groups or persons of color are frequently stated concerns (Lo, 1995, Pugh and West, 1994-95). Patients have feared that cost efficiency drives the discussions about choices.

In addition to the timing of discussions and special support needs, certain formats of advance directives provide optimum clinical clarity. Emanuel (1995), Lo (1995), and Hammes & Rooney (1998) recommend that these formats address specific pain and symptom control, nutrition and hydration, ventilation, antibiotics, cardio-pulmonary resuscitation, hospitalization, and quality of life, as well as including an appointed agent.

To determine a patient's position on all of these clinical questions requires incremental, episodic, interdisciplinary efforts (Luptak & Boult, 1994). Partnering of disciplines is a recommended feature of comprehensive efforts on behalf of successful ACP (Colvin et al., 1993; Luptak & Boult, 1994). Advance directives, once recognized, are used to influence medical treatment decisions (Hammes and Rooney, 1998; Morrison, Olson, Mertz and Meier, 1995). "When families discuss their values and choices in advance, it is possible to change the attitude towards medical treatment that only prolongs a hopeless situation. When directives guide family members regarding stopping treatment, the family finds both emotional comfort and moral direction in what is always a difficult decision" (Lutheran Hospital, training manual, 1993, p. 6).

According to Emanuel (1993) and Mezy et al. (1997), instructional directives are best able to represent a patients' wishes in the clinical context if they make use of "scenario- and treatment- specific statements, perhaps combined with other types of value statements" (Emanuel, 1993, p. 8). Gibson (1990) theorizes that underlying the completion of an advance directive is the inaccurate assumption that future medical conditions and treatments can be thought of in advance. She recommends a broad articulation of patient values and beliefs, from which future surrogate medical decision-makers may extrapolate.

Practitioners state that individuals tend to perceive treatment and interventions differently as they age and as they adjust to illness. This adds to the complexity of ACP, requiring appropriate mechanisms to ensure choices are articulated, current, and upheld (Knee & Vourlekis, 1995) across different systems and care providers. For instance, one such mechanism involves discouraging transfers to hospitals when such intervention might contravene a previously noted preference (Ackerman, 1997).

According to Lynn (1997) and Roter et al. (2000), expert advance care planning will focus more on process, and getting to know patient's spiritual and psychosocial supports and values. Miles et al. (1996), in their review of the literature, found advance planning therapeutic, integrative, and an end in itself, not necessarily a means to formulating a written document.

Best-Practice Models

Medical social work theory joins other medical disciplines in defining best practice models. Abramson (1990) defines the medical social worker's role as a questioner of the purpose of technology, an encourager of dialogue, a negotiator among participants, and an advocator for patients. This integrates the social work role of support for self-determination into medical host settings. Luptak and Boult (1994) recommend incremental, episodic, interdisciplinary efforts in their study of outpatients, physicians, and social workers collaborating in advance care planning. Colvin et al.(1993) affirm the importance of trusting empathic relationships built over time. Each of these models recommend the attention to patients prior to crisis. They stress advocacy, informing patients about how technology would impact the patient in relation to his or her individual diagnosis, utilizing the strengths of multiple disciplines and developing trust as hallmarks of "best practice."

Abramson (1990) recognized that supporting patient autonomy consists of several recommended efforts. These include: (1) involving patients and families, (2) addressing conflicts that may interfere with patient choice, and (3) creating a sense of choice through discussion of available options and encouraging others to promote patient autonomy. Using the premise that the desire to maintain autonomy is common to all human beings (Reynolds, 1989 cited by Freedburg, 1989), models that support autonomy consistently return to the effectiveness of hearing a story and being sensitive to people and cultures different from the listeners'. The above models guide work with geriatric patients, the terminally ill, and patients with chronic debilitating disease. These are persons most likely to complete an advance directive (Hammes & Rooney, 1998). These patients are motivated by the recognition that their decisions and instructions to caregivers and family at this stage affect their comfort and quality of late life.

Introduced in the studies are Living Will/Health Care Declaration and Durable Power of Attorney for Health Care (DPOAHC); these are types of advance directives, ways to spell out wishes and to have control over one's destiny and define durable powers, which are effective even if one becomes incapacitated. Such a directive may say, for example, "I want everything attempted, but at a certain point, some things can be discontinued." Bern-Klug, Gessert and Forbes (2001) define social workers' key role as "context interpreters." By filling in the vacuum of information about the progression of disease, such as dementia, social workers are able to assist families in applying the values they know to be the patients'.

Miles et al.(1996), Silverman (1987), and Spiro et al. (1993) recognized that narrative must join technology if professionals are to know patient values and concerns. Emanuel (1993) proposed a model of discussion led by health care professionals, who use their knowledge to inform and assist patients in deciding the amount and type of care pertinent to their disease process, and the patients' notions of what constitutes quality of life.

The current issues that complicate the right to refuse treatment involve finding appropriate mechanisms to ensure that an individual's choices are articulated and upheld, or determining who can articulate the patient's wishes, if the patient can no longer do so

(Knee & Vourlekis, 1995). Patient surrogates are responsible to facilitate "indirect autonomy," a notion from the literature on adult development (Agich, 1990 and Collopy, 1990 in Bailey & DePoy, 1995) conceptualizing autonomy as one ages. According to Bailly & DePoy (1995), the definition of autonomy shifts from the capacity to directly act on decisions, to the capacity to have decisions implemented. Advance care planning allows for indirect autonomy via the documentation of preferences for end-of-life care, including the appointment of surrogate decision-makers.

Research on the effectiveness of advanced care planning has resulted in identifying some elements of best practice. Ethical principles that frame the relationship between patient and health care provider include beneficence, non-malificence, autonomy, and self-determination (Beaucamp & Childress, 1994). Legislation, which ties together health care organizational practices with these principles, is entitled, *The Patient Self-Determiniation Act (PSDA) of 1990* (P.L. 101-508). It was designed to increase patient involvement in decisions about life-sustaining treatment by ensuring that advance directives for health care are available to physicians when critical medical decisions are made (Greco, Schulman, Lavizzo-Mourey, & Hansen-Flaschen, 1991, cited in Sansone & Phillips, 1995). It requires both hospitals and health care providers who admit patients to inform them of their right to choose or decline treatment. According to Colvin et al. (1993) the PSDA has the impact of requiring extensive dialogue, inquiry, and reflection as it continues to evolve into the practice of health care systems. "We need to think of advance directives as a process of understanding" (Colvin, 1993, p. 565).

Gaps in Literature

Gaps in the literature occur around the impact of the PSDA. Scholars suspect that the law promoted more documentation than dialogue. In addition, Sansone and Phillips

(1995) state that almost all empirical studies between 1980 and 1995 that deal with the accuracy of surrogate decision making have questioned the ability of surrogates to make decisions for incapacitated elderly. More research is needed to determine practices that improve or inhibit surrogates from being part of the discussion of end-of-life issues. Bern-Klug et al. (2001) see families stepping up to the hard decision of letting go of loved ones. The alternative is keeping a demented nursing home patient alive through aggressive treatment that cannot give them back the life the patient valued. They recommend providing families with information which will help them in that process. Therefore, research about how social workers and others step up to the task of informing families is a subject for future inquiry.

According to Miles et al.(1996) shaping advance planning to therapeutically focused integrations, such as helping people integrate dying into the context of personal histories of a good life rather than giving them actual control over their clinical care, means we need more after-death studies of how the family perceived the role of the advance planning process. This was the step taken by Hammes and Rooney (1998). How helpful conversations are at the end of life for integration of life stages, rather than what they elicit in clinical direction, can reasonably be the next step in research. This secondary analysis of 18 organizations pertinent to end-of-life discussions may not tell us all that would be wished for, but it will indicate more about the content of the discussions, as well as the concerns of those initiating advance planning.

Attorney Kathy Myerle, an author of MN Advance Directive legislation, states that communication is the greatest issue of the PSDA (K Myerle, July 17, 1999, personal communication), yet little is known about the conduct of advance planning discussions. Particularly unknown are discussions by medical social workers, nurses, chaplains, and other trained facilitators who make up the expanded role that physicians were formerly thought to hold exclusively. More exploration is needed on an interdisciplinary model of advance care planning (Luptak et al., 1994 ; Miles et al., 1996 ; & Sansone & Phillips, 1995).

Summary

This chapter summarized the literature, specifying what we know, how well we know it and where the gaps are in our knowledge. It also explains how this study intends to further research defined gaps in order to provide practice recommendations for facilitators of advance care planning. Chapter 3 will further define the theory that frames this research. It will address Abramson's recommendations for empowering patients during the narrative, and utilize Rank's theory of supporting patient-centered discussion.

CHAPTER 3: THEORETICAL FRAMEWORK

Introduction

This chapter will describe a theoretical framework for understanding how self-determination is achieved and why. First, informed consent leads to moral responsibility (Silverman, 1987) of individuals to make choices, when they are capable of rational decision-making. Second, a body of literature recommends how informed consent and choice are converted into directing care at the end of life. Theoretically, successful consideration (reflection), recording, and communication equate with patient self-determination and autonomy in a medical goal setting (Hammes & Rooney, 1998). There is a belief that self-determination comes most effectively from a narrative process with the patient, including respect for his or her personal and cultural values and beliefs; this is "best practice" in advance planning. Abramson's autonomy model is used to describe this phenomenon as it relates to the expected findings of this study. The "enhanced autonomy" model of Quill and Brody (1996), and Freedburg and Abramson's work are cited as reference points for the discussion of findings reported in Chapter 5.

Autonomy Theory

"To be effective, any skilled service must evolve organically from the expressed needs of the people who use it" (Reynolds, 1938 in Freedburg, 1989, p. 37). Freedburg explains that client self-determination is a principle of practice. She credits Kasius' (1950) conception of functional and diagnostic schools of thought. A functional approach with clients was prescribed as the way to self-actualization. This work originated in the notion of the unborn will (Rank, 1937 in Freedburg, 1989), which is the organizing force in the personality that gives rise to the autonomous self. The self-directing force of the will can be pushed toward individual growth, in part through meaningful interaction with persons and events in the environment. The theory provides a contrast between the goal centered (diagnostic) pursuits that Silverman (1987) ascribes to the medical field in general versus the functional-organic efforts that a narrative approach to defining client/patient wishes provides.

Over the years researchers have examined how a person is treated under a paternalistic medical system. Paternalism occurs when the discussion is limited by the practitioner's goal(s), creating an imbalance of power, rather than a natural progression of discussion, evolving from a patient's and practitioner's exchange of beliefs, questions, and expertise. Patients are experts about what is right for them; practitioners need to be prepared to inform them well of possible outcomes, comparing them with the patients' overall goals in life. "The preferences of patients demand respect on the basis of the ethical principle of autonomy. Respect entails that patients should be truthfully provided the information necessary for an informed consent or refusal of treatment. Their preferences should be followed, although certain exceptions, based on ethical principles other than respect for autonomy, are allowed" (Jonsen, Siegler & Winslade, 1998, p. 106). An exception would be cases where the patient's preference conflicts with reasonable medical practice, or when the patient's behavioral choices make achievement of their medical goals impossible (Jonsen et. al., 1998).

"It is unlikely that physicians would have turned as quickly to the problems of informed consent in the mid-1970s, if it had not been for several leading court decisions that disputed the common practice of allowing community standards to determine how much information should be disclosed to patients" (Brody & Tomlinson, 1986, p. 233). One of the standards set by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is for patient involvement in decision-making involving their care (JCAHO, 2000).

Explaining how the treatment will improve the quality of the patient's life is of primary importance. Respect for patient autonomy requires presenting an opportunity for choice by giving pros and cons of alternative medical treatments, in a readily understandable language. Limiting the physician's decisions to the physician and the patient's decisions to the patient is critical if autonomy is to surpass paternalism. For example, a surgeon determines the risks and benefits of a particular surgical procedure, but whether those risks and benefits are worth it to the patient, given the patient's life goals and life plans, is a matter for the patient to decide (Brody & Tomlinson, 1986).

Informed consent is the basis for decision-making. Developing patients' awareness about their options and hearing their stories are ways medical personnel can humanize an increasingly technologically driven facet of society. While touch was once the key provision in health care, intensive-care efforts define much of end-of-life care, even when disease has overpowered the cure. This keeps the comforting of hospice so removed that one often races into death via efforts to outrun the disease. What are health care workers' ethical responsibilities in the face of suffering? They should lie in informing and listening to patients and in developing care plans when cure plans are no longer reasonable. This is where advance care planning could refocus efforts, to the human needs and quality of life as each individual defines it.

According to Bailly (1995), the PSDA recognizes and supports individual choice; thus advance directives empower people by ensuring autonomy. This presumes that the directive comes out of informed consent.

Application of Functional Autonomy Theory and Models

"A solution to the discord of paternalism and self-determination is to adopt a consumer-centered approach to practice" (Tower, 1994, p. 191), thus engaging the patient in the planning. Medicine joins social work in recommending patient-centered practice. Quill and Brody (1996) want practitioners to make a patient's overarching goals about life and death the focus of planning, rather than immediate demands of "do you want us to attempt to restart your heart?" They condemn the practice of merely providing a check list from which the patient is to choose. They require the practitioner share their expert advice. When physicians make decisions, they don't "wander alone, for fear of being influenced by the biases of others"(Quill & Brody, 1996, p. 765). "It is patronizing to imagine that our patients cannot make decisions in a similar manner, especially when many are desperately asking for guidance. Accepting the physician's acceptance of their power to offer recommendations—while obligating the physician to fully understand the patient's reasoning when those recommendations are rejected—enhances rather than reduces the patient's power and competence" (Quill & Brody, p. 766). Tower (1994) citing Freedburg and Abramson, reaffirms that the inherent dilemma in the philosophy of self-determination is agency and practitioner control. This conflict is referred to as the autonomy-paternalism dilemma (Abramson, 1985).

Goal-centered practice would lead practitioners to prioritize the completion of an advance directive, thereby putting choice-making (prematurely) the focus, rather than focusing on contextual considerations that are part of person-in-environment practice. As physician experts (Roter et. al., 2000) in end-of-life planning and social work theorists agree, it is not goal-centered discussion, but patient-focused discussion, that is the quality approach to patient self-determination. Abramson (1990) recognized that supporting patient autonomy consists of several recommended efforts. These include: (1) involving patients and families, (2) addressing conflicts that may interfere with patient choice, and

(3) creating a sense of choice by discussing available options and encouraging others to promote patient autonomy. This indicates that a key feature of choice-making is the timing, and that the patient should be able to determine when the discussion best suits his or her frame of mind and circumstance. A self-determination model was developed by Marcia Abramson (1990) to explain the components of support for individuals as they confront stages of development and health care decisions related to aging and chronicity. She ascribes to completely informing and supporting individuals and clearly facilitating communication of the individual's choices to assure self-determination.

Summary

This chapter provided connections between autonomy theory and models that lead to informed consent. It presents a framework for understanding which elements of social work practice are most likely to foster and support patient's autonomy and avoid unnecessary or unethical paternalism. It is important to note, however, that relationship ethics come into play when substituted autonomy is necessary. (See Chapter 6, discussion, for more on relationship ethics.) Chapter 4 will review the methodology, followed by Chapter 5, (findings); and Chapter 6 (discussion).

CHAPTER 4: METHODOLOGY

Overview of Chapter

This chapter describes the nature of the research, explains the rationale for using a survey method for data collection, and defines the concepts and variables. Concepts include "the five promises" (Hammes & Briggs, 2000) by which advance planning is currently judged in the study population. The section ends with recognition of the ethical issues of research and explanation of the relationship of "blind" data use to expedited research.

Research Design

Information from an interview survey completed in 1996 (Krage, 1996) under the direction of Gundersen Lutheran Medical Center staff formed the basis of this study, making this a secondary analysis design. The survey data were originally collected as a five-year retrospective, following the implementation of the Patient Self-Determination Act of 1991.

A researcher interviewed practitioners in teams from local clinics, hospices, nursing homes, hospitals, and home care programs. Respondents were asked a number of questions related to the implementation of the PSDA (see the copy of survey in Appendix A). Exact profiles of participants from each organization are unknown, other than which disciplines were involved, and who practices advance care planning versus those who are administrators. We do know that social workers were among the respondents at both clinics, both hospices, seven of eight nursing homes, one of two hospitals, and two of four home care programs. The health care organizations studied were chiefly nonprofit, a mix of religious-sponsored and influenced, and non-secular, and included all area health care providers, except those serving only religious orders.

A survey interview method was chosen for several reasons. According to Rubbin and Babbie (1993), survey interviews provide the flexibility of self or surveyor administering, allow for deeper probes when administered face-to-face, and are usable with groups of respondents, gathered in the same place at the same time. The survey interview gets higher response rates (Rubbin & Babbie), and allows the survey interviewer to provide a guard against confusing questions. Furthermore, the survey can be structured for ease of entering information into a computerized data bank. A problem that Rubbin and Babbie (1993) noted includes the social desirability factor, with respondents tending to respond with answers they believe the interviewer would favor.

This thesis study analyzed the results of the interview survey, a source of secondary data for the purpose of answering questions related to social work practice improvement.

Thus there is no cost for mailing, developing cover letters or collating answers. Practitioners and respondents remain anonymous. Names are not included and the reporting of data is in aggregate, not for individual organizations. The response rate was excellent, in that 100% of the sampled organizations responded to the original survey that this secondary analysis utilizes, creating a validity that is not always present in surveys, which generally tend to have a low response rate. Finally, survey research enables multiple variables to be analyzed simultaneously, and allows for the researcher's examination of correlations between variables. Many questions are asked on a given topic, giving flexibility in analysis. "Finally, standardized questionnaires have an important strength in regard to measurement generally" (Rubin & Babbie, 1993, p. 364). Although this survey did not use a nationally standardized instrument, the same questions were asked of all subjects.

Research Question

The research question of this study asks: "What is the relationship between La Crosse area advance care planning practices and recommended practice to assure patient self-determination?" This study focuses on practitioners as they work with patients in various degrees of illness and varying levels of care. It seeks to understand current practice in the La Crosse area among social workers who assist patients in developing advanced care plans.

Concepts

Literature on concepts regarding self-determination includes medical, non-medical, and medical social work as well as generalist social work. The literature considers a patient-centered process as best practice for advance care planning; it is most likely to elicit patient concerns and questions. Another framework for the concept of best practice is Abramson's model for social workers to support autonomy (see p. 32 and Chapter 2). A study by Hammes and Rooney (1998) identified interdisciplinary communication, access to information regarding all treatment and quality-of-life issues, support of trusted caregivers and surrogates, and documentation and transfer of patient's directives as priorities in quality advance care planning. Federal and state law, quality reviewers for health care organizations, and court decisions have set the current standards for opening discussion, honoring directives, and educating the public. Local care providers have promised to support these standards.

Certain concepts were operationalized by specific items in the original survey. For example, "Including surrogates" was operationalized by the question of whether patient beliefs and values were discussed with family for future decision-making (i.e., when the patient is incapacitated and surrogates need to answer for the patient). The "retrievability" of directives (the ability to obtain completed directives for use in crisis), and "portability" of directives (the usefulness of a directive in various health care circumstances), are examples of concepts this study researches. Additional operationalized terms are as follows:

Goals: The intent of the practitioner while engaging patients in advance directive discussion. Examples of goals include:

(a) informing patients and residents of their legal right to limit or refuse treatment;

(b) completing a legal document;

(c) educating the person regarding future medical decisions; or

(d) organizing a values history by helping the person discuss their values and goals for future medical care with family and staff.

(These are operationalized by questions 4, 13, 23, 32, and 42 from the survey; (d) is analyzed in Table 5.1 in Chapter 5.)

Timing: the time at which facilitators of advance care planning choose to discuss end-of-life planning with patients. Examples might include times of pre-admission, admission, after family is assembled, at a care conference, or when there is a change of status, such as patient clinically declining. Timing is operationalized by questions numbered 8, 17, 27, 36, and 46 and analyzed in Table 5.3 where discussion of treatment options are shown at pre-admission, admission, care conferences, change of status, and all other times. Again, this is the course of a journey through health care.

Training: The specific preparation of facilitators of advance care planning at each organization, beyond their professional preparation, e.g., coaching a physician has had for techniques for gaining insight into patient perspectives. Attendance at a "Respecting Your Choices" training is an example in the La Crosse area. While this is operationalized by questions 6, 15, 25, 34, and 44, I have not shown this in a table. It is not part of the three foci of the final secondary analysis

Self-determination: The individual's ability to advise and have their advice followed in end-of-life care, regarding treatment choices or limitations. Self-determination is operationalized by survey questions 8g, 17g, 27g, 36g, and 46g. The question relates to quality of life, and whether it was included in the process of considering future health care decisions. If the practitioner did not inquire into the patient's story, including having a narrative interaction regarding what constitutes quality of life for the patient, then self-determination was limited by the omission of a key concept. Other survey pieces pertinent to self-determination include whether a patients' expressed preferences were communicated and available for use as needed. See communication of the directive, below.

Communication of the directive: How does each organization respect a patient's choice in their communication of the directive. This includes filing, documenting the patient/caregiver discussion, and transmitting the AD when the patient is transferred to another health care organization. Whether the document/expressed preferences of the patient are available ("retrievable") and "portable" (meaning useable in a variety of health circumstances), are shown in Table 5.2 and answered in survey questions 51 through 57.

Inpatient/outpatient: Inpatient is acute care, outpatient is all other health care, including that which is provided in an established program or building such as hospice programs (when provided outside the hospital) or nursing home care. Outpatient care is that which does not qualify as inpatient stays for purposes of reimbursement. The type of care is operationalized by looking at the types of organizations surveyed: hospitals (2 were surveyed) versus all other places of care (16 were surveyed). They are operationalized in the demographics section of the survey, and mailed to organizations before the date of the actual survey interview.

Including Surrogates: The procedure of holding discussions with the person(s) that the patient is naming as health care agent, or designating to speak on their behalf in case of incapacity. This is operationalized by question 50 in the survey.

The five promises: These statements of intent were developed in 1996 (Hammes & Briggs, 2000) by experts using the community of La Crosse; these promises serve as a way of determining differences in response to the process of advance planning versus reaction to the legal mandate for health organizations compliance.

Population

This study sets out to examine the practices of social work practitioners who are providing coaching and guidance for advance directives in many health care settings.

Sample

The survey sample consisted of designated persons knowledgeable about advance directive facilitation at each of the 18 health care organizations in the La Crosse area. The sample came out of a list of contacts developed through participation in the La Crosse Advance Directive Study (Hammes & Rooney, 1998). The health care organizations were originally asked to include in the survey interview a nurse, social worker, nursing supervisor, and anyone else involved in advance care planning at their organization; sometimes this included pastoral care or other trained ACP facilitators. In one nursing home, the director who supervised the social workers who were the advance care planners actually met with the surveyor and answered the survey questions on behalf of social workers who could not wait out a delayed time of the meeting. In three nursing homes only the social worker responded to the survey.

Measurement issues

Secondary analysis relies on previous researchers' standards of questioning and documentation of answers. Because the population of the study is from an assorted group of disciplines, their responses may limit the generalization of answers to social work practice. Since the questionnaire (Appendix A) was developed to collect organizational responses as well as the presence of multiple disciplines' involvement, it is necessary to extrapolate from the previously collected data to determine the implications for social work. In retrospect, a better approach would include directly surveying social workers only, or case studies to determine the support and dialogue that made up advance care planning.

Data Collection

Advance directive activity of advance care planning facilitators was extracted from a survey of 18 community health care organizations in the La Crosse area. (See Appendix A for a survey sample). Those 18 organizations were studied via a face-to-face survey, during November 1995 through February 1996 (Krage, 1996). These same organizations were identified as the study group through their simultaneous participation in the La Crosse Advance Directive Study (LADS) (Hammes & Rooney, 1998).

Data for this study were stored in the computer data bank at the sponsoring organization, Gundersen Lutheran Medical Center. The survey instrument was initially piloted in a smaller community, across the same types of health care organizations. These include nursing homes, hospice programs, home care agencies (including public and private), clinics, and hospitals.

Data Analysis

Utilizing the print outs which gave cumulative responses as well as responses by each of the five types of organizations surveyed, this researcher prepared grids that would help determine themes in the study. Tables were then prepared from the grid. Themes became apparent and were assembled on a composite table. The main theme is changes in approach to advance directives over the time span of care.

This study utilized three foci to answer the research question: First, are surrogates involved in discussions of patients' values and beliefs? Second, are all options for care and treatment included in the discussions, including quality of life? Finally, according to the results of the secondary analysis of the survey, how well do practitioners believe patients' directives are communicated? These foci were chosen because the literature indicates they are the key features for patient autonomy in self-determination in advance care planning. Once the findings were assembled, the extent to which these three key factors in advance care planning were accomplished addressed the research question.

Human Subjects

The institutional review board (IRB) review took place at Gundersen Lutheran Medical Center. A letter of consent is included in Appendix B of this thesis. The study was not submitted for additional IRB at Augsburg since this writer and the sponsoring organization recognized that secondary data analysis usually presents low risk to human subjects. Confidentiality is intact because individuals are not identified or reported in any way. Organizations are not receiving summaries of this material. The facilitators interviewed gave their perspectives regarding the advance directive work in their organization. No possibility of retaliation exists since we are not seeking a right/wrong or legal/illegal data piece. This research is for the understanding and use of social work professionals as they adjust practice, and mimics health care organizations' internal quality improvement activity. As such, this research is a collection of data for reference purposes.

Summary

This chapter specified the research question and gave an overview of the research design, including the population and study sample. Measurement issues were discussed and the data collection instrument was presented. Data analysis procedures were explained, and the human subject issue addressed. Chapter 5 presents the findings of this study.

CHAPTER 5: FINDINGS

Chapter Overview

This chapter provides a summary of the findings from the secondary analysis of survey results and addresses the research question: "What is the relationship between La Crosse area advance care planning practices and recommended practice to assure patient self-determination?" It does so by organizing results from the survey in three areas of focus for secondary analysis: First, are surrogates involved in discussions of patients' values and beliefs? Second, do options for care and treatment discussed include quality of life? Finally, how well do practitioners believe patients' directives are communicated?

Profile of Respondents

Respondents included 18 teams of practitioners from La Crosse area health care organizations involved in advance care planning with patients. Teams ranged from a single respondent per organization to 7 staff members representing their organization as survey respondents. Profiles of respondents show that administrators of nursing homes were respondents in 2 surveys. Social workers were respondents in 15, nurses in 13, chaplains were in 6, and volunteers or others in 2 surveyed teams.

According to the above respondents, social workers and nurses are the most likely team members to counsel patients in treatment and care choices across all five types of health care organizations: hospital, nursing homes, home care agencies, hospice, and clinics. Pastoral care providers assist with advance care planning at hospitals and some nursing homes, social workers have the primary role of facilitator at nursing homes, and a mix of disciplines share responsibility for education and preparation for end-of-life planning in clinics. Some home care and hospice programs have their own social workers, while some contract out for advance directives counseling.

Research Question

What is the relationship between advance care planning in La Crosse, Wisconsin and recommended practice to support patient self-determination? Recommended practice requires (1) That practitioners attend to the process of planning rather than an outcome, and (2) that conversations be held at non-crisis times and include key persons in a patient's relationship circle (Roter et. al; 2000; Lynn, 1997; Luptak & Boult, 1994; Colvin et al. 1993; Gibson, 1990). Such practice, combined with Abramson's (1990) model for practice, which supports autonomy, frames the inquiry of this study.

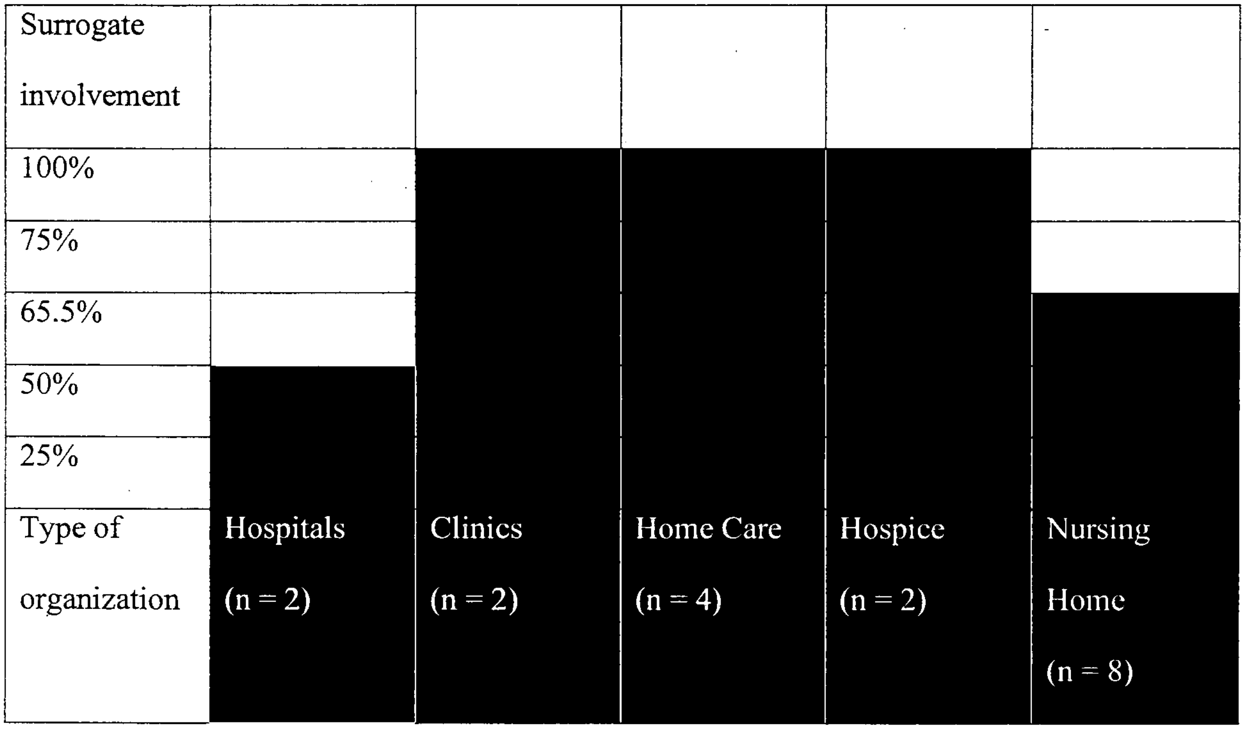
Preliminary Results

It is important to recognize that each finding reported herein is based on what respondents said in response to the survey. These findings report what the respondents perceived based on their practices and observations, they are not indicative of total organizational response to the mandate for advance care planning.

In summary, the practice of including family and surrogates in discussions of patient beliefs and values appears frequent, although not universal. Treatment options discussed all too often exclude the quality-of-life issue. Finally, practitioners believe advance directives are well communicated and accessible, with the document itself being in the patient's file and retrievable by other providers as needed. Some problems with the secondary release of information, once the advance directive goes to medical records, have been noted.

Table 5.1

Frequency of Surrogate Involvement in Advance Care Planning Discussion.



Surrogate involvement					
100%		■	■	■	
75%		■	■	■	
65.5%		■	■	■	■
50%	■	■	■	■	■
25%	■	■	■	■	■
Type of organization	Hospitals (n = 2)	Clinics (n = 2)	Home Care (n = 4)	Hospice (n = 2)	Nursing Home (n = 8)

Focus 1: Surrogate Involvement in Discussion of Patients' Beliefs and Values

Table 5.1 indicates that according to respondents to the survey, by the time patients experienced a change of health status during their care, practitioners intend to involve surrogates in discussions of advance care planning at 50% of hospitals (1); 100% of clinics, home care, and hospice programs; and 65.5% of nursing homes. Both hospitals intend to involve surrogates at "other times", such as in public education sessions, or outpatient appointments. The raw data for Table 5.1 come from Appendix A. Survey questions 4 (time of pre-admission), 13 (time of admission), 23 (routine care conferences), 32 (if significant change in patient's condition occurs) and 42 (any other times advance directive education and information is offered). These questions are the same question, asked repeatedly at various times in the patient's journey through health care. The raw data shows the reported intent of the practitioner, including (1) to meet legal standards to inform and advise; (2) to complete an advance directive; (3) to educate; and (4) to facilitate review of patient values and goals with their relationship circle. (This fourth intent is a best-practice indicator, and is the only intent shown by percentage in Table 5.1). Staff reports 50% of hospital (1), up to 75% of nursing homes (6), and 100% of clinics (2), home care agencies (4), and hospice programs (2) practice the fourth intent.

Further research could define the rationale for delaying this effort from early to late in the course of illness. Experts now support what this analysis found in 1995 and 1996; that the late consideration of patient's wishes, for example in intensive care units, is more intense than in early planning. Unfortunately, without early discussion, the patient's values and preferences may insufficiently inform later decision-making during a crisis. The social work practitioner is in a key position to affect this process, and start it at an earlier time. The term "relationship circle" is used interchangeably with family and surrogate, because it seems a fluid expression of those close to the patient. Family may or may not be the surrogate of preference, for instance, for a gay or lesbian patient.

Table 5.2

Health Care Organization Responses to Survey Questions, by Percent of Those Surveyed.

SURVEY QUESTION	**Percentage of Organizations**
Attempted to include family in advance planning.	100% (18)
Documented patient's response to advance planning attempts in chart.	94% (17)
Used a specific form as an education flow chart.	44% (8)
Document in the progress note.	61% (10)
In physician progress notes?	6% (1)
In nursing notes?	53% (9)
Documented patient's decision on a special form reserved for this purpose.	89% (16)
Documentation is easily identifiable	
By nursing staff	94% (17)
By physicians	100% (18)
Patient or resident's advance directive or documentation of treatment is transferred with the patient if he or she is transferred to another health care organization.	89% (16)

To summarize the findings, the practice of including persons from the patient-relationship-circle (family or surrogates) in discussions appears frequent, although not universal. While the *intent* shown in Table 5.1 is to include such persons, the actual inclusion comes about less frequently than best practice dictates. Reported frequency is shown in Table 5.2, and indicates 100% of the 18 responding organizations believe they make an effort to include family or surrogates in the discussion. This breaks down as follows: at pre-admission and times of significant change, only one of the two hospitals involved family or surrogates, and at other times, such as admission, neither hospital involved family or surrogates. According to respondents both of the clinics included family, but only at times of significant change. Three (75%) of home care agencies included family in advance planning discussions at admission and all did so at times of significant change. Six (75%) nursing homes reported this practice either in the admission process or at times of change. Both hospice programs included families in discussion at admission and times of significant change. The "times of significant change" are periods when the patient appears to be markedly different, perhaps failing to take nutrition. The term "pre-admission" refers to the period immediately prior to the person becoming a patient in the health care organization. For example, a pre-admission visit may take place when the nursing home staff visit the patient in the hospital in preparation for transfer to the nursing home. "Care conference" refers to a multidisciplinary meeting with the patient and family or surrogate.

Some reporting could not thoroughly show subtleties in the practice of the hospital's social workers, chaplains, and others pertinent to end-of-life planning. Chapter 6 will further comment on this issue and the shortcomings of this study.

Table 5.3

Preparation for Decision-making: Options Discussed Between Patient and Provider

OPTIONS DISCUSSED	WHERE	FREQUENCY OF DISCUSSED OPTION				
		At Pre-Admission	At Admission	At Care Conference	At Times of Significant Change	All Other Times
CPR	Hospital		1		2	1
	Clinic		1		1	2
	Home Care		4		4	1
	Nursing Homes	5	5	2	2	2
	Hospice		2		1	1
Tube Feeding/ Hydration	Hospital	1			1	1
	Clinic		1		1	2
	Home Care		3			1
	Nursing Homes	1	3		2	1
	Hospice		2		2	1
Intubation/ Ventilation	Hospital		1		1	1
	Clinic		1		1	2
	Home Care		2		3	1
	Nursing Homes	1	1			1
	Hospice	1			1	1
4.Hospitalization	Hospital					1
	Clinic				1	1
	Home Care		1		2	1
	Nursing Homes	1	4	1	2	2
	Hospice				2	1
Pain Management	Hospital					1
	Clinic		1		1	1
	Home Care		3		2	1
	Nursing Homes		2	1	3	1
	Hospice		2			1
6.Antibiotics	Hospital				2	1
	Clinic				1	2
	Home Care				2	1
	Nursing Homes		2	1	2	2
	Hospice		1		1	1
Quality of Life	Hospital					1
	Clinic				1	1
	Home Care		1		2	1
	Nursing Homes		1		2	2
	Hospice					1

Focus 2: Discussion of Options

To simplify interpretation of Table 5.3, the reported results are for the pre-admission through times of significant change of health care status. Interpretation does not include the " all other times" category of discussion of options, since these other times are public education forums or walk-in visits for completion of advance directives. Table 5.3 presents treatment options that need to be included in "best practice" conversations. It is clear thataccording to survey respondents there is no standard among the 18 organizations, as the table reflects a variety of treatment options discussed and excluded from discussions. For instance, many discussions included cardiopulmonary resuscitation (CPR) only. According to the survey respondents the issue of tube feeding as an option was raised at one hospital when a significant change occurred in the patient's health. One of two clinics discussed this option, 3 of 4 home care agencies, and up to 3 (36%) of nursing homes discussed tube feeding as part of the admission process or at times of change. This may have been because many people have already opted out of this type of care by the time their condition changes at nursing homes. Hospice discussions proceeded according to need, and occurred at the discretion of the practitioner.

During the period of pre-admission through times of significant change of health status, Cardiopulmonary Resuscitation (CPR) is discussed most often. Intubation and ventilation were discussed at only 50% of hospitals and clinics, and 25 % to 36% at all other health care organizations shown on the table. Pain management was discussed at one of the clinics (50%), neither hospital (recall here that we are not including "all other times, if we were, one hospital would have discussed pain management), nor 75% of home care programs and 25 % to 36% of nursing homes. Antibiotics were discussed by

50% of hospitals and clinics, 25% of home care agencies and nursing homes. Quality of life was discussed in none of the hospitals, one of the clinics, two of the home care agencies, and up to two of the nursing homes. Only one hospital asked about tube feeding, intubation, and antibiotics. Neither hospital asked about pain management or quality of life.

To summarize, one clinic reported offering the full range of treatment questions when a patient experienced changes in health status. Home care agencies reviewed CPR with all patients during times of significant change in health; intubation/ventilation was brought up by three of the home care agencies at this time; and two of the home care agencies included options of hospitalization, pain management, antibiotics, and quality of life in their discussions. Times of significant change in health status are the only times a physician is counted as one of the facilitators of ACP.

These findings indicate that one measure of autonomy and informed consent was not met, since the patient was excluded from considering all options. This indicates the facilitators and their organizations have been determinative, "involving the use of an independent action by the practitioner on behalf of a client or client group without their awareness or acquiescence" (Rothman, 1994, p. 117). Among nursing homes, up to 50% discussed a patient's right to avoid hospitalization. Thus many patients, even if they wish a non-intrusive end of life, may be subjected to a hospital admission in their final days.

Focus 3: Practitioner's Comments on Communication of Advance Directives

The findings shown in Table 5.3 indicate a well-developed effort to communicate patient's end-of-life treatment wishes within the health care system. Responses to an open-ended question indicate a problem regarding transferring patients' directives with them from one health care organization to the next. Practitioners reported difficulty in getting advance directives released. For instance, to get a directive on file in a clinic to use when the patient is also served by a home care agency is cumbersome. While the standard procedure is that a directive follows the patient, the overriding issue of privacy sometimes creates a problem with releasing information. This creates delays at times, and is distressing for caregivers, particularly when a patient is very near death and a directive is crucial for decision-making. A periodic review of documents (patient preferences) was apparent at 33% of organizations that reportedly held regular care conferences.

Table 5.4

Frequency of Advance Care Planning in Health Care Organizations

Organization category	**At Pre-admission**	**At Admission**	**At Routine Care Conference**	**At Times of Significant Change**	**Other Times (includes public education programs)**
Hospital (2)	2	2	NA	2	2
Clinic (2)	NA	1	NA	2	2
Home Care(4)	NA	4	2	4	3
Nursing Homes (8)	6	8	6	3	6
Hospice (2)	0	2	0	2	2
Totals	8	17	8	13	15

Note: NA = Not Available

Opportunities that supported decision-making and completion of ADs were reported as most frequent in hospitals (see Table 5.4), the least preferred time for non-crisis planning. This may be because all the key players, including family and direct caregivers (including physicians) can be readily convened during hospitalization; family or supportive others are generally available in the intensive care unit. Although survey respondents report a high incidence of planning when patients have a health status change, research indicates that planning is best done in non-crisis times.

Further evidence of communication difficulties is seen in practitioner concerns, obtained from question 60 in the original research. Nursing home staff state that the process of activating the Durable Power of Attorney for Health Care (DPOAHC) is getting more "familiar" though still cumbersome. Activating DPOAHC for hospice (palliative care) patients is difficult because a physician order is required. Nursing home practitioners experience showed it was necessary to readdress the patient's choices. They stated that choices the patient made as recently as hours or days before coming to the nursing home, or hospice, "in transition from one program to another, might have no (medical) order to fit what the patient says (prefers) now".

Some nursing home staff wondered whether patients were rushed through the process of appointing a health care agent in order to complete the disposition to nursing home. This is another opportunity for further research. Others recognized that this pressure was one feature of Wisconsin transfers from hospital to nursing home that made the completion of the form likely, if the family wished to avoid court costs and a guardianship hearing, and the patient was able to bestow power of attorney for health care. It should be noted, however, that individuals may decline to complete more than the section that bestows power to be placed in a nursing home or community residential facility. Patients need not answer treatment option questions if they are unsure or unable to make an informed consent. In the experience of some social workers, patients may be unable to do complex thinking but are still able to clearly indicate that a trusted son or daughter is the one they want as their agent (surrogate decision-maker).

Finally, organizations identifying themselves as influenced by their religious sponsorship had the following concerns. A nurse/chaplain/social work group stated that stated that they were uncomfortable offering "pain medication which could have the effect of shortening life, it is too near the slippery slope". A hospice and a home care group were the organizations interviewed who identified this concern. Thus social workers need to be aware that equal access to self-determination, including pain control, is an ongoing issue, requiring that practitioners be conscious of personal and organizational values pertinent to "comfort care" in health care settings that have the "slippery slope" concern.

Summary of Findings Relative to La Crosse Systems

When the results of the analysis are compared with the five promises (Hammes & Briggs, 2000) that La Crosse health care systems now hold as a standard for best practice, here is how the data compare: Promise 1) *We will initiate the conversation*: most facilities do this; to a great extent they offer what the law requires, but the data do not tell us that the conversation includes quality-of-life issues at the time of the survey in 1995 through 1996. Promise 2) *We will provide assistance with advance care planning*. All 18 responding organizations do assist those who ask for advance directive counseling and or form completion. Some require the patient travel to another campus, at times isolating planning from key surrogates. Promise 3) *We will make sure plans are clear*: Each organization showed a process of documenting plans, used a uniform document, and honored other clear and convincing evidence of a patient's wishes. Promise 4) *We will maintain and retrieve plans*: Survey respondents reported consistent efforts here; although they could not always be sure if a patient's directive that was created at another health care facility was present on the chart, they did have a process to seek the missing documents. Promise 5) *We will appropriately follow plans*: Respondents' responses on the original survey (question 59 on Appendix A) indicate that organizations do follow patients' wishes. Typically, respondents indicate a call is made to notify next of kin that the patients' directive is being invoked and the patients' expressed preferences are reviewed during this call. Following this call, measures are carried out per the physician orders, in response to the patients' advance directive.

Chapter Summary

This chapter discussed the results of the study in relation to the research question. Responses to the questions from the survey tool were presented. Themes were identified and discussed in examining responses to the questions. Chapter 6 reports the significance of the data, strengths and limitations of the study (including research design) and implications for social work practice. Recommendations for future research are offered.

CHAPTER 6: IMPLICATIONS/DISCUSSION

Chapter Overview

This chapter will review the study's major findings in regard to the frequent involvement of social workers, and inconsistent content and surrogate involvement in advance planning discussions; and describe its significance to the existing literature. Limitations are identified, as well as the implications for social work practice and policy. This chapter concludes by discussing areas for future research direction.

Current Practice recommendations for Supporting Patient Autonomy

"Recent research suggests that preferences for care are not fixed but emerge in a clinical context from a process of discussion and feedback within the network of the patient's most important relationships. Clinical trials emphasizing this approach have been successful. The approach that emphasizes communication, building trust over time, and working within the patient's most important relationships offers a hopeful model for clinicians working in intensive care units" (Prendergast, 2001, p. N35). This model, from Colvin et al. (1993) is now the national standard. This study could not describe in sufficient depth the process of discussion and feedback within the patient's most important relationships. In the end, 5 years after the original research was done, and 10 years after the PSDA became law; it all comes back to listening to the patient's story. While the PSDA's intent was to keep hospitals from overtreating, the current practice in ICUs is to honor the interpretation of patient wishes via discussion with those closest to the patient. Social workers may find this environment, where family and physicians are most likely to be committed to finding the way to best care for patients, is the ideal forum for facilitating follow through of patient expressed wishes.

Treatment options discussed may vary according to the opportunity and discretion of the practitioner. Practitioners in some religiously sponsored organizations may feel discomfort with discussing pain relief that might result in death. This reluctance may indicate some practitioners are guided by their own values as opposed to primarily engaging the patient's values. Successful communication of a patient's advance directives among organizations is a continuing role for social workers, involving the ongoing education of staff to provide true access for patient preference. Missing documents can easily mean a patient who is incapacitated has lost the opportunity to direct end-of-life decisions.

This study sought to determine whether, with the passing of the Patient Self-Determination Act, there is a standard of practice among La Crosse health care organizations. The original study had an interdisciplinary focus. With the secondary focus narrowed to social work practitioners, the study applies patient-centered practice theory, and several models for achieving patient autonomy. These include the "enhanced autonomy" model (Quill & Brody, 1996); the incremental, episodic, interdisciplinary model (Luptak & Boult, 1994); and Abramson's empowerment model (1985). These truly support autonomy by finding a balance between the power of health care providers and patient choice. These three models include a social-work medical and non-medical model, and a physician-practice model. The "enhanced autonomy" model includes active listening, honest sharing of perspectives, suspension of judgement, and genuine concern about the patient's best interest. In this fusion of theory and models, we have the rationale for developing advance care planning as a way of facilitating self-determination (the spirit of the law), rather than a quick nod to the letter of the law. The fusion supports interdisciplinary discussion and feedback, assuring that the patient's voice is heard.

Inconsistent Support for Self-Determination

This study indicated that informing patients of treatment options during advance care planning occurred inconsistently across systems and organizations. One problem is that each organization discusses from seven to zero treatment options at the time they review the right to an advance directive. It appears that at times they may be encouraging the completion of an advance directive document prior to having clinical discussions. Another problem found is that often one discipline had the main responsibility for advance directives counseling. These limitations, along with variance in content and involvement of surrogates, suggests that the nature of La Crosse area advance care planning at times may inhibit self-determination regarding end-of-life care.

Integrating advance care planning into ongoing medical treatment decisions should be the focus for social workers in medical host settings. In order to see how this is being brought about, field observations would be a better research technique. It could provide advance care planning data, from beginning to end, with a single individual's advance planning process. The following are ways practitioners may support patients in managing future medical options and quality of life. (1) See patients as early in their chronic illness as possible; (2) integrate information from that discussion into the patient's chart for direct caregivers; and (3) Affirm beliefs (such as the brief use of feeding tubes if the patient is comatose, or "make sure I'm as free of pain as possible").

Quality Indicators Related To Advance Care Planning, Now and In the Future

According to Knee and Vourlekis (1995), prominent influences on evolving concepts of patients' rights include professional standard setting for institutions and practitioners. An example are the five promises (stated in Chapter 5) adopted by one system in La Crosse and proposed by the advance directive community task force as a La

Crosse community standard for advance care planning.

Already it is apparent that the community agrees to initiate conversations, though the depth and breadth of these vary according to preparation of the practitioner, and whether they take place over time (episodes and increments of advance care planning). The organizations certainly consult these documented conversations when patients are no longer able to speak for themselves (Krage, 1996). The problem lies in the clarity of plans, and that improves as surrogates are included in conversations. The tri-state POAHC document issued in 1998 has also enhanced clarity. Assuring that completed documents are available is a continuous quality improvement effort in small community hospitals, teaching hospitals, nursing homes and international medical care centers.

Strengths and Limitations

Strengths included a high return rate (100%) for the original study. This provided a solid base of data for analysis from which it is possible to determine a relationship between advance care planning practices and patient self-determination. Respondents represent the total population of organizations in the area. The community's practitioners are not culturally diverse. The Native American, Hmong, and Amish people served by the community healthcare organizations are not represented among the practitioners. Also, practitioners did not representative the age of the patient population served, although they were representative of the adult children of the patient population. Different results might have been apparent with a broader cultural diversity among practitioners; Miles et al. (1996) indicate that some problems in advance planning disappear when practitioners are of the culture of the person requiring the planning for end of life.

The instrument was well constructed with both open-ended and closed-ended questions, providing quantitative data for precision and generalizability; and qualitative data for in-depth exploration of concerns related to systems problems. It was administered by an outside volunteer, and thus collected concerns that may not have been reported had the surveyor been one of the local health care employees. Since it was face-to-face, it allowed for coaching in areas that respondents might have otherwise declined to answer or found unclear.

This study, in which the author of this thesis was the interviewer, was limited by the type of research chosen, meaning that response bias could have come into play when respondents wanted to impress the surveyor with their efforts toward good planning. It was further limited by using a secondary analysis of many disciplines, rather than purely social work responses. The greatest limitation was the original interviewer's choice not to separate participants by profession for analysis. It seemed the way to protect sources, and be inclusive of all organizations' practitioners, but caused a loss of focus and clarity about the one profession most sought after. In hindsight, better methods to address the research question would be interviews and focus groups with social workers, focusing on how planning relates to types of illness and patient fears and values. Needs-assessment strategies generally offer a more precise picture of practice.

Another more effective approach would be the observation of social workers in the process of advance planning. The reported information in this analysis was diluted because, in the majority of the 18 interviews, several disciplines responded. It also featured a paraprofessional speaking for all the disciplines at one of the hospitals, while the other hospital had three professionals responding to the survey. This may have created inaccuracy about how often surrogates are involved. There were no statistics captured in the study to explain the percent of advance care planning done by the paraprofessional versus a professional. It may be that the paraprofessional did the more straightforward assisting of completion of advance directives, while the professionals did the more complex advance care planning process. Limited collection of data did not allow the researcher to be clear about this process..

Implications of Social Work Practice and Policy

This study of exploring how patient self-determination is related to advance care planning has direct implications for social work practice. By defining variables important to patients as they develop their advance directives, social workers support patient self-determination and provide therapeutic intervention. Medicine primarily provides for technological diagnosis and treatment, but the values and preferences of patients must not be ignored. Social workers have the responsibility for assessing and assuring that patient's values and beliefs impact their health care. Ongoing research could evaluate social worker's direct practice with patients, involving social workers in evaluating patient experiences (such as pain and distress), promoting autonomy, and directing change in advance care planning procedures. Ongoing evaluation helps build clearer policy and lead to more effective practice across medical settings.

Social workers' roles have changed since the passage of the Patient Self-Determination Act. They have bureaucratic authority to become involved in discussions that had been extensively the physician-patient domain. Despite the changes, inpatient roles for social workers appear generally focused on discharge planning at several medical centers where I have been able to observe, i.e., in Rochester and Winona in Minnesota and La Crosse, Wisconsin. If social work professionals wish to immediately expand their clinical efforts or research in end-of-life planning, NASW suggests they pursue and develop work in clinics and roles beyond discharge planning (NASW, 1998). The history of medical social workers is one of discharge planning, providing safe placement in the continuum of care as it developed over the last two centuries (Freedburg, 1989). This advocacy role, supporting choices of treatment, is an opportunity to be involved on the very eve of the changing tide of paternalism in medicine. In planning and honoring patient preferences and values, social workers decrease anxiety and increase support for autonomy. Social workers must also take care not to contribute to a new paternalism of being overly responsible for the patient's wishes. Each person, barring certain vulnerabilities, is responsible for developing his or her own choices and rationale. Social workers need to assess the extent to which patients and families need coaching in the developing of advance directives, and remove themselves in cases where the patient's desire is to continue without a written plan for end-of-life care. As long as patients understand the risks, including the default of life-prolonging treatment in the absence of a directive, the decision about whether to create a directive remains their choice.

Here are ways that social workers can improve outcome in advance care planning and thus effect care of the patient.

1. Monitor systems upkeep by serving on quality improvement committees.
2. Act as a resource regarding the latest research and indicators for ACP.
3. Document conversations of patient preferences and values, integrating this into team practice.
4. Keep focus on the patient's perspective despite the pressures to meet goals such as discharge planning.
5. When called upon to consult and build clinical clarity for medical practice, social workers need to assess the context within which end-of-life decisions are being asked. When the patient and family are unclear that attempts to assist them are ongoing,

they cannot get to the point of letting go of some treatment option, such as cardiopulmonary resuscitation. Through listening to stories, social workers will be more likely to know the appropriate next step for reassuring and normalizing patient and family fears in critical situations.

6. Assume the role of teacher for new staff.

Honoring the Choices Patient's Make

Some assume that people do not want or need the opportunity to take care of end-of-life concerns. On the contrary, Dr. Ira Byock, past president of the American Academy of Hospice and Palliative Medicine, has stated that doctors and medical staff can do much to help clarify patient care preferences, but they do not write down the preferences, or they lose them, and that when they do find them, they are not good at honoring them (I. Byock, personal communication, November 3, 1998).

Not all organizations transfer the advance directives with the patient. One organization stated this is only true if the information came from elsewhere, because by law they cannot release medical information that originated elsewhere. A policy is needed to address this "slip" in communication, which causes additional time and effort to "rebuild" any effort that had already been completed with the patient in terms of advance care planning. The need for explaining the patients' rights, and the effort to get patients to complete Health Care Power of Attorney documents, while significantly related to federal and Wisconsin law, must remain secondary to engaging patients in addressing medical treatment based on their values and preferences.

Implications for Future Research

Advance directives were designed to help patients establish the level of care they would receive if they were to be rendered incompetent. Medical social work advocates are in an exemplary position to discover and record what sort of existence is meaningful to an individual patient. Future research could build on the results of this study, exploring the nature of the documentation of patients' expressed values and preference. A note by a physician or other practitioner that a patient initiated discussion of end-of-life issues, or even a quote from the patient, can greatly impact future decision-making.

Field observation shows a need for focused conversations with specialized patient populations, e.g., open-heart surgery or dementia-related illness or neurology patients (L. A. Briggs, personal communication, March 21, 2001). Comparison of a variety of health care organizations in this study shows that professionals use discernment regarding the timing of discussions about end-of-life issues; still, research repeatedly suggests earlier intervention, primarily in outpatient settings, would be the proper areas for planning for eventual incapacity. For instance, the chronic progressive neurological population would be an important diagnostic group to focus on.

Because of the great need to facilitate advance care planning for the populations mentioned above, case studies of patients in ambulatory care could be developed and compared to determine what information patients in specific diagnostic groups most need in order to feel prepared to complete advance directives. Another study could explore the family's needs for supporting patient wishes. For instance, the family need additional support to carry out the patient's expressed wishes when they are called on as the surrogate decision-maker.

Institutional barriers continue to be a problem. Rather than specifics of care, studies should focus on the ability of the team to access the right discipline early on to answer patient's questions in a way that will provide knowledge and support regarding future care options.

International, National, and State Perspectives

For the sake of a global outlook on the issue of planning for end-of-life care, it is helpful to refer to interviews of practitioners (physician and social work), conducted during the Augsburg U.S. and U.K. study abroad in health and social welfare. Among the practitioners I interviewed in 1998 in the U.K. and in research articles in the *British Journal of Medicine*, the theme in ACP is discretion of the practitioner, particularly the physician. When the patient and physician are mutually ready for a review of end-of-life care, they discuss it not because of a law mandating such discussion in health care organizations, but because it makes sense. While U.S. practitioners respond to the mandate of the PSDA of 1991, the U.K. practitioners respond to their intuitive discernment. This is much like the older, paternalistic practices. Respondents in Bristol pointed out that America's system seems to be responding to liability issues, threats of lawsuits by citizens known to be a litigious population. They suggest this is a negative and reactionary response to end-of-life care. Safford and Krell (1997) corroborate a practice of treating patients with a poor prognosis in more aggressive fashion than the patient wishes in order to ward off litigation.

International comparisons show advance care planning is likely not to be completed with the assistance of a social worker or sister (nurse). Discussions of end-of-life care, when they occur for purposes of guiding medical care, are more often physician-led, partly because the absence of law means social workers and others need not focus on this particular aspect of patient care. This is a loss, as it influences the culture of health care. One might ask about the advocacy for autonomy in England. Is this solely in the hands of physicians and surgeons? Further study since 1998 indicates British physicians' desires to respond to advance care planning needs via a values history. This philosophy supports the pursuit of overarching goals of patients, as opposed to the specific treatment-goal-oriented approach which is normative according to U.S. literature (Roter et al., 2000). This year, through a visiting physician program here in La Crosse, I was able to revisit the question of discretion with Dr. Carolyn Lucas of the U.K. She theorized that the British practice of discernment often amounted to avoidance of the issue of advance planning for end-of-life care. Social workers may have little leverage for becoming involved in this planning.

In the U.S., states vary in the demands they place on surrogates. In Minnesota, next of kin make decisions for incapacitated family. In Wisconsin, incapacitated patients who have not previously delegated an agent require a guardian appointed by the court, in order for withdrawal or withholding of medical care and placement in community or long-term care. Written to protect patient rights, this law forces many cases into guardianship at the worst time for patients and their family. Thus one optimal time for ACP discussion is early, with an approach that concentrates on values, and with the law as an influencing but not the dominant factor in early discussion and reassurance of patient autonomy. Optimal timing, along with incorporation of surrogate decision-makers, sets the stage for understanding what a loving son or daughter might decide for the patient, sometimes over years of a parent's mental incapacity. Social workers, who are in a pivotal role in the preparation and facilitation required for quality advance care planning, need to continually prepare themselves as experts in recognizing needs. These include facilitating filling in the information vacuum that family members tend to face when they are asked to make decisions about invasive tests and treatments that impact the incapable patients' quality of life. How will a loving son/daughter respond when called upon to make choices for an incapacitated parent? Hopefully, their choices will be guided by compassion, by an advance care plan, and be fully informed via practitioners who are attuned to end-of-life care. Practitioners who attend to the three foci of this study will support decision-makers in their most difficult moments, assuring best practice and the best response.

In the end, autonomy depends on a process, the focusing of attention by practitioners on the expressed preference of the individual they serve.

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ANALYSIS OF HEALTH ORGANIZATIONS ADVANCE DIRECTIVE PRACTICES IN A MIDWESTERN COMMUNITY

ORGANIZATION NAME:

1. Type of organization: (COMPLETE PRIOR TO APPOINTMENT)

   a. Hospital
   b. Long-term care facility
   c. Home health organization
   d. Hospice
   e. Clinic

2. Does your organization have a religious affiliation that influences operating policy?

   a. Yes
   b. No

I am going to ask you a series of questions regarding your usual practices about advance directives and advance directive education. Many of these questions will be about different times in which advance directives may come up for your patients or residents.

*****HOSPITALS ONLY***   OTHER ORGANIZATIONS GO TO Q12, PAGE 3.**

3. During the PRE-ADMISSION PERIOD, are your patients exposed to any education or information on advance directives or end-of-life planning?

a. YES →

b. NO

4. Which of the following are the goals of this encounter? You may have more than one. Are the goals:

   a. to inform patients or residents of their legal rights to limit or refuse medical care and have an advance directive,

   b. to get the patient or resident to complete a legal document,

   c. to educate the person regarding potential future medical decisions,

   d. to help the person discuss their values and goals for future medical care with family and staff,

   e. OR is there some other goal for this encounter at PRE-ADMISSION? → ______________________

   ____

5. Who at your organization is responsible for this education?

   a. RN   b. social worker   c. chaplin   d. physician   e. other → ____________

6. What preparation has this person had? ______________________________ none

7. Who, if anyone, besides the patient or resident is encouraged to be included in this encounter?

   ____

8. What are the treatment options that are typically discussed at this encounter? (DON'T READ ENTIRE LIST, CIRCLE ANY RESPONSES GIVEN.)

   a. CPR   b. tube feeding/ IV hydration   c. intubation/ ventilation   d. hospitalization   e. pain management/ comfort care   f. antibiotic use

   g. quality of life   h. OTHER → ______________________

9. What types of materials do you use at PRE-ADMISSION regarding advance directives and end-of-life decision-making?

   ____

   MAY I HAVE A COPY OF THIS TO TAKE WITH ME?

10. Where does this encounter usually take place?

    a. patient/resident's bedside or room   b. classroom or conference room
    c. social worker's office   d. chaplain's office
    e. other→ ______________________

11. What is the average length of time at PRE-ADMISSION that is spent on advance directives and end-of-life planning? Would you say on average it is:

    a. less than 15 minutes   b. 15-30 minutes   c. 30-60 minutes   d. more than 60 minutes?

12. During ADMISSION, are your patients or residents exposed to any education or information on advance directives or end-of-life planning?

a. YES →

b. NO

13. Which of the following are the goals of this encounter? You may have more than one. Are the goals:

   a. to inform patients or residents of their legal rights to limit or refuse medical care and have an advance directive,

   b. to get the patient or resident to complete a legal document,

   c. to educate the person regarding potential future medical decisions,

   d. to help the person discuss their values and goals for future medical care with family and staff,

   e. OR is there some other goal for this encounter at ADMISSION? → ______________________

____

14. Who at your organization is responsible for this education?

a. RN b. social worker c. chaplin d. physician e. other → ______________

15. What preparation has this person had? ______________________________ none

16. Who, if anyone, besides the patient or resident is encouraged to be included in this encounter?

____

17. What are the treatment options that are typically discussed at this encounter? (DON'T READ ENTIRE LIST, CIRCLE ANY RESPONSES GIVEN.)

a. CPR b. tube feeding/ IV hydration c. intubation/ ventilation d. hospitalization e. pain management/ comfort care f. antibiotic use

g. quality of life h. OTHER → ______________________________

18. What types of materials do you use at ADMISSION regarding advance directives and end-of-life decision-making?

____

MAY I HAVE A COPY OF THIS TO TAKE WITH ME?

19. Where does this encounter usually take place?

   a. patient/resident's bedside or room b. classroom or conference room
   c. social worker's office d. chaplain's office
   e. other→ ______________________________

20. What is the average length of time at ADMISSION that is spent on advance directives and end-of-life planning? Would you say on average it is:

a. less than 15 minutes b. 15-30 minutes c. 30-60 minutes d. more than 60 minutes?

21a. Do you have routine care conferences for your patients or residents?

a. Yes →

21b. How often are these care-conferences held?

____

CONTINUE ON WITH QUESTION 22, NEXT PAGE.

b. No → GO TO QUESTION 31, PAGE 6

22. During ROUTINE CARE CONFERENCES are your patients or residents exposed to any education or information on advance directives or end-of-life planning?

a. YES →

b. NO

23. Which of the following are the goals of this encounter? You may have more than one. Are the goals:

a. to inform patients or residents of their legal rights to limit or refuse medical care and have an advance directive,

b. to get the patient or resident to complete a legal document,

c. to educate the person regarding potential future medical decisions,

d. to help the person discuss their values and goals for future medical care with family and staff,

e. OR is there some other goal for this encounter at this CARE CONFERENCE? → ________________

____

24. Who at your organization is responsible for this education?

a. RN b. social worker c. chaplin d. physician e. other → ________________

25. What preparation has this person had? ____ none

26. Who, if anyone, besides the patient or resident is encouraged to be included in this encounter?

____

27. What are the treatment options that are typically discussed at this encounter? (DON'T READ ENTIRE LIST, CIRCLE ANY RESPONSES GIVEN.)

a. CPR b. tube feeding/ IV hydration c. intubation/ ventilation d. hospitalization e. pain management/ comfort care f. antibiotic use

g. quality of life h. OTHER → ____

28. What types of materials do you use at CARE CONFERENCES regarding advance directives and end-of-life decision-making?

____

MAY I HAVE A COPY OF THIS TO TAKE WITH ME?

29. Where does this encounter usually take place?

a. patient/resident's bedside or room
b. classroom or conference room
c. social worker's office
d. chaplain's office
e. other→ ____

30. What is the average length of time at CARE CONFERENCES that is spent on advance directives and end-of-life planning? Would you say on average it is:

a. less than 15 minutes b. 15-30 minutes c. 30-60 minutes d. more than 60 minutes?

31. When there are significant changes in your patient/residents condition, are they exposed to any education or information on advance directives or end-of-life planning?

a. YES →

b. NO

32. Which of the following are the goals of this encounter? You may have more than one. Are the goals:

a. to inform patients or residents of their legal rights to limit or refuse medical care and have an advance directive,

b. to get the patient or resident to complete a legal document,

c. to educate the person regarding potential future medical decisions,

d. to help the person discuss their values and goals for future medical care with family and staff,

e. OR is there some other goal when your patient or resident's condition is worsening?→ ______

______

33. Who at your organization is responsible for this education?

a. RN b. social worker c. chaplin d. physician e. other → ______

34. What preparation has this person had? ______ none

35. Who, if anyone, besides the patient or resident is encouraged to be included in this encounter?

______

36. What are the treatment options that are typically discussed at this encounter? (DON'T READ ENTIRE LIST, CIRCLE ANY RESPONSES GIVEN.)

a. CPR b. tube feeding/ IV hydration c. intubation/ ventilation d. hospitalization e. pain management/ comfort care f. antibiotic use

g. quality of life h. OTHER → ______

37. What types of materials do you use at this time regarding advance directives and end-of-life decision-making?

______

MAY I HAVE A COPY OF THIS TO TAKE WITH ME?

38. Where does this encounter usually take place?

a. patient/resident's bedside or room b. classroom or conference room
c. social worker's office d. chaplain's office
e. other→ ______

39. What is the average length of time at this encounter that is spent on advance directives and end-of-life planning? Would you say on average it is:

a. less than 15 minutes b. 15-30 minutes c. 30-60 minutes d. more than 60 minutes?

). Are there any other times in which you offer advance directives education and discussions?

a. Yes →

b. No

41. When are those times? ____________________

42. Which of the following are the goals of this encounter? You may have more than one. Are the goals:

- a. to inform patients or residents of their legal rights to limit or refuse medical care and have an advance directive,
- b. to get the patient or resident to complete a legal document,
- c. to educate the person regarding potential future medical decisions,
- d. to help the person discuss their values and goals for future medical care with family and staff,
- e. OR is there some other goal for this encounter? → ____________________

43. Who at your organization is responsible for this education?

a. RN b. social worker c. chaplin d. physician e. other → __________

44. What preparation has this person had? ____________________ none

45. Who, if anyone, besides the patient or resident is encouraged to be included in this encounter?

____

46. What are the treatment options that are typically discussed at this encounter? (DON'T READ ENTIRE LIST, CIRCLE ANY RESPONSES GIVEN.)

a. CPR b. tube feeding/ IV hydration c. intubation/ ventilation d. hospitalization e. pain management/ comfort care f. antibiotic use

g. quality of life h. OTHER → ____________________

47. What types of materials do you use at this time regarding advance directives and end-of-life decision-making?

____

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48. Where does this encounter usually take place?

- a. patient/resident's bedside or room
- b. classroom or conference room
- c. social worker's office
- d. chaplain's office
- e. other→ __________

49. What is the average length of time at this encounter that is spent on advance directives and end-of-life planning? Would you say on average it is:

a. less than 15 minutes b. 15-30 minutes c. 30-60 minutes d. more than 60 minutes?

56. And how about physicians, do you think that this documentation of decisions or preferences are easily identifiable by them?

50. Do you typically try to schedule discussions about advance directives and end-of-life treatment planning when family members or other surrogate decision-makers are available?

a. Yes

b. No

51. Do you have a place in the patient or resident's medical chart that you document information regarding education provided to the person, and their response to this education?

a. Yes →

b. No

52. Where is this documented? Is it:

a. on a form specifically recording exposure to education

MAY I HAVE A COPY OF THIS FORM?

b. in progress notes → Which one? MD RN SW

OR

c. some other place → Where is this? ____________

____

53. Once a decision or preference has been indicated by the patient or resident, is this information documented on a special form for these purposes?

a. Yes → Where is this form kept in the medical record? ____________

____

MAY I HAVE A COPY OF THIS FORM?

b. No Special form → Is this information documented somewhere else? (If so, where?) ____________

____

54. Where in the medical record is a written advance directive such as a Power of Attorney for Health Care or Living Will, kept?

55. Do you think that the documentation of patient or resident's decisions or preferences are easily identifiable by nursing staff?

a. Yes

b. No

Gundersen
Lutheran

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November 26, 1996

Kathy Krage
13 Wall Street
Box 462
Fountain City, WI 54629

Dear Ms. Krage:

This letter is written to formally record the decision by the IRB at Gundersen Lutheran regarding your research project entitled: Analysis of Health Organizations' Advance Directive Practices in a Midwestern Community. This project was reviewed before you began your project and the IRB at Gundersen Lutheran determined that your project was exempt from review.

This decisions was made because your study is of organizational behavior and practice and did not study specific individuals. Also you were conducting a survey that had no risk to those being interviewed, you were not recording or keeping any specific information about individuals and your questions did not seek information that might place the those interviewed at risk for criminal or civil liability or pose a danger to an individual's standing, employability, or reputation.

For all these reasons the Gundersen Lutheran IRB determined your could conduct your research without additional review.

I hope that your project has gone well.

Sincerely,

Bernard J Hammes

Bernard J. Hammes, Ph.D.
Chair, IRB

PRACTITIONER PERSPECTIVES ON END-OF-LIFE PLANNING

KATHERINE M. KRAGE

Submitted in partial fulfillment of
the requirement for the degree of
Master of Social Work

AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

2002