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ADVANCE DIRECTIVE CHOICES AMONG
REGISTERED NURSES IN TENNESSEE: USE
OF JOHNSON'S BEHAVIORAL SYSTEM MODEL

A Thesis
Presented for the
Master of Science
Degree
The University of Tennessee, Knoxville

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DEDICATION

This thesis is dedicated to the two most important people in my life: Parrish Osborn, nanny "extrodinaire", for your enormous amount of love and encouragement, not to mention, patience and expertise in proof reading and editing this manuscript-- even in the wee hours of the morning; and to my daughter, Katherine Morgan, who by your simple existence and unconditional love, have always been my inspiration to continue striving to be more than I am. I was merely reaching for my dreams, but because of you both, I soared to unimaginable heights and held the stars.

In addition, there have been many family and friends who touched my life, leaving me a better, more capable person. They instilled in me the belief that "obstacles are only preparation for future opportunities". It was that philosophy which enabled me to learn from the past while enjoying the present, but still be motivated to work towards a successful future. In the end, it is the pride and recognition of family and friends for which I am eternally grateful.

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Finally, without a bridge between my professional and personal life, these results would not be as gratifying. Special thanks to the Campbell County High School Army Junior Reserve Officer Training Corps of Cadets, along with instructors LTC. Salveson (Ret) and MSgt. Tierney (Ret) for allowing me to become a part of their lives and, in doing so, contribute something of myself to their futures.

Abstract

The Patient Self-Determination Act was introduced to support autonomy through the use of Advance Directives (ADs), in hopes of ensuring people a more compassionate and dignified death, yet use of a living will or healthcare power of attorney remains low, 15-20%. One inherent limiting factor in AD implementation appears to be lack of patient-provider communication, reportedly due to healthcare professionals' discomfort raising such issues. Since nurses are the largest group of healthcare professionals, the future responsibility for initiating AD conversations may likely fall to them.

According to Johnson's Behavioral System Model, nurses use themselves as a primary resource when assisting patients to recognize alternative choices. However, research shows that nurses are not very different from the general population regarding AD implementation. This non-experimental study explored responses of a random sample (N = 131) of Tennessee Registered Nurses (RNs) regarding how their personal CHOICES were related to professional ACTIONS concerning AD implementation. Results from a mailed self-report questionnaire, "Your Views On Advance Directives", indicated that while RNs overwhelmingly support ADs, the majority had not personally implemented one.

Significance related to having implemented ADs were older age, more years of RN experience, implementation of an Estate Will, and past experience withholding a patient's life-sustaining treatment. Significant reasons for lack of discussions with family or physicians concerning end-of-life wishes included: Subject never came up and current state of health did not warrant it. Inconsistencies existed between what the

RNs' believed professional responsibilities should include and what their current activities were regarding counseling, educating, and assisting patients with ADs.

Findings support that nurses' personal CHOICES and ACTIONS are similar to the general population; while professionally, they do not differ much from other healthcare providers. Results highlight several areas for educational interventions aimed at nurses including: Emphasizing mandated nursing responsibilities regarding counseling, educating, and assisting patients with ADs; stressing that ADs are not only for the old and sick; and reinforcing the benefits of discussing end-of-life wishes with family and physicians. By first addressing their own personal CHOICES and ACTIONS concerning ADs, nurses may become effective resources for patients and other health team members.

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Chapter I

Introduction

Advance Directives (ADs) are a result of the Patient Self-determination Act (Omnibus Budget Reconciliation Act of 1990, Public Law 101-508). A common definition for an Advance Directive "... is a written instrument under state law that is executed by a competent adult relating provisions of health care if and when the person becomes incompetent and unable to make decisions" (Barnett & Pierson, 1994, p.58). Society's philosophical struggle to determine who should be in charge of end-of-life choices resulted in this most notable legislative enactment, the Patient Self-determination Act (PSDA), as well as Advance Directives. The PSDA requires that any health care agency or facility receiving reimbursement from Medicare and/or Medicaid must ensure patients are informed of their rights regarding acceptance or refusal of medical treatments (DesRosiers & Navin, 1997). Advance Directives may be issued orally, but to ensure decreased likelihood of future conflicts, they are almost always written (Choo, 1995; Glick, Cowart, & Smith, 1995). Currently, Advance Directives have statutory backing in all 50 states (Tonelli, 1996).

The literature usually discusses Advance Directives as two types, the durable power of attorney for health care and the living will (Lewis, 1998; Mezey, Bottrell, Ramsey, & the NICHE Faculty, 1996). The first type, a durable power of attorney for health care, sometimes referred to as a proxy directive, enables designation of a health care proxy or surrogate decision-maker. It does not list preferences for care. The second type, a living will, is a mechanism by which patients may put in writing their wishes regarding certain treatments that may prolong life.

For the most part, patients and providers agree that Advance Directives are beneficial (Meier et al., 1996; Thayer, 1997). However, despite strong support, Advance Directives are still not broadly used (Choo, 1995; Emanuel & Emanuel, 1998; Meir et al., 1996). The literature documents baseline prevalence of Advance Directives as low as 0-7% (Rubin, Strull, Fialkow, Weiss, & Lo, 1994) and as high as 25% (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; Lewis, 1998). In order to increase use, research has focused on ways to intervene in the Advance Directive process by describing the attitudes and characteristics of those who choose to implement Advance Directives. Yet, the continued low use of Advance Directives, even among those most intimately involved with death and dying, indicates that the answers remain elusive (Thayer, 1997).

Purpose of Study

The purpose of this investigation is to explore the personal and professional CHOICES and ACTIONS regarding Advance Directive implementation among a randomly selected group of Registered Nurses in the state of Tennessee using Johnson's Behavioral Systems Model as a conceptual framework.

Background

There is one irrefutable fact of life: everyone must die. However, the skyrocketing advancements in technology may allow the circumstances surrounding one's death to become negotiable (Haisfield-Wolfe, 1996). Technological advancements, while not entirely bad, do come with some expense. Wise (1997) suggested that with the advancement of various technological tools, such as x-ray, computers, and laboratory tests, diagnosis of disease has become more timely and accurate. This greatly

increases treatment options and patient survivability. Brant (1998) relates that technological advances have made death seem to be nothing more than a mechanized, impersonal failure to be endured along with feelings of pain and loss of control.

The trend has been to regain control of the dying process by reacquainting society with the ideology of death as an extension of life, the final phase of living (Haisfield-Wolfe, 1996). This resulted in a shift in society's feelings concerning end-of-life decisions from submission to omnipotent doctors, to a more general wish for increased personal control (Gordon & Singer, 1995). In death as in life, some people are happy to leave all the choices of living and dying to their family, friends, or physicians. Others are determined to maintain control over all their health care decisions, especially those associated with death. Yet, some providers are slow to relinquish control, fearing that by providing too much information they are actually adding to the patient's discomfort (Markson et al., 1997; Meier et al., 1998). However, increased knowledge and control may actually improve a person's overall well being (Fairchild, 1996; Henderson, 1990). By conveying the words necessary to ensure that death proceeds according to personal values and wishes, Advance Directives have been heralded as the means for individuals to regain or maintain control over decisions related to the circumstances surrounding their deaths (Virmani, Schneiderman, & Kaplan, 1994; Weber, 1995).

Advance Directives are not a recent development. As early as 1969, references were made to the living will as a means to protect one's body (Fox, 1993). Nevertheless, ongoing changes in society, including those associated with technology, healthcare delivery, and attitudes towards end-of-life treatments, have spurred an

evolution of Advance Directives (Wise, 1997).

In the 1970's, society began to focus less on quantity of life and more on the quality of the life that new technology had extended (Wise, 1997). Some technological interventions resulted in what is referred to as a persistent vegetative state, that is, a condition resulting from irreversible brain damage where the individual is unresponsive to their environment. In 1995, Weber reported estimates of as many as 35,000 Americans being maintained in a persistent vegetative state. Furthermore, these individuals could potentially be kept alive indefinitely in a condition obviously lacking quality of life and possibly resulting in increased financial and psychological burdens for the family (Lippman, 1991; Weber, 1995). In 1968, the 22nd World Medical Assembly put forth that "...clinical interest lies not in the state of preservation of isolated cells but in the fate of the person.... The point of death of the different cells and organs is not as important as the certainty that the process has become irreversible..."(Weber, 1995, p.21).

Society's changing regard for the settings in which persons receive health care also influenced the development of Advance Directives. Hospice, home care, transitional units, and residential facilities for the elderly and others incapable of self-care increased. Although people wished to die at home, as many as 80% died alone, without family support, in hospitals and nursing homes (Ross & West, 1995). Hospitals, which were better suited to care for patients in an acute medical crisis, became places where many were left to die (Wise, 1997). Furthermore, hospitals have historically provided health care according to medical rules, which meant the access to, and the quality of care was not always equal. Patients had little knowledge or

control regarding the treatments initiated or withheld. As the public became more informed about health care, demand for more say in the decision-making process increased (Wise, 1997).

In 1972, the National Welfare Rights Organization introduced the Patient Bill of Rights, which was considered to be an important basis for Advance Directives (Wise, 1997). The Patient Bill of Rights set forth that patients had the right of equal access to care, the right to the truth concerning their conditions, required hospitals to get consent before initiating treatments, and gave patients the option to refuse treatments.

In discussions regarding patient's rights, Karen Ann Quinlan and Nancy Cruzan are both familiar names. These two young women were left permanently unconscious, one from a drug overdose and the other from a car accident. Their family and friends were forced to go to court to have life-sustaining treatments stopped. First, the Quinlan case was of such ethical magnitude because it was played out in public domain, making life and death issues more relevant to everyday life (Wise, 1997). Next, the Cruzan case was responsible for influencing a Missouri Senator to draft legislation resulting in the Patient Self-determination Act (Lippman, 1991).

Problem

Even though the statement of the Patient Self-determination Act (PSDA) mandates that facilities receiving federal funds provide information to patients regarding their right to accept or refuse medical treatment upon admission to a hospital or before receiving care, it is not specific as to the manner in which this information is to be conveyed or by whom (Rein et al., 1996). The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) puts forth specific requirements for organizational

responsibility in following through with the PSDA (Dunlap, 1997; Krozek & Scoggins, 1998). According to JCAHO, patients should have control over their care, to include the right to make decisions concerning the care they choose to, or not to receive. In addition, the patient should have an equal say in any end-of-life decisions (Dunlap, 1997). Also, facilities are required to document the process by which these are offered (Galambos, 1998; Haynor, 1998; Krozek & Scoggins, 1998).

Societal wishes for increased control over decisions concerning end-of-life care are virtually assured by legislative backing, yet actions do not indicate that individuals are choosing to take control of those decisions (Johns, 1996). Many people are facing death without exerting their autonomy to make choices regarding Advance Directives. In addition, there appears to be growing frustration and disillusionment with the dying process which has sparked increased interest in Dr. Jack Kevorkian, along with support for physician-assisted suicide (Basile, 1998; Gordon & Singer, 1995; Last Acts, 1998). It is believed that Dr. Kevorkian "...tapped into a seething vein of societal disquiet about medical infringements on personal autonomy... mindless application of life-prolonging technology and the tangled ethical, legal, and professional constraints within which... the healthcare system has done a terrible job of managing death..."(Weber, 1995, p. 18). If health care professionals do not want this to become the only choice patients and families have, more effective strategies to implement Advance Directives must be developed.

Some of the various reasons Advance Directives are not implemented include: procrastination, depending on family members, knowledge deficit, uncomfortable discussing topic, belief that a lawyer is needed, fatalism, fear of signing legal

documents, and fear of not receiving care (Kirmse, 1998, p.85). Another frequently cited reason is that patients are waiting for their health care providers to initiate Advance Directive discussions (Morrison, Morrison, & Glickman, 1994). Feelings are that, when the time is right, the health care provider will bring the topic up. Because of the complex nature of Advance Directives, after discussions take place, implementation usually increases (Gordon & Shade, 1999; Markson, Fanale, Steel, Kern, & Annas, 1994; Reilly et al., 1994), as do reports of patient satisfaction with care (Bradley, Horwitz, Rizzo, & Wetle, 1996). Unfortunately, health care providers are waiting for patients to bring up the topic of Advance Directives (Elpern, Yellen, & Burton, 1993; Hiltunen et al., 1995; Kirmse, 1998; Reilly, et al., 1994). In the end, what too often occurs is that patients are left waiting for discussions that never take place (Hiltunen et al., 1995; Markson, Fanale, Steel, Kern, & Annas, 1994; Morrison, Morrison, & Glickman, 1994; Reilly et al., 1994).

Most physician studies involving professional actions regarding Advance Directive implementation address issues concerning barriers to communication between physicians and patients. Providers list concern for decreasing patient's hope and a lack of time as reasons for not communicating with patients more often about Advance Directives (Johnston, Pfeifer, & McNutt, 1995; Markson, Fanale, Steel, Kern, & Annas, 1994; Morrison, Morrison, & Glickman, 1994). In addition, the health care professional's personal feelings regarding end-of-life decisions may also be a barrier to effective Advance Directive communication (Peacock, 1994; Rein et al., 1996). Some reports go so far as to suggest that many providers are uncomfortable bringing up discussions regarding end-of-life care and Advance Directives. One study (Bus et al,

1998) found that medical students felt unprepared to discuss Advance Directives and listed the following five areas as having a significant relationship to increased feelings of preparedness: adequate exposure, adequate role models, ability to correctly define Advance Directives, number of end-of-life discussions witnessed, and older age (Bus et al., 1998). Yet, another study (Morrison, Morrison, & Glickman, 1994) reported that providers were comfortable and willing to discuss these issues once the patient brought up the topic.

Within Nursing there has been a continued effort to clarify and define the role of the Registered Nurse in end-of-life care (Boyle, 1996; Haisfield-Wolfe, 1996; Hall, 1994; Hiltunen et al., 1995; Leith, 1998; Peacock, 1994; Rank, 1994; Schlenk, 1997; White, 1997). In the past, nurses were expected to defer such life and death issues as Advance Directives to physicians (Haisfield-Wolfe, 1996; Kirmse, 1998; Weiler, Eland, & Buckwalter, 1996). Nurses' involvement was educating or comforting patients and their families. Historically associated with the bedside, nurses have developed a relationship with patients that is conducive to sensitive discussions, such as Advance Directives (Puopolo et al, 1997). It is felt that nurses are in the perfect position for facilitating Advance Directive implementation because they are compassionate and more assertive in holding the patient's right for autonomy as most important (Fairchild, 1996; Haisfield et al., 1994; Hiltunen et al., 1995). Nurses have always been very strong advocates for patients' rights. It seems natural that advocacy include the patients' right to self-determination.

However, nurses are not faring much better in regard to end-of-life care issues. It would seem that a nurse's unique experiences in caring for patients would effect

personal and professional choices regarding Advance Directives, motivating them to action. Yet, research suggests that nurses are not much different than the general public in personal Advance Directive use, nor different from other providers when it comes to Advance Directive actions in their professional roles (Thayer, 1997).

Significance of Study

The significance of this study is to add to Nursing's knowledge base concerning how Registered Nurses' personal and professional choices and actions are related to Advance Directive implementation. Growing numbers and expanded roles signify that the Registered Nurse should prepare to assume the responsibility for Advance Directive discussions with patients. It is agreed that this is a role for which nurses are ideally suited. The American Nurses' Association (ANA), among other professional organizations, has made it clear that nurses are expected, even mandated, to professionally play a primary role in the implementation of Advance Directives (ANA, 1991; Fairchild, 1996; Jarr, Henderson, & Henley, 1998).

Unfortunately, nurses are not leading the way, professionally or personally, in Advance Directive implementation. The Study to Understand Prognosis and Preference of Outcomes and Risks of Treatment (SUPPORT) was a five-year study involving five healthcare centers looking at end-of-life decision-making and communication among providers, patients, and families. (Hiltunen et al., 1995; Puopolo et al., 1997). This study involved more than 9,000 subjects. The study found that, despite having a nurse facilitator to augment staff communication, the end-of-life care that patients received was not significantly affected. Whether this was due to ineffective role implementation or inability to identify activities within the role that

made differences in patient care is unclear. What is clear is that nursing lost an opportunity to further define their role in end-of-life care.

Fairchild's (1996) study to identify factors affecting implementation of Advance Directives reported that patients felt nurses were not only well-suited to assist with Advance Directive discussions but that those nurses who had Advance Directives themselves were considered ideal resources. This further supported Pinch, Miya, Boardman, Andrews, and Barr (1995) who reported that helping staff to write personal Advance Directives may increase their ability to educate and assist patients with their own Advance Directives. Researchers have attempted to identify successful interventions for increasing Advance Directive use, yet few have addressed how the personal characteristics of the Registered Nurse might influence their effectiveness when intervening in the Advance Directive process (Davison & Degner, 1998).

Research Questions

The following are specific questions to be addressed by this study:

1. What are the observable ACTIONS of nurses regarding personal implementation of Advance Directives?
2. Is there a difference in the SET of the nurses who chose to implement an Advance Directive and those who chose not to implement an Advance Directive?
3. Does the nurse's personal CHOICES and ACTIONS regarding implementation of Advance Directives relate to their professional CHOICES and ACTIONS regarding Advance Directives?

Conceptual Framework

Johnson's Behavioral System Model (JBSM) was the guiding framework for this study. JBSM views the behavioral system as being composed of subsystems that interact to maintain balance in the system as a whole (Johnson, 1980). The stable system is characterized by patterned observable behavior. The subsystems are said to share common goals or drives developed by maturation, experience, and learning. Changes in one subsystem will often result in changes within another subsystem. There are seven subsystems identified by Dorothy Johnson (1980). They include affiliative, dependency, ingestive, eliminative, sexual, aggressive, and achievement.

Subsystems have both a structure and function. The structure consists of a goal or drive, set, choice, and action. The subsystem's goals are listed by Grubbs (1974) as:

1. Affiliative Subsystem- to relate or belong to something or someone.
2. Dependency Subsystem- to maintain environmental resources needed for obtaining help, assistance, attention, permission, reassurance, and security.
3. Eliminative Subsystem- to expel biologic wastes.
4. Ingestive Subsystem- to take in resources from the environment to maintain integrity of the organism or to achieve a state of pleasure.
5. Sexual Subsystem- to procreate, to gratify or attract, to fulfill expectations associated with one's sex role or identity.
6. Aggressive/Protective Subsystem- to protect self or others from real or imagined threatening objects, persons, or ideas.
7. Achievement Subsystem- to master or control oneself or one's environment.

(p.171)

Grubbs (1974) further defines the structural component ACTION as the actual observed behavior. CHOICE involves the alternative behaviors one sees at their disposal for action and may be affected by a person's past and present social, psychological, and physical development (Grubbs, 1974). Finally, SET may be defined as one's tendency to act in a certain way. SET may be influenced by the person's social environment and education level (Grubbs, 1974). Variables related to maturation, experience, and learning may be compared to a person's demographic and personal characteristics, which in turn may effect one's SET. The SET plays a part in the CHOICES a person considers, and in their observable behavior as well as the selection of goals (Grubbs, 1974, p.173).

In addition to structure, each of the subsystems has functional requirements that must be met in order to achieve proper development. These may be met internally, by the individual, or externally, with another's help (Johnson, 1980). These functional requirements are to be protected from noxious influences, nurturance through input from the environment, and stimulation to enhance growth and prevent stagnation (Johnson, 1980, p.212). The subsystems are "self-maintaining and self-perpetuating" if internal and external environmental conditions are orderly and predictable and the functional requirements are being met (Johnson, 1980, p.212). If the conditions are not met, behavior may become "disorganized, erratic, and dysfunctional "(Johnson, 1980, p.212).

In the event of an imbalance in the system the nurse is to act as an external regulatory agent for the patient, assisting in maintaining positive behaviors when the patient encounters situations in which they are unable to adapt. Grubbs (1974)

explains that "... using herself as a primary resource,... the nurse mobilizes all other resources in the situation to stimulate and nurture the person to the point of optimal functioning... resocializing the patient and members of his family to take on desired and appropriate roles,... mobilizing coping abilities for actual or potential stresses..."(p.162). The "... lower limit of acceptable behavior that a nurse cannot support is behavior that... exceeds society's limits... or it is behavior which threatens the survival of the individual either biologically or socially..."(Grubbs, 1974, p.162).

When behavioral system imbalance is suspected, it is important to do a thorough assessment to identify where the imbalance originates and which functional requirements are not being met (Grubbs, 1974). According to Johnson (1980), an assessment would most likely include the following:

1. Observable behavior (action)-when does it occur, what stimulates it?
2. Function of the behavior-what are the intended/unintended consequences of the behavior, for what subsystem is the behavior functional, what is the effect of the behavior on other subsystems?
3. Set-what is focused on by the individual in this situation, what need or concern are they aware of, and can they communicate it? What is the usual or preferred behavior?
4. Choice-does the individual use or know of alternative behaviors for this situation, what other choices are available, is the behavioral choice appropriate, how does the individual perceive the appropriateness of the choice?
5. Drive-how often does the behavior occur, what factors inhibit or decrease the desired actual behavior?
6. Sustenal imperatives-what is the source of nurturance, protection, and stimulation for the actual and desired behavior?
7. Variables-what internal/external factors beyond the person's control are positively or negatively affecting behavior?
8. Regulating and control mechanisms-what physiological, sociologic, cultural, or psychologic mechanisms might be operating, as inferred from observed behavioral patterns? (p. 239-240)

The observed behavior or ACTION addressed by this study is that people relinquish control over end-of-life decisions by choosing not to implement Advance Directives. An ACTION identified that effects Advance Directive implementation is the frequency of discussions between health care professionals and patients. The intended consequence of Advance Directive implementation is, in the event of incapacitation, being able to maintain control over end-of-life decisions. Unintended consequences of choosing not to implement Advance Directives are possible exposure to painful and unwanted stimuli or treatments, as well as, prolongation of the dying process.

The CHOICE regarding Advance Directive implementation was a functional behavior for the Achievement Subsystem. The Achievement Subsystem's goal is master or control of oneself or one's environment (Grubbs, 1974, p.171). However, it may also indirectly effect all of the subsystems, most notably the Aggressive/Protective Subsystem. The goal of the Aggressive/Protective Subsystem is to protect self or others from real or imagined threatening objects, persons, or ideas (Grubbs, 1974, p.171). When issues and choices regarding end-of-life decisions arise, patients most often focus on and trust their health care provider for guidance that is relevant and timely. Many patients relate a need to discuss the topic of Advance Directives with their health care provider but are reluctant, or unable, to communicate with them.

The variables in JBSM may most easily be associated with a person's demographic or personal characteristics. These variables include: biologic, developmental, cultural, ecologic, familial, psychologic, sociologic, and level of wellness. The variables are

those factors having the capacity to influence the behavior system, including ACTION, CHOICE, and SET (Grubbs, 1974). Understanding the variables results in knowledge of the source of sustenal imperatives and regulating or control mechanisms influencing behavior. The nurse is able to define the problem as effecting structure or function and to choose the mode accommodating effective interventions.

If, as it has been suggested, personal knowledge and actions regarding Advance Directives will increase the effectiveness of professional CHOICES and ACTIONS (DesRosiers & Navin, 1997; Puopolo et al., 1997; Rank, 1994), it would follow that, investigations must begin by looking at nurses' personal Advance Directive CHOICES and ACTIONS in order to increase their professional effectiveness. When the literature reports that, "...even those nurses most familiar with the conflicts associated with end of life issues do not routinely plan for their own future medical incompetence..."(Thayer, 1997, p.6), it makes one consider the source the patient is being offered and just how effectively nurses may stimulate patients' ACTIONS if they have not, at the very least, considered their own personal CHOICES regarding Advance Directive implementation.

In the past, the usual behavior has been for the patient to leave end-of-life decisions up to the physician, family, or significant other. Too often, geographic or emotional separations within families cause conflicts. Gone are the days when the physician who assisted with your birth is still the same one providing comfort when you die. These changes may create behavioral system imbalance, resulting in a sense of urgency, with people scrambling for ways to attain some measure of control over themselves and their environments.

Summary

When patients perceive a lack of alternative CHOICES, ACTIONS such as physician assisted suicide, may be seen as a way to control end-of-life care. In this way, they may avoid the pain and suffering many fear will accompany their deaths. Due to the legal and moral implications of physician assisted suicide that patients and health care professionals face, the result is an option that Johnson's Behavioral System Model would view as a behavior that threatens the individual physically and psychologically, as well as, one that exceeds society's limits (Johnson, 1980).

Legislation has ensured patients certain rights. Included in these rights is access to a provider who recognizes the need for end-of-life discussions and is comfortable initiating such conversations. An integral part of the nurses' role is to act as an external regulator for an imbalanced behavior system. In using themselves as a source, the nurse assists the patients to identify alternative CHOICES and regain balance in the behavioral system. However, it is important to assess the quality of the "source" being made available to assist patients in order to understand how the Registered Nurse may effectively stimulate patients' ACTIONS regarding Advance Directives.

Chapter II

Review of the Literature

In an attempt to better understand the low rate of implementation, researchers have addressed almost every aspect of the Advance Directive process. Primarily, Advance Directive research has focused on issues surrounding patient and physician use. This research has expanded to include nurses and their involvement in the implementation of Advance Directives. The following is a review of the literature regarding the ACTION, CHOICE, and SET of patients, physicians, and nurses regarding Advance Directives interventions.

Patients

Earlier Advance Directive studies focused on differences in the observable behavior, or ACTION of the patient regarding implementation of Advance Directives (Gross, 1998; Reilly et al., 1994; Rein et al., 1996; Rubin, Strull, Fialkow, Weiss, & Lo, 1994; Stelter, Elliott, & Bruno, 1992; Sulmasy, Song, Marx, & Mitchell, 1996; Teno et al., 1997). Other research included looking at the alternative behaviors patients felt they had available for ACTION, or their CHOICES (Cugliari, Miller, & Sobal, 1995; Elpern, Yellen, & Burton, 1993; Fairchild, 1996; Glick, Balasingam, Dolan, & Casper-Isaac, 1998; Gross, 1998; High, 1993; Palmer, 1995; Sugarman, Weinberger, & Samsa, 1992; Wise, 1997) and the tendency to behave in a particular way, or the SET of those who did and did not implement Advance Directives (Brincivalli, 1995; Emanuel, Barry, Stoeckle, Ettelson, & Emanuel., 1991; Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998; Havens, 1995; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). While understanding the characteristics or

demographics was helpful and established baseline prevalence rates, the results were often mixed and their interventions, mostly educational, did little to effect the overall rates of Advance Directive implementation among patients (Emanuel, Weinberg, Gonin, Hummel, & Emanuel, 1993; Glick, Cowart, & Smith, 1995; Rubin, Strull, Fialkow, Weiss, & Lo, 1994; Teno et al., 1997).

Another focus of research was the actual Advance Directive forms, such as readability, specificity, and even availability (Dunlap, 1997; Hague & Moody, 1993; Haynor, 1998; Lewis, 1998; Ott & Hardie, 1997; Weber, 1995). These areas were thought to have an effect on a patient's tendency to make certain CHOICES regarding Advance Directives. This resulted in such changes as disease specific Advance Directives (Berry & Singer, 1998; Holley, Stackiewicz, Dacko, & Rault, 1997; Lewis, 1998), interactive Advance Directive computer programs (Mercer, Chiriboga, & Sweeney, 1997), as well as improved computer access for a hospitalized patient's completed Advance Directive. While these have been used to enhance patient's decisions and make the Advance Directive process somewhat more user friendly, the overall rate of Advance Directive implementation has been effected very little (Stelter, Elliott, & Bruno, 1992).

Various studies attempted to address the barriers to Advance Directive implementation that patients had identified. One particular study (Stelter, Elliott, & Bruno, 1992) identified these reasons for not implementing Advance Directives: needing help with Advance Directive forms, fear of upsetting family members, or waiting for the physician to initiate the conversation. In the end, the inherent limiting factor in Advance Directive implementation seems to be the patient-physician

discussion. Many patients were willing to discuss Advance Directives once their physicians brought up the topic. At the same time, physicians reportedly were willing to discuss Advance Directives if their patients brought up the topic (Johnston, Pfeifer, & McNutt, 1995; Morrison, Morrison, & Glickman, 1994). Yet, neither readily initiates such discussions and the use of Advance Directives remains low.

Physicians

While research in medicine began by addressing the ethical issues surrounding Advance Directives, the focus has turned to the personal and professional ACTION, CHOICE, and SET of the physician. Research has attempted to identify physician attitudes and opinions regarding Advance Directive implementation (Haisfield et al., 1994; Layson et al., 1994; Markson et al., 1997), as well as address such issues as why physicians tend to make specific CHOICES (Gillick, Hesse, & Mazzapica, 1993; Johnston, Pfeifer, & McNutt, 1995; Reilly et al., 1994). For instance, once it was identified that patients were waiting for their physicians to initiate Advance Directive conversations, it became important to understand why physicians chose to have infrequent discussions with their patients regarding Advance Directives (Johnston, Pfeifer, & McNutt, 1995; Morrison, Morrison, & Glickman, 1994). A study by Haisfeld, et al. (1994) identified several barriers to provider and patient discussions about end-of-life issues and Advance Directives. Lack of time with patients, no reimbursement for services, unfamiliarity with the patient, and age or severity of illness are ones common to many health care settings. However, one barrier listed was unusual in that physicians reported discomfort when discussing Advance Directives.

Markson et al., (1997) addressed the personal ACTIONS of physicians regarding

Advance Directive implementation. The study involved 653 Veteran Administration physicians who responded to a mailed survey assessing their opinions and attitudes regarding Advance Directive implementation. In the sample, 27% had either completed a personal Advance Directive or discussed the issue with their physician. However, it was not specific as to the number who had actually implemented a personal Advance Directive versus those that had discussed the matter with their physicians. Seventy-two percent of the sample said they had discussed these issues with their families. Inconsistencies were reported between the physician's personal beliefs and professional behaviors concerning Advance Directive discussions. In their (Markson et al., 1997) study, 89% believed it was the physician's responsibility to initiate advance preference discussions, but 59% reported they actually initiated such discussions.

Nurses

Nurses are expected to be assertive in discussing issues concerning end-of-life care with their patients, including Advance Directives (DesRosiers, & Navin, 1997; Jarr, Henderson, & Henley, 1998). In fact, considering that Johnson's Behavioral System Model expects nurses to be informed and comfortable enough with the topic of Advance Directives that they may use themselves as resources when assisting patients, it would seem that this would be an area highly investigated or documented. In fact, the scarcity of studies addressing the ways in which nurses' personal ACTION, CHOICE, and SET impact their professional practice is the reason for this current study.

Through the years, nurses, dealing with patients in one capacity or another, have managed to remain a constant figure in an otherwise continuously changing health care environment. While early nursing research on Advance Directives focused on ethical issues or explored nurses' attitudes and knowledge (Gillick, Hesse, & Mazzapica, 1993; Hiltunen et al., 1995; Weiler, Eland, & Buckwalter, 1996), more recent studies address the nurses' roles in Advance Directive implementation (Boyle, 1996; Haisfield-Wolfe, 1996; Hall, 1994; Hiltunen et al., 1995; Leith, 1998; Peacock, 1994; Rank, 1994; Schlenk, 1997; White, 1997). Even though the role of the nurse has become more specialized and autonomous, nurses are still described by patients as being "well-qualified, sensitive, and appropriate facilitators" regarding Advance Directive discussions (Peacock, 1994, p.58). In fact, several studies looking at patient preferences identified the nurse as someone with whom patients are comfortable discussing Advance Directive issues (Fairchild, 1996; Haisfield et al, 1994; Hiltunen et al., 1995; Johnston, Pfeifer, & McNutt, 1995). Yet, nurses have not been as supportive as patients would have them be. A study by Rank (1994) attempting to evaluate the effectiveness of various methods used to disseminate information and explanations about Advance Directives to a group of hospitalized patients (N=46) found that nurses' discomfort in discussing Advance Directives may be reflected in their behavior, which in turn, further influences patients' attitudes and behaviors regarding Advance Directives.

Molloy et al. (1997) examined Canadian home care nurses' professional ACTIONS and CHOICES regarding Advance Directive implementation with their patients.

Researchers provided a one day seminar for home health providers that included both

a lecture and group work on Advance Directives. Molloy postulated that proper knowledge would increase the nurses' motivation for approaching patients to discuss Advance Directives. The study involved nurses from two regions who were to approach their patients with information about Advance Directives. The nurses reported that 70% of the patients that were approached implemented an Advance Directive. In their study, the nurses identified lack of time as a main barrier to communication with patients. However, the authors reported that one region had an unexplained higher Advance Directive implementation rate, and they speculated that possibly it was due to a difference in attitudes between the nurses. In addition, the authors thought it possible that certain nurses showed more enthusiasm or were more convincing concerning the project. Although the personal Advance Directive use of the nurses was not reported, the authors concluded it would be more effective to have designated nurses responsible for Advance Directive discussions with patients.

Boyle's (1996) study described Nurse Practitioner's (NP) professional ACTIONS regarding Advance Directives. Surveys were mailed to a random sample of 600 California nurses to assess in what manner they discussed Advance Directives with their patients. The survey return rate was 49% (n = 297). The authors reported that 58% discussed Advance Directives with patients once a month and 24% said they discussed Advance Directives one to five times a month. There seemed to be high involvement by the nurses, however, it was unclear what amount of interaction was considered a discussion. This study did not report nurses' personal Advance Directive use.

When addressing the personal ACTIONS of nurses regarding Advance Directive implementation, Fox (1993) reported that 62% of their sample (n=87) intended to implement an Advance Directive and 18% had already implemented one. The majority of the sample was described as being over age 31, well educated, female, working in critical care or medical surgical units, and having a low knowledge regarding Advance Directives. The authors questioned whether or not nurses' dealings with patients concerning Advance Directives would be influenced by the nurses' Advance Directive knowledge and perceptions and, if the effectiveness of those dealings could alter the benefits patients' associated with Advance Directives.

The characteristics of both nurses and physicians who had living wills were studied by Anderson, Walker, Pierce, & Mills (1986). Their sample consisted of 185 nurses and 85 physicians. According to the results, 20% of the nurses and physicians had implemented a living will or "something similar" (p.275). This included respondents who stated that they had not signed a living will but had made similar arrangements. By "similar arrangements", four nurses and three physicians stated they had "signed agreements" (p.275). In addition, 26 nurses and seven physicians stated they had "verbal agreements with family or friends" (p.275). Only 6.5% (n=12) of the nurses and 7% (n=6) of the physicians answered that they had actually signed a living will.

In another study (Stechmiller, Conlon, & Anderson, 1991), the author analyzed Anderson, Walker, Pierce, and Mills' (1986) data for variables believed to be predictive of personal ACTIONS regarding implementation of living wills. The results identified three variables: Religion (agnostic versus atheist), length of exposure or experience with terminally ill, and the nature of the relationship with the terminally

ill person (personal versus professional). It was concluded that nurses and physicians exposed to the suffering of friends or family, which had been brought on by the absence of a living will, might choose to protect themselves from a similar experience.

Leith (1998) surveyed nurses at the Canadian Critical Nurses' Association National Conference to explore their personal and professional ACTIONS as well as their experience, knowledge, and opinions related to Advance Directives. The findings indicated that the majority (80%) of nurses had cared for a person with an Advance Directive and that the majority (89%) were in favor of Advance Directives. In addition, nurses reported their personal Advance Directive implementation rate as 26%. The sample was 94% critical care nurses with an average age of 37 and average years of intensive care experience of 12.

Thayer (1997) tested the effectiveness of educational interventions to increase discussions and implementation of Advance Directives. It was hypothesized that by exposing nurses and nursing students to the issues around Advance Directives, advance care planning would be more likely to occur, both personally and professionally. The sample (n = 293) included 102 nurses and 191 nursing students. Only a minority of the sample had been involved previously in decisions to withhold life support from patients. Of the nurses, 30% had been involved in decisions regarding withholding life support from family or significant others compared to less than 20% of the nursing students. Most of the sample, 96%, agreed that it was beneficial for patients, as well as the nurses/nursing students themselves to implement Advance Directives (n = 281). Yet, only 7.2% of the nurses and 7.6% of the nursing students had actually completed a personal Advance Directive. Among the reasons

cited for not completing an Advance Directive, the majority (59% & 57% respectively) of the sample had either not thought of it or simply put the task off. Furthermore, only 6.2% had discussed Advance Directives with their own provider. Among the reasons for not having discussions with their providers were: the physician did not bring it up (78%), current state of health (74%), and did not think of it (58%).

Two research questions were examined by Thayer (1997). The results for the first hypothesis showed that the willingness of the nurses and nursing students to counsel, educate, and assist patients in Advance Directives increased after being given a chance to practice Advance Directive implementation, but it was not a statistically significant increase. The second hypothesis, that the second group of nurses and nursing students would complete more Advance Directives post intervention, was not supported. Post intervention, 18% completed a living will and 17% completed a designated proxy, but there was no increase in discussion of these issues between the nurses and nursing students' families or physicians.

At the same time, it has been suggested that when nurses are provided Advance Directive education as part of structured classes or orientation, they report being more prepared to deal with such issues. This, combined with Rank's findings, suggests support for the belief that the experience of implementing one's personal Advance Directive, or considering the available choices for end-of-life care, would likely impact the Registered Nurse's capacity to stimulate and nurture the patient's ability to identify Advance Directive choices (DesRosiers & Navin, 1997).

Summary

The literature contains many reports supporting and acknowledging Advance Directives as beneficial. At the same time, implementation remains low. One of the reasons cited by patients for not implementing Advance Directives is that they are waiting for the health care professional to initiate discussions about end-of-life issues. However, health care professionals are uncomfortable raising these issues with patients and, communication regarding Advance Directives is infrequent, at best. The nurses' discomfort with Advance Directive discussions may be reflected in their behavior, further influencing patient's attitudes. The literature supports that the ACTION of implementing one's personal Advance Directive, or considering the available CHOICES for end-of-life care, will likely impact the Registered Nurse's capacity to stimulate and nurture the patient in identifying alternative CHOICES.

Chapter III

Methodology

This study explored the personal ACTION, CHOICE, and SET of Registered Nurses regarding Advance Directives and how those may have impacted on their professional ACTIONS as external regulatory agents in stimulating patients to identify alternative behaviors or CHOICES regarding Advance Directives. Registered Nurses were selected as the sample for this study due to their unique role in patient care and because they have been mandated by the American Nurses' Association and the Joint Commission on Accreditation of Healthcare Organizations to actively assist patients in making end-of-life decisions, including Advance Directives (Jarr, Henderson, & Henley, 1998; Krozek & Scoggins, 1998). In addition, patients have expressed their willingness to discuss Advance Directives with nurses.

Design

This cross sectional non-experimental study examined responses to a revised self-administered questionnaire, Your Views on Advance Directives (see Appendix A). Permission to distribute this instrument for responses by this investigator was obtained (see Appendix B).

Sample

After receiving Internal Review Board (IRB) approval using Form A (see Appendix C), a letter was sent to the Tennessee Department of Health Statistics requesting names and addresses of 400 state licensed Registered Nurses (see Appendix D). The Department of Health Statistics' computer system randomly selected the 400 Registered Nurses based on the following inclusion criteria: An active license to

practice as a Registered Nurse in the state of Tennessee (TN) and currently residing within the state of TN. The accessible population included all licensed Registered Nurses in the state of TN, which is currently estimated to be 50,000. Of those, approximately 46,000 (92%) are Caucasian, 3360 (6.8%) African American, 250 (0.5%) other racial/ethnic minority background, and 388 (0.8%) unknown (personal telephone conversation with Alice Jackson, TN Department of Health Statistics, January 20, 1999). The resulting sample reflected the target population.

According to Polit and Hungler (1995), χ^2 analysis using alpha level 0.05, effect size 0.3, and power 0.8 requires a sample size of at least 88 with a minimum of 30 in each group with and without Advance Directives. The response rate for mailed surveys is usually about 25%. With an expected response rate of 25%, and so that a reminder mailing would not be necessary, 400 surveys were mailed in order to receive the minimum of 88 responses.

Instrument

The instrument used for this study was a revision of Your Views on Advance Directives (Thayer, 1997). The questionnaire, Your Views on Advance Directives, was originally designed for assessing:

- (a) self-reported involvement of the respondents in facilitating advance care planning with patients,
- (b) any advance care planning the respondents might have undertaken for themselves,
- (c) and included questions about selected personal characteristics that had been found in the literature to be related to completion or non-completion of Advance Directives. (Thayer, 1997, p.73)

The instrument was developed as part of an educational program designed by the Greater Miami Chapter of the American Association of Critical Care Nurses (GMAC AACCN) for local chapter members. It was based on the literature and on the concepts of individual autonomy. Content validity for this initial instrument, which used a Yes/No format with open-ended questions, was established through 100% agreement by four nursing experts (three clinical nurse specialists and one nurse educator) who were at that time practicing nurses at four large community hospitals in the Miami area. Three of the nurses were also members of their hospital ethics committees. The instrument was used in a program in Advance Directives for Critical Care Nurses presented by the GMAC AACN group to 23 members of the local AACN chapter.

The instrument was then revised based on the results of its first use and on the following studies: Emanuel et al. (1993); Emanuel et al. (1991); Garrett, Harris, Norburn, Patrick, & Danis (1993); Rubin, Strull, Fialkow, Weiss, & Lo (1994); Sachs, Stocking, & Mills (1992); Silverman, Tuma, Schaeffer, & Singh (1995); and Stelter, Elliott, & Bruno (1992). In the author's original revision Yes/No questions were used, but for a majority of responses a 5-point Likert Scale was used to increase variability. Further validity was demonstrated with the new instrument in three areas: medical ethics relating to advance directives, management of patients experiencing end-of-life issues, and nursing practice. There was 97% agreement from seven experts, including: A nurse attorney; two nurses and a physician who were members of an ethics committee in a large, federal medical center; a medical attorney chairing the ethics committee of a large county medical center; a social worker/lawyer chairing the ethics

committee of a federal medical center; and a doctoral-prepared clinical nurse specialist.

The instrument contains three sections. The first section is concerned with demographic and personal characteristics, including: Age, marital status, gender, ethnicity, religious conviction, education, living arrangements, clinical specialty, state of health, and completion of Estate Will. The second section of the instrument is entitled Advance Directives and Your Patients. There are five items in this section, two that are answered with Yes/No responses, three answered with a 5-point Likert Scale (SA to SD). The third section, entitled Advance Directives and You consist of six questions: three questions are answered Yes/No; two questions have both Yes/No and a 5-point Likert Scale (SA to SD); and one question has only a 5-point Likert Scale (SA to SD).

Data Collection

Form A was used for Institutional Review Board approval from the University of Tennessee, Knoxville, College of Nursing. The sample was randomly selected by the computer system at the Tennessee Department of Health Statistics. It is believed that the potential for risks, stress, or discomfort from participating in this study was minimal. No part of the study involved invasive interventions. All respondents were greater than age 18 years (the minimum age granted a Registered Nurse license). The random sample was reflective of the target population of licensed Registered Nurses in the state of Tennessee with respect to race. Because the data was not readily available from the Tennessee Department of Health Statistics for nurses' gender, the sample was compared to data from the National League for Nurses (1997) and found to be similar.

The information sheet included with the questionnaire contained the study purpose and a point of contact at the University of Tennessee, Knoxville, for questions (see Appendix C). The voluntary nature of the study was explained and subjects informed that return of the questionnaire constituted willingness to participate and thus, consent.

A packet was mailed to the 400 Registered Nurses. Each packet contained a cover sheet explaining the study, the revised questionnaire, Your Views On Advance Directives, and a postage paid envelope for returning the completed questionnaire.

The returned questionnaires were coded #1-131. The code numbers were used to keep track of questionnaires and to assist in providing for confidentiality when entering the data into the computer for analysis, as well as when reporting the data. The names and addresses were received on address labels so no master list was retained.

Data Analysis

Data from the returned questionnaires was coded and entered into the password-protected University of Tennessee, Knoxville, computer account of this investigator. Measures of central tendency were used to identify sample characteristics. To answer question one, descriptive statistics were used to identify the observable ACTIONS of Registered Nurses regarding Advance Directives. For question two, chi-square and t-test were used to ascertain whether there was a difference between those Registered Nurses choosing to, or not to, implement an Advance Directive. Chi-square analysis was used to answer question three to determine whether Registered Nurses' professional CHOICES and ACTIONS are affected by their personal CHOICES regarding Advance Directives. An alpha level of .05 was selected as the level of significance. SPSS PC version 8.0 was used to conduct the analysis.

Chapter IV

Results

This random sample of Registered Nurses ($N = 131$) represented a 33% response rate. The majority of respondents were Caucasian females (see Table 1), which is characteristically representative of the population of Registered Nurses currently licensed in the state of Tennessee. The mean age was 41 years ($SD = 9$ years) and ranged from 23 to 65 years. Most of the respondents were married or in a committed relationship and lived with someone else. The most common religion chosen was Protestant. The current state of health was assessed by a majority of the sample as good.

The range for years of experience as a Registered Nurse was a minimum of one year and a maximum of 37 years (mean = 15 years, $SD = 9$ years). Among the respondents, the majority held an Associate Degree and were working full time, with their primary position being Staff Nurse. Many of the respondents checked multiple areas for clinical specialty, with Medical/Surgical the most common (see Table 2). The practice settings were varied, but most respondents worked in a hospital or medical center. Finally, the majority of the respondents had not completed an Estate Will.

Research Question One

The observable (reported) ACTION of Registered Nurses indicated that only 31% had implemented an Advance Directive. Of those with Advance Directives, 70 % had implemented both a living will and a designation of a health care surrogate/proxy, 15% had implemented only a living will, and 15% had only a designation of a proxy.

Table 1.
Personal Information (SET)

Characteristic	N	%
Gender		
Male	9	6.9
Female	122	93.1
Marital/Relationship Status		
Divorced/Separated	19	14.5
Married/Committed Relationship	101	77.1
Single	9	6.9
Widowed	2	1.5
Living Arrangements		
Alone	23	17.6
With Someone Else	100	76.3
Race-Ethnic Origin		
Caucasian	124	94.7
African American	7	5.3
Religion		
Catholic	14	10.7
Protestant	105	80.2
Non-Denomination/Christian	4	3.1
None	6	4.6
Personal Assessment of Health		
Excellent	56	42.7
Good	70	53.5
Fair	5	3.8
Completion of Estate Will		
Yes	57	43.5
No	72	55.0

Note. N = 131; some total percentages do not equal 100 due to missing data.

Table 1. (continued)

Personal Information (SET)

Nursing Degree and Employment Characteristics	N	%
Employment Status		
Full time	102	77.9
Part time	21	16.0
None/Unemployed	7	5.3
Highest Nursing Degree		
Diploma	20	15.3
Associate Degree	48	36.6
BSN	41	31.3
MSN	21	16.0
Primary Position Held		
Staff Nurse	68	51.9
APN	14	10.7
Nurse Manager	14	10.7
UR/UM/CQI/JCAHO Coord./etc.	9	6.9
Nurse Administrator	7	5.3
Unemployed/Retired	5	3.8
Other:	9	6.9

Inservice/Staff Development, Academic Faculty,
 Physician's Assistant, Community/Home Health,
 Family Practice Office, FNP Student, Pharmacist,
 Coord. Health Management Program, Dental Office Staff,

Note. N = 131; some total percentages do not equal 100 due to missing data.

Table 2.
Clinical Specialty and Practice Setting of Sample

Characteristic	N
Clinical Specialty	
Med/Surg	39
Critical Care	28
Peds/Neonatal	20
Gerontology	15
Community/Home Health/Public Health/Parish Nursing	13
ER/Trauma	12
Psychiatric	10
OB/L&D/Women's & Maternal/Child Health	10
Anesthesia/Surgery/PACU/Preop/Procedures	9
Ambulatory	8
UR/UM/JCAHO Coord/Case Manager/Workman's Comp	4
Nephrology/Dialysis	4
Administration	2
Oncology	2
Other:	11
Cardiology/Cardiac Rehab/Telemetry	
Plastic Surgery, Neurology, Orthopedics,	
Rehab, Family, Family Practice, Retail	
Practice Setting	
Hospital/Medical Center	78
Home Care	12
MD Office/Clinic	10
UR/CQI/HOM/Managed Care/Case Management	8
Unemployed/Retired	7
Public Health	5
Other:	6
Skilled Nursing Facility, Outpatient Surgery,	
Nursing School, Corporate Office	

Note. Clinical Specialty N equals greater than 131 due to multiple responses.

Note. Practice Setting N does not equal 131 due to missing data.

Research Question Two

Chi-Square and t-tests were used to explore the SET of Registered Nurses who had chosen to, or not to, implement an Advance Directive as evidenced by their observable ACTIONS. Significance was noted in the observable ACTIONS of the Registered Nurses regarding implementation of Advance Directives and their SET in the following areas: Estate Will, primary position, and past experience with Advance Directive decisions (see Table 3). Of those with Advance Directives, 80% had also completed an Estate Will. For primary position, the completion rates for Advance Directives among the five groups analyzed were: Staff Nurses 18%, Nurse Administrators/VP 29%, Nurse Managers 50%, APNs 57% and UR/UM/CQI 44%. Only those primary position categories with five or more responses were analyzed by χ^2 . Concerning past experience with Advance Directive decisions, 65% of Registered Nurses had been involved in a decision to withhold or withdraw life-sustaining therapy from a patient under their care. Of those, 39% had implemented an Advance Directive.

The t-test analysis showed a difference in observable ACTIONS regarding Advance Directive implementation with age and years of RN experience (see Table 4). Of those with Advance Directives, 50% were over age 45 and 90% were over age 35. In regard to years of RN experience, 50% had greater than 17 years experience and 90% had greater than 7 years experience.

Table 3.
Analysis of Personal ACTIONS and SET

Characteristic (N = 131)	Chi-Sq	df	p value
Advance Directive and (Set)			
Gender	0.019	1	0.891
Marital Relationship	4.644	3	0.200
Living Arrangements	0.021	1	0.884
Race-Ethnic Origin	3.369	1	0.066
Religion	5.172	3	0.160
Personal Assessment of Health	2.841	2	0.242
Highest Nursing Degree Held	3.674	3	0.299
Employment Status	0.145	2	0.930
Primary Position Held	20.413 *	7	0.005
Clinical Specialty	3.192	7	0.790
Current Practice Setting	8.281	6	0.218
Estate Will	34.510 *	1	0.000
Been involved in decision to withhold/withdraw therapy from:			
Patient	6.036 *	1	0.014
Family/friend	1.532	1	0.216

* p < .05, 2-tailed

Table 4.
Differences in Age and Years of RN Experience for Those W/Without ADs

Age/Years	t
AGE	3.404 *
YEARS OF RN EXPERIENCE	2.804 *

* p < .05, 2-tailed

Research Question Three

Chi-square analysis was used to ascertain whether a relationship existed between the Registered Nurse's personal CHOICE and ACTION regarding Advance Directive implementation and their professional CHOICES and ACTIONS. The Registered Nurse's personal CHOICE was represented by the response to: Generally a good idea for nurses to complete an Advance Directive, and their personal ACTION by the response to: Have completed an Advance Directive. The professional CHOICES were represented by the responses to: Generally a good idea for patients to complete Advance Directives and As part of their professional responsibilities the Registered Nurse should be involved in counseling, educating, or assisting patients with Advance Directives. The reasons given by the Registered Nurse for not being involved in those Advance Directive responsibilities was considered a professional CHOICE. The professional ACTION was assessed by the Registered Nurse's response to: Currently, I am counseling, educating, or assisting patients in regards to Advance Directives.

Table 5 compares professional CHOICE and ACTION questions (SA-SD) to the personal CHOICE and ACTION of the respondents regarding Advance Directive implementation (Yes/No). Due to the small number of responses in some categories, the Likert Scale was collapsed into three categories for analysis. The responses were SA/A, U, and D/SD. Results of the analysis yielded significance among the areas: Generally good for nurses to complete Advance Directives and Generally good for patients to complete Advance Directives (see Table 6). Analysis of the personal CHOICES or reasons given by Registered Nurses for their personal ACTION, not completing an Advance Directive, showed no significance (see Table 7).

Table 5.

Personal and Professional CHOICES and ACTIONS (N = 131)

		PERSONAL CHOICE		PERSONAL ACTION	
		It is generally a good idea for nurses to complete ADs		Have you completed an AD document (LW or POA for HC	
		YES	NO	YES	NO
PROFESSIONAL CHOICE					
It is generally a good idea for patients to complete an AD	SA / A	118	9	41	87
	U	1	1	0	2
	D / SD	0	0	0	0
Nurses SHOULD:					
Counsel patients about ADs	SA / A	99	6	36	70
	U	7	1	1	7
	D / SD	11	5	3	11
Educate patients about ADs	SA / A	106	9	37	79
	U	7	0	1	6
	D / SD	6	1	2	5
Assist patients to complete AD forms	SA / A	54	4	18	41
	U	21	3	6	18
	D / SD	43	3	16	30
PROFESSIONAL ACTION					
Currently, I					
Counsel patients about ADs	YES	42	71	17	22
	NO	4	5	30	54
Educate patients about ADs	YES	57	57	21	18
	NO	4	5	41	44
Assist completing AD forms	YES	13	100	7	33
	NO	3	7	10	74

Table 6.
 Analysis of Personal and Professional CHOICES and ACTIONS (N=131)

	Chi-Sq	df	p value
PERSONAL CHOICES:			
Generally a good idea for nurses to complete an AD			
AND			
Generally a good idea for patients to complete ADs	5.070 *	1	0.024
Nurses Should			
Counsel patients	4.457	2	0.108
Educate patients	1.007	2	0.604
Assist w/ AD forms	0.906	2	0.636
Currently, I			
Counsel patients	0.188	1	0.665
Educate patients	0.103	1	0.748
Assist w/AD forms	2.777	1	0.096
PERSONAL ACTIONS:			
Have you completed an AD			
AND			
Generally a good idea for patients to complete ADs	0.936	1	0.333
Nurses Should			
Counsel patients	2.301	2	0.317
Educate patients	0.978	2	0.613
Assist w/ AD forms	0.718	2	0.698
Currently, I			
Counsel patients	0.700	1	0.403
Educate patients	0.337	1	0.562
Assist w/ AD forms	0.717	1	0.397

* p < .05, 2-tailed

Table 7.

Personal CHOICES Related to Personal ACTION for No Completed AD (N=90)

		N	Chi-Sq	df	p value
Not completed AD because:					
Difficulty	SA / A	9	0.665	2	0.717
obtaining correct	U	5			
documents	D / SD	63			
Not certain which documents to choose					
	SA / A	14	2.694	2	0.26
	U	8			
	D / SD	56			
Unable to choose appropriate surrogate					
	SA / A	10	0.769	2	0.681
	U	8			
	D / SD	60			
Been putting it off/procrastinating					
	SA / A	69	0.333	2	0.847
	U	5			
	D / SD	15			
Too upsetting to do					
	SA / A	5	3.138	2	0.208
	U	11			
	D / SD	62			
Difficult decision to make					
	SA / A	28	0.331	2	0.848
	U	2			
	D / SD	50			
Relying on others to make decisions					
	SA / A	22	4.921	2	0.085
	U	10			
	D / SD	52			
Too young/seems more relevant to sick or old					
	SA / A	20	0.818	2	0.664
	U	2			
	D / SD	61			
Have not thought about it					
	SA / A	18	0.159	2	0.924
	U	2			
	D / SD	61			

Note. All nonsignificant at $p = .05$

Among those Registered Nurses not completing an Advance Directive, significance was related to personal ACTIONS regarding discussions about wishes for medical treatments with family (see Table 8) and physicians (see Table 9). The majority of Registered Nurses reported that they had discussed their wishes for medical treatments with their family, significant other, or close friend. Of those who had not held such discussions, the most significant reasons given were: The subject never came up, Current state of health does not seem to warrant the discussion, and Too young. At the same time, 7% of the Registered Nurses had participated in similar discussions concerning their wishes with their physicians. The most significant reason given for the lack of such discussions was: Current state of health does not seem to warrant a discussion. Significance was noted as associations for: As part of professional responsibilities, nurses should counsel, educate, and assist and Been involved in decision to withhold/withdraw therapy from patient ($\chi^2=0.004$, $df=2$, $N=129$). Finally, there was significance reflecting association of Current practice setting, and Not involved in Advance Directive discussions because it is Not in my job description ($\chi^2=0.034$, $df=12$, $N=99$).

Summary

This chapter included results of an analysis of the professional and personal CHOICES and ACTIONS of a random sample of 131 Registered Nurses. Using frequencies, χ^2 , and t -tests, the sample was described in terms of their characteristics and their responses to questions about professional and personal experiences with Advance Directives.

Table 8.

Personal ACTION and CHOICES Related To Discussion With Family/Friend

		N	Chi-sq	df
PERSONAL ACTION				
Discussed with family or friend	Yes	95		
	No	13		
PERSONAL CHOICES				
NOT discussed because:				
Subject never came up	SA / A	12	11.377 **	1
	U	0		
	D / SD	7		
Health does not warrant it	SA / A	11	12.058 **	1
	U	0		
	D / SD	8		
Too young	SA / A	6	6.491 *	2
	U	1		
	D / SD	10		
Never thought about it	SA / A	4	4.364	2
	U	1		
	D / SD	11		
Don't know	SA / A	1	1.538	2
	U	1		
	D / SD	13		

* $p < .05$, 2-tailed** $p < .01$, 2-tailed

Table 9.
 Personal ACTION and CHOICES Related to Discussion With Physicians

		N	Chi-sq	df
PERSONAL ACTION				
Discussed with physician	Yes	9		
	No	97		
PERSONAL CHOICES				
NOT discussed because:				
Physician did not bring it up	SA / A	53	4.827	2
	U	4		
	D / SD	13		
Do not have a Primary Care physician	SA / A	17	0.747	2
	U	3		
	D / SD	55		
Physician seemed busy	SA / A	14	0.663	2
	U	9		
	D / SD	45		
Health does not warrant it	SA / A	67	5.923 *	2
	U	6		
	D / SD	14		
Too young	SA / A	17	1.099	2
	U	7		
	D / SD	45		
Never thought about it	SA / A	29	1.836	2
	U	4		
	D / SD	37		
Don't know	SA / A	18	4.983	2
	U	9		
	D / SD	26		

* $p < .05$, 2-tailed

Overall, the following areas revealed significance related to completion of Advance Directives: Older age, greater number of years of experience as a Registered Nurse, completion of an Estate Will, and primary position being Staff Nurse. There was also significance between: Generally a good idea for nurses to complete Advance Directives and Generally a good idea for patients to complete Advance Directives. Finally, the reasons why discussions about future wishes for medical treatments did not occur with family or physicians was found to be significant.

Chapter V

Discussion and Implications

The purpose of this study was to explore the personal and professional CHOICES and ACTIONS regarding Advance Directive implementation among a randomly selected group of Registered Nurses in the state of Tennessee using Johnson's Behavioral System Model (JBSM) as a conceptual framework. Research to discover ways of increasing Advance Directive implementation has rarely focused on those most closely associated with patients, the Registered Nurses. Yet, it is believed that nurses who have experience with Advance Directives, especially their own, are much better resources for addressing such issues with patients (Fairchild, 1996; Pinch, 1995). Registered Nurses are responsible for counseling, educating, and assisting patients with Advance Directive issues, yet research that addresses how the Registered Nurse's personal and professional CHOICES and ACTIONS may be interrelated or effected by their SET, is scarce.

According to JBSM "...all the patterned, repetitive, and purposeful ways of behaving that characterize each man's life are considered to comprise his behavioral system "(Johnson, 1980, p.209). The behavioral system is made up of seven subsystems, which themselves have a structure and function. The subsystem's structure consists of a goal or drive, ACTION, CHOICE, and SET. ACTION is defined as actual observed behavior. CHOICE involves the alternative behaviors one sees at their disposal for action and may be affected by a person's past and present social, psychological, and physical development (Grubbs, 1974). SET, or the tendency for one to act in a certain way, may be influenced "through maturation,

experience, and learning...(Johnson, 1980, p.211)". Maturation, experience, and learning are variables that may compare to an individual's personal or demographic characteristics. Finally, SET plays a part in the CHOICES a person "considers" and in their observable behavior (Grubbs, 1974, p.173).

Action

Findings of this study concerning the Registered Nurses' personal ACTIONS of Advance Directive implementation were 31%, slightly higher than reported in the literature. The ACTION of implementation of an Advance Directive within the general population is estimated at 7-25% (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; Lewis, 1998; Rubin, Strull, Fialkow, Weiss, & Lo, 1994). Among physicians, 7-27% have implemented Advance Directives (Anderson, Walker, Pierce, & Mills, 1986; Markson, Fanale, Steel, Kern, & Annas, 1994). Several studies have documented nurse's ACTIONS regarding Advance Directive implementation as 6-27% (Anderson, Walker, Pierce, & Mills, 1986; Crego & Lipp, 1998; Fox, 1993; Leith, 1998; Thayer, 1997).

Set

Five areas of the Registered Nurse's SET were significantly related to the ACTION of Advance Directive implementation. The first two were older age and greater years of RN experience. The likelihood of Advance Directive implementation increased as the Registered Nurse's age increased, as well as when years of RN experience increased. This is similar to the findings reported in Thayer's (1997) study. The third area of significance showed that those with an Estate Will were more likely to have implemented an Advance Directive. This is possibly due to some lawyers combining

the paperwork, making it convenient to complete Advance Directives at the same time as an Estate Will (Mansell, Kazis, Glantz, & Heeren, 1999). In fact, Fairchild (1996) found that almost one third of her subjects cited lawyers as a motivating factor for implementing their Advance Directives. Considering 25-50% of people implement an Estate Will, this could be an important area for community education (Ross & West, 1995).

The fourth area was in the primary position held by the Registered Nurse. Staff Nurse was the primary position for over one half of the sample, but accounted for only one third of the implemented Advance Directives. The majority of the Staff Nurses listed Hospital/Medical Center as their current practice setting. Environments within these settings should be more conducive to Advance Directive implementation due to ready access of appropriate documents and trained personnel for assistance. Together, primary position as a Staff Nurse and practice setting within a Hospital/Medical Center means that the Registered Nurses should have had greater exposure to Advance Directive information, if only as a by-product of the patient education that is mandated by the Patient Self-Determination Act, Medicare, Health Care and Finance Administration, as well as the American Nurses' Association Position Statement for Advance Directives (ANA, 1991). That almost half of the Registered Nurses stated: Advance Directive counseling, educating, and assisting were not in their job descriptions, may be evidence of a lack of exposure.

The last area found to be significant within the SET was related to the Registered Nurse's past experiences with Advance Directive decisions. Nurses who had been involved in decisions to withhold or withdraw life-sustaining therapy for a patient in

their care were more likely to have implemented an Advance Directive. While this was similar to findings in Leith's (1998) study, the same did not hold true for experiences involving a family member/significant other/close relative or friend in this study.

Other data analyzed relating to the Registered Nurse's SET included race/ethnic origin, religion, current health status, marital status, and education level. The literature is very supportive of cultural differences concerning end-of-life care (Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998; Kagawa-Singer, Martinson, & Munet-Vilaro, 1998; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). One such study (Rubin, 1994) found that African Americans and Hispanics completed Advance Directives less often than non-Hispanic whites and Asians. The current study's sample consisted of Caucasian and African Americans only, and a significance may have resulted with greater representation of other races and ethnic groups. The number of African Americans in the current study was small, and of those, none had completed an Advance Directive.

The effects of a small sub-sample may have impacted the variable of religion, where the majority were Protestant and only a small number of responses were Catholic, Non-denominational, or none. Stechmiller, Conlon, & Anderson (1991) identified religion, specifically being an Atheist or non-Christian, as a variable that was predictive of nurses and physicians signing a living will. In the current study, religion was not significant to Advance Directive implementation. However, it was thought provoking that those checking 'none' for religion favored Advance Directive implementation slightly more than those having a particular religious affiliation did.

Taking into account that the group selecting 'none' for religion was small, care must certainly be taken with generalizations. Yet, it does highlight the importance of not overlooking churches and religious groups when providing Advance Directive education in the community.

Another area of the SET that may have been related to low implementation of Advance Directives was the current health status of the respondents. The majority of this sample rated their health as good. This is similar to Thayer's (1997) study where it was speculated that the state of health may have influenced how often nurses had to see their physicians. This could also provide an explanation for the low number of Registered Nurses having discussed their end-of-life wishes with their physicians.

In addition, most of the respondents in this study were married or in a committed relationship. Having someone available with whom to discuss wishes regarding end-of-life care may have an adverse effect on Advance Directive implementation (Thayer, 1997). The importance of implementing an Advance Directive may be lessened when one is depending on family to make these decisions. This was reinforced by the number of respondents who answered: Had discussed preferences with a family member/significant other/a close friend. In fact, nearly one fourth of those without Advance Directives reported that they were relying on others (family/physician) to make the decisions for them. There were several written comments relating to this. For example, when responding to the question Have you completed an Advance Directive, some of the written comments included: Verbally to spouse and family; Wishes have been discussed with family; and Discussion only, have not completed. Furthermore, when responding to Why Advance Directives had not been completed,

written comments included: I am relying on family to make decisions; Have handwritten and made wishes known to family; Spouse knows my wishes; Husband and I do know each others wishes; and Discussed with husband.

No significance was noted relating Advance Directive implementation to education level. Previous research has indicated that education beyond the high school level increases one's likelihood of having an Advance Directive (Garrett, Harris, Norburn, Patrick, & Danis, 1993). Finally, almost one half of the respondents answered: Advance Directive responsibilities not in job description. This was significantly related to: Current practice setting and Been involved in decision to withhold/withdraw life-sustaining therapy from a patient.

Choice

When looking for a relationship between the Registered Nurse's professional and personal CHOICES and ACTIONS, several areas of significance were noted. The first of these was between the Registered Nurse's personal CHOICE of: Generally a good idea for nurses to complete Advance Directives and professional CHOICE of: Generally a good idea for patients to complete Advance Directives. There was also significance noted among the Registered Nurse's personal CHOICES for not discussing wishes with family members. These included: Subject never came up, Health does not warrant it, and Too young. The response: Health does not warrant it was also the most frequently chosen reason for why discussions about future wishes for medical treatments did not occur with physicians. These reasons were reflective of those previously discussed as reported in the literature. Considering one's self too

young or healthy for Advance Directives is unfortunate. Approximately one third of deaths occur in those under age 65, many sudden and unexpected (Haynor, 1998).

It is not surprising that the Registered Nurses in this sample answered so positively concerning patients and nurses completing Advance Directives. The literature has shown that the majority of people feel that Advance Directives are beneficial. Yet, it is interesting that even though Registered Nurses overwhelmingly supported Advance Directive implementation, barely a third had completed one for themselves. In Thayer's (1997) study almost the same percentage of nurses and nursing students supported Advance Directive implementation, but the baseline completion rate was somewhat lower. Leith's (1998) results also indicated a strong support by nurses for Advance Directives, along with a corresponding low personal completion rate.

Choices relating to why Advance Directives were not implemented were also closely correlated with Thayer's (1997) work. Unlike reports in the literature stating that many people put off making Advance Directive decisions because they are difficult and uncomfortable to make, the majority in this current study were simply procrastinating. Procrastination was also what the majority of nurses in Thayer's (1997) findings reported as their reason for not completing Advance Directives. In fact, many may be procrastinating because, as the literature reports, they wish to allow their family or physician to make these decisions.

The results for professional CHOICES and ACTIONS: Counseling, educating, and assisting patients regarding Advance Directives, was also similar to Thayer's (1997) study. The majority of Registered Nurses viewed education and counseling as being part of the nurses' professional responsibilities, with responses favoring education. In

the current study, less than half agreed that assisting patients with Advance Directives should be part of the nurses' professional responsibilities. This may be due, in part, to the ambiguousness of the word assist. Assist may be interpreted as simply as assisting the patient in locating appropriate documents, or as complex as, assisting the patient in understanding diagnoses, helping to explore treatment options, or choosing appropriate surrogates. The way one defines Assist and interprets the responsibilities associated with Assist may depend upon the Registered Nurse's past experiences, current responsibilities, and comfort level dealing with the subject of Advance Directives. However, since more than half of the current sample reported: Being involved in the decisions to withhold or withdraw life-sustaining therapy for a patient whose care they were involved with, and almost half had been involved in a similar Decision for a family member/significant other/close relative or friend, it seems unlikely that experience alone is sufficient to increase one's comfort level in dealing with Advance Directive issues.

Fairchild's (1996) findings indicated that almost one quarter of the subjects with Advance Directives had personal experience with the prolonged death of a relative or close friend, yet the majority did not list this as a motivating factor for implementing an Advance Directive. Instead, they reported their decisions regarding Advance Directives had already been made and the experience with the prolonged death only spurred them to act on their decisions. In the current study, the Registered Nurse's experience with Withholding or withdrawing life-sustaining therapy for a family member, significant other, or close relative/friend was not found to be a significant factor in Advance Directive implementation.

The Registered Nurse's professional CHOICES did not match their ACTIONS with regard to counseling, educating, and assisting patients with Advance Directives as part of their current job responsibilities. While more Registered Nurses are involved in Advance Directive education than counseling or assisting, they comprise less than half of the current sample. In Thayer's (1997) study, the nurses' responses were similar, especially in order of frequency. However, a greater number of the nurses in Thayer's (1997) study reported that they 'assisted patients'. As previously discussed, the majority of Registered Nurses in the current study reported that they did not participate in these Advance Directive responsibilities because 'counseling, educating, and assisting patients with Advance Directives' was: Not in their job descriptions.

After exploring the personal ACTION, SET, and CHOICES of this random sample of Registered Nurses, the results supported Thayer's (1997) findings showing little difference between nurses and the general population regarding Advance Directive implementation. Even though the majority of Registered Nurses agreed that their professional responsibilities should include the ACTIONS of counseling, educating, and assisting, less than half stated they actually performed these duties. As previously discussed, this is also similar to what Markson et al. (1997) reported concerning the discrepancy between the professional responsibilities and ACTIONS of physicians in their study.

With the nurses in the current study, the inconsistency may have been due to such a large number believing that Advance Directive responsibilities are currently not part of their job descriptions. However, for the majority of the Registered Nurses, the primary position held, clinical specialty, and current work setting, were all areas where

patient education should be occurring. Furthermore, the American Nurses' Association has mandated that nurses are expected to play a primary role in the implementation of Advance Directives (ANA, 1991). In this study, inconsistency between the Registered Nurse's personal and professional ACTIONS and CHOICES leads one to wonder if nurses are somehow negatively influencing patients' decisions regarding Advance Directives. This influence may be due to a lack of Advance Directive knowledge, misinformation regarding job responsibilities, or perhaps, due to unconscious bias from personal Advance Directive CHOICES. Regardless, it is clear that Registered Nurses are not the professional resources for end-of-life discussions expected by patients and society.

Limitations

There were several limitations that may limit the ability to generalize the findings of this study. The sample, though randomly selected, was not necessarily ideal regarding clinical specialty and job setting. Due to the nature of Advance Directives, those Registered Nurses working with children, in OR/Surgery, or in office environments were, by their job descriptions, most often exempt from the professional responsibilities addressed by this study and their responses may have affected the results. Using the mail for surveying has limitations as well. The response rate is generally low and there is always the possibility that the responses of those choosing not to participate would have affected the outcome.

Closed-ended surveys limit the depth of information available for analysis. Because Advance Directive decisions are difficult, at best, use of open-ended questions would allow discussion by nurses concerning their CHOICES and

ACTIONS associated with Advance Directives and how they arrived at the decisions they have made. In addition, based on written comments by the respondents, there seemed to have been some concern with the meaning of certain questions related to: Assisting patients or completing forms that may have affected responses.

Implications

Using Johnson's Behavioral System Model as a conceptual framework provides guidance for understanding the Registered Nurse's personal ACTION of Advance Directive implementation, as well as their personal CHOICES related to not implementing an Advance Directive. In addition, the model enhances understanding of what the variables are that effect one's SET, and how those may predispose Registered Nurses to certain personal and professional CHOICES and ACTIONS. Finally, based on the assessment of the SET, CHOICE, and ACTION, JBSM guides interventions based on focus and mode. The focus of interventions is on the structural part of a subsystem or the supply of sustenal imperatives (Johnson, 1980, p.242). If structure is involved, focus would be on the GOAL, SET, CHOICE, or ACTION of the subsystem. Otherwise, the focus is on the source and sufficiency of functional requirements. Interventions aimed at structure may include broadening CHOICES, altering the SET, changing the ACTION, strengthening the drive, or altering the GOAL by manipulating structural units or imposing temporary controls that regulate interaction of the subsystems.

If functional, a mode (which is the method used to alter behavior) is chosen that will supply sustenal requirements. According to Johnson (1980), the four choices available for carrying out the mode of interventions are:

1. Restrict - the imposition of limits or external controls on behavior.
2. Defend - supplies protection by preventing damage from exposure to unnecessary stressors or coping with threats in the patient's behalf.
3. Inhibit - supplies nurturance by suppressing ineffective responses.
4. Facilitate - supplies nurturance and stimulation to expedite the incorporation of new demands and to increase the use, or opportunity to use, a behavior. (p. 242)

Based on the current findings, the Registered Nurse's personal CHOICE to not implement an Advance Directive may result in loss of control over end-of-life decisions causing potential imbalance in the Achievement Subsystem. A CHOICE such as this may result from a lack of knowledge of available alternative CHOICES, or because of a SET where the tendency is to rely on others because: That's the way it's always been done. Interventions should be designed to facilitate awareness of alternative CHOICES, as well as opportunities to increase the desired ACTION. These interventions may include education on availability of resources and assistance for implementing Advance Directives, reinforcement or encouragement for seeking out those resources, and increased opportunities for discussions with primary care providers.

The inconsistency between the Registered Nurse's professional CHOICES and ACTIONS (counseling, educating, and assisting) requires interventions aimed at protection, nurturance, and stimulation in order to facilitate incorporation of new demands, to increase the use or opportunity to use the new behavior, as well as external regulation of the patient's behavior (Johnson, 1980, p.242). These

inconsistencies in nursing practice should be addressed by administration, policy and legislation, education, and research.

Administration is responsible for setting and enforcing policies and procedures that restrict or set limits on behaviors not in adherence with guidelines put forth by the Patient Self-Determination Act (PSDA), ANA Position Statements and Standards of Practice, as well as the Joint Commission on Accreditation of Healthcare Organizations. Policies should be in place that defend Advance Directive decisions so that patient's end-of-life wishes are followed. In addition, interventions within the workplace should include staff education concerning the legislation of the PSDA, the mandates of ANA Position Statement on Advance Directives, as well as JCAHO requirements as each relates to specific role responsibilities. The legal aspects of counseling, educating, and assisting patients with Advance Directives should be presented by the agency's legal representative.

Thinking of the Advance Directive responsibilities of counseling, educating, and assisting as a multidisciplinary endeavor, underscores the importance of Advance Directive information being disseminated to all employees annually with other orientation and training. Use of focus groups would provide a means for all staff members to explore how values regarding end-of-life issues may effect their interactions with patients. Finally, a multidisciplinary team specifically trained to assist patients and staff with Advance Directive issues would be most effective and efficient for assuring continuity of care. This is especially true considering that the literature reports the characteristics important for those providing Advance Directive

information as: having medical expertise; sufficient time; understanding of ethics and hospital goals; and acting as a back-up for staff (Haisfield et al., 1994).

According to Crego (1998), many nurses report being unprepared for Advance Directive discussions with patients. That study (Crego, 1998) attempted to describe the Advance Directive knowledge of nurses working in a 600 bed acute care teaching hospital. It was reported that only 14% (N=339) of those nurses had personal Advance Directives. Even though their knowledge level was graded at 78%, there were 55% who reported that their understanding of Advance Directives was not good and 92% thought that additional education was needed to enhance their Advance Directive understanding. These findings emphasize the need for nursing education to be diligent in preparing graduates for the responsibilities associated with Advance Directives. Information, specific to their level of practice, would be best given as part of a required class on end-of-life care or a course on ethical/legal issues of healthcare. Such a class would provide the environment and opportunity for thorough exploration of Advance Directive issues and responsibilities. Additionally, in order for nurses to be proper patient advocates, they must be trained as members of interdisciplinary healthcare teams and taught to communicate effectively with other team members.

With more services being provided in outpatient settings, it may prove more effective to move Advance Directive counseling, education, and assisting to the Primary Care Clinic. In this way, Advance Directive discussions may support behavioral system balance by preventing future imbalance in the Achievement or the Aggressive/Protective Subsystems, thus becoming health promotion and prevention focused. For example, by addressing Advance Directive issues in the Primary Care

Clinic, the patient and the provider may develop a level of trust and comfort with one another and the issues involved. Advance Directive discussions could occur over time and, as health needs changed, decisions could be made to address those changes. With ongoing communication, the provider supports a balanced behavioral system by enabling the patient to maintain control over end-of-life decisions. Increased control prevents the possibility of patient exposure to noxious stimuli or unnecessary threats, thus avoiding CHOICES such as physician assisted suicide. Maintaining stability of the behavioral system leads to more optimal health and well being of both the individual and society. Moreover, just as JBSM is used for nursing interventions with the individual, it may also be used for assessing imbalance in society as a whole. For example, the CHOICE of physician assisted suicide may be viewed as a behavior that threatens society both physically and psychologically. The observed ACTION of physician assisted suicide is evidence of an imbalance within the societal behavior system. The necessity becomes to identify and supply the sustenal imperatives or functional requirements needed so alternative choices are available to physician assisted suicide. Therefore, the goals of Nursing, as well as the responsibilities of nurses, are dictated by both individual and societal needs.

Nurses not only have a responsibility for maintaining competency regarding Advance Directive issues, but must also be advocates for legislative changes. Enhancing patient care areas to create an environment that is conducive to Advance Directive discussions requires increased staffing as well as, reimbursement for services. This would result in staff having ample time and resources to meet patient's needs. Finally, nurses should be involved in research to find the most effective and

efficient way to address these issues. Some of the research questions posed as a result of the current study include:

1. What are nurse's thoughts and feelings regarding their own personal Advance Directive CHOICES and ACTIONS as well as how those decisions effect their patient interactions?
2. Do patients report that nurses influence their Advance Directive ACTIONS, and if so, how?
3. Do nurses report the same motivating factors for personal Advance Directive ACTIONS as reported by the participants in Fairchild's (1996) study?
4. How prepared to discuss end-of-life issues with patients do graduating nurses feel? Is there a difference between the levels of education and feelings of being prepared?
5. Is there a relationship between "locus of control" and nurses' personal CHOICES and ACTIONS concerning Advance Directive implementation?
6. Is nursing care guided by the patient's implemented Advance Directives?
7. Are nurses in Primary Care Clinics addressing the issues around 'counseling, educating, and assisting' patients with Advance Directives differently than in other patient care settings?

Summary

When end-of-life choices are in conflict with what nursing, or even society considers optimal, Johnson (1980) cautions nurses to remember that, at the time, those were probably the best choices based on the person's current values and learning (p.214). If necessary, nursing is to be an external regulatory force acting to maintain

behavior at an optimal level under those conditions that might be a threat to physical or social health. This may be done through external control or manipulation of the environment, changing structural units, or by fulfilling the functional requirements of the subsystems. In order to do this, it is imperative that nurses personally set the example regarding end-of-life discussions and Advance Directive decisions, thus effectively stimulating and nurturing others to ACTION regarding Advance Directive implementation.

Nurses are challenged to provide care to an ever-increasing number of vulnerable individuals. Many patients are living longer with chronic, debilitating diseases giving rise to ethical issues such as futility and cost of care. It has been estimated that by the year 2000, 35% of the population will be over age 65, with the fastest growing segment being those over age 85 (Mezey, Bottrell, Ramsey, & The NICHE Faculty, 1996). In addition, as many as 30% of these elders will not have anyone available to make their health care decisions when the need arises. As the largest group of health care professionals, nurses must be prepared for role expansion in order to provide individualized and culturally appropriate Advance Directive counseling, education, and assistance across a spectrum of sites.

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APPENDICES

APPENDIX A
REVISED QUESTIONNAIRE
YOUR VIEWS ON ADVANCE DIRECTIVES

CODE# _____

1

Your Views On Advance Directives

A. Personal Information

Please take a moment to complete the demographic information listed below. Please mark only one response unless otherwise indicated.

GENDER: Male Female

AGE _____

MARITAL/RELATIONSHIP STATUS

Divorced/Separated
 Married/living in a committed relationship with a partner/significant other
 Single
 Widowed

LIVING ARRANGEMENTS

Living alone Living with someone else

RACE-ETHNIC ORIGIN

American Indian
 African American
 Asian or Pacific Islander
 Hispanic
 White (not of Hispanic origin)
 Other (Please specify) _____

RELIGION

Catholic
 Jewish
 Protestant
 None
 Other (Please specify) _____

PERSONAL ASSESSMENT OF YOUR PRESENT STATE OF HEALTH

Excellent Good Fair Poor

HIGHEST NURSING DEGREE HELD

Dipl ADN BSN MSN DSN

YEARS AS A REGISTERED NURSE _____

EMPLOYMENT STATUS

Full time Part time None

PRIMARY POSITION HELD

(If employed, please check category that best describes you)

Staff nurse
 Advance Practice Nurse (CNS/NP)
 Nurse Manager (Head Nurse)
 Inservice/Staff Development
 Nurse Administrator/VP
 Academic Faculty
 Other (Please specify) _____

CLINICAL SPECIALTY

(Please check all that apply)

Ambulatory
 Critical care
 Emergency/Trauma
 Gerontology
 Medical-Surgical
 Pediatrics/Neonatal
 Psychiatry
 Other (Please specify) _____

CURRENT PRACTICE SETTING

Hospital/Medical Center
 Urgent Care
 MD Office/Clinic
 Hospice
 Home Care
 Adult Daycare
 Outpatient Surgery
 Public Health
 Student Health Center
 Occupational Health Clinic
 Skilled Nursing Facility
 Other (Please specify) _____

*COMPLETION OF ESTATE WILL

Yes No *(The legal documentation of a person's wishes about what is to be done with their property after they die)

Your Views On Advance Directives

Please indicate whether you agree with the following statements by circling either *Yes* or *No*, or the response that most closely matches your opinion:

- SA - strongly agree
- A - agree
- U - undecided
- D - disagree
- SD - strongly disagree

B. Advance Directives* And Your Patients

**(Advance directives (ADs) are written documents that express what life-sustaining treatments you would want if you were to become decisionally incapacitated)*

1. Have you ever been involved in a decision to withhold or withdraw life-sustaining therapy for a patient whose care you were involved in?	Yes	No			
2. It is generally a good idea for patients to complete an advance directive such as a living will or a health care surrogate/proxy designation.	SA	A	U	D	SD
3. Nurses, as part of their professional responsibilities, should:	SA	A	U	D	SD
-Counsel patients about advance directives ("counsel" in this context refers to a discussion related to the issues involved in advance care planning, not the specific patient's prognosis)					
-Educate patients about advance directives	SA	A	U	D	SD
-Assist patients to complete advance directive forms	SA	A	U	D	SD
-Other (Please specify)	SA	A	U	D	SD
4. Currently, as part of my professional nursing responsibilities, I:					
-Counsel patients about advance directives	Yes	No			
-Educate patients about advance directives	Yes	No			
-Assist patients to complete advance directive forms	Yes	No			
-Other (Please specify)	Yes	No			
5. I am NOT involved in the advance directive responsibilities listed above (counseling, educating, assisting with AD completion) because:					
-They are not in my current job description/responsibilities	SA	A	U	D	SD
-They are in my current job responsibilities, but I feel uncomfortable performing them	SA	A	U	D	SD
-They are in my current job responsibilities, but I have more urgent priorities	SA	A	U	D	SD
-They are in my current job responsibilities, but I need more education about advance directives to perform them effectively	SA	A	U	D	SD
-Other (Please specify)	SA	A	U	D	SD

C. Advance Directives And You

1. Have you ever been involved in a decision to withhold or withdraw life-sustaining therapy for a family member/significant other/close relative or friend?	Yes	No
2. It is generally a good idea for nurses to complete an advance directive such as a living will or a health care surrogate/proxy designation.	Yes	No

Your Views On Advance Directives

Please indicate whether you agree with the following statements by circling either Yes or No, or the response that most closely matches your opinion:

- SA - strongly agree
- A - agree
- U - undecided
- D - disagree
- SD - strongly disagree

C Advance Directives And You (continued)

3. Have you completed any of the following advance directive documents:					
-Living Will	Yes	No			
-Designation of a Health Care Surrogate/Proxy	Yes	No			
-Other (Please specify)	Yes	No			
<i>If you have NOT completed an advance directive, please complete this section.</i>					
4. I have not completed an advance directive because:					
-I have had difficulty obtaining the documents	SA	A	U	D	SD
-I have not been certain about which type of document(s) to choose	SA	A	U	D	SD
-I have not been able to choose an appropriate surrogate	SA	A	U	D	SD
-I have been putting it off/procrastinating	SA	A	U	D	SD
-It is too upsetting to do	SA	A	U	D	SD
-It is a difficult decision to make	SA	A	U	D	SD
-I am relying on others (family/physician) to make the right decision when the time comes	SA	A	U	D	SD
-I am too young- completing an advance directive seems more relevant to the sick and old	SA	A	U	D	SD
-I have not thought about it	SA	A	U	D	SD
-Other (Please specify)	SA	A	U	D	SD
5. Have you ever discussed with a member of your family/ your significant other/a close friend your preferences in the type of medical treatments that you would want if you were seriously ill and unable to make health care choices for yourself?					
	Yes	No			
<i>If you have NOT, please explain:</i>					
-The subject never came up	SA	A	U	D	SD
-My current state of health did not seem to warrant the discussion	SA	A	U	D	SD
-I'm too young	SA	A	U	D	SD
-I never thought about it	SA	A	U	D	SD
-I don't know	SA	A	U	D	SD
-Other (Please specify)	SA	A	U	D	SD
6. Have you ever discussed with your physician, your preference in the type of medical treatments that you would want if you were seriously ill and unable to make health care decisions?					
	Yes	No			
<i>If you have NOT, please explain:</i>					
-The physician did not bring up the subject	SA	A	U	D	SD
-I do not have a primary care physician	SA	A	U	D	SD
-The physician seemed too busy	SA	A	U	D	SD
-My current state of health did not seem to warrant the discussion	SA	A	U	D	SD
-I'm too young	SA	A	U	D	SD
-I never thought about it	SA	A	U	D	SD
-I don't know	SA	A	U	D	SD

APPENDIX B
PERMISSION TO USE QUESTIONNAIRE

TO: ANN THAYER
FROM: BRENDA MORGAN
SUBJECT: DATA COLLECTION QUESTIONNAIRE
DATE: 11/16/98

I am beginning work on my master's thesis at the University of Tennessee, Knoxville. My goal is to survey practicing nurses within the state of TN to ascertain the prevalence of Advance Directives. I am interested in using parts of your questionnaire and wondered how to go about getting permission. I do not plan to alter it in any way, but only intend to use certain sections. I would also like to use the same format you used to gather demographics, but I do plan to leave out certain things and add in others that are more specific to my population.

I have enclosed both my home and e-mail addresses, as well as, my home telephone number.

Thank you,
Brenda Morgan
Brenda Morgan, RN

Home - 223 Thelma Circle
Jacksboro TN 37757
423-566-7423
e-mail bmorgan5@utk.edu

*You have permission contingent upon
your explanation of your proposed changes*

*Ann Thayer RN, MSN, EdD.
good luck in your study and let me
know your results.*

TO: Ann Thayer, RN, MSN, EdN

FROM: Brenda J. Morgan, RN, BSN

SUBJECT: Revised questionnaire

DATE: 20 Jan 1999

As per your request, I am sending the revised version of your instrument, "Your Views on Advance Directives". The only major changes I made were in Part A, Personal Information. You will also notice that Part D was changed to allow for any additional general comments rather than asking for comments specific to advance directives. The wording in Parts B and C remain unchanged.

If the changes meet with your approval, I would appreciate a letter (for inclusion in my thesis) stating permission to use this revised version of your instrument. I have enclosed a stamped, addressed envelope for your convenience or you may email your response.

Thank you for your time and for the use of your instrument. I look forward to sharing my findings with you.

Brenda J. Morgan, RN, BSN
BRENDA J. MORGAN, RN, BSN
bmorgan5@utk.edu

You have my permission.

Ann Thayer

APPENDIX C
FORM A / IRB APPROVAL

FORM A

IRB#- _____

Certification for Exemption from IRB Review for Research Involving Human Subjects

- A. PRINCIPAL INVESTIGATOR and ADVISOR: Brenda J. Morgan (PI)
Dr. Debra Wallace (advisor/committee chair)
- B. DEPARTMENT/UNIT: University of Tennessee College of Nursing
- C. COMPLETE MAILING ADDRESS AND PHONE NUMBER OF PI and
ADVISOR: PI/223 Thelma Circle, Jacksboro, TN, 37757/ (423) 566-7423/
bmorgan5@utkcc.utk.edu Advisor/1200 Volunteer Blvd., Knoxville TN 37996-
3569/ (423) 974-7596
- D. TITLE OF PROJECT: Advance Directive Choices Among Registered Nurses
- E. EXTERNAL FUNDING AGENCY AND ID NUMBER: N/A
- F. GRANT SUBMISSION DEADLINE: N/A
- G. STARTING DATE: Upon IRB Approval
- H. ESTIMATED COMPLETION DATE: April 1999
- I. RESEARCH PROJECT: Thesis
1. Objectives of Project:
- (a.) Determine the prevalence of Advance Directives (living wills and power of attorney for health care) among a random sample of 400 Registered Nurses in Tennessee. It is anticipated that the sample will be reflective of the target sample of licensed Registered Nurses in Tennessee. There is no risk to the subjects from participating in this study. All subjects will be over age 18.
 - (b.) Determine whether there are sociodemographic differences between Registered Nurses who do and do not choose to implement personal Advance Directives.
 - (c.) Determine if having a personal Advance Directive is related to the professional actions of the Registered Nurses regarding Advance Directives.

2. **Subjects:** For this non-experimental study, respondents will be from a random sample of 400 Registered Nurses currently residing in Tennessee. After IRB approval, a request will be sent to the Department of Health Statistics for a randomly selected list of 400 Registered Nurses from among all of the licensed Registered Nurses in Tennessee. The inclusion criteria will be that the Registered Nurses have an active license to practice in the state of Tennessee and are currently residing in Tennessee. Each Registered Nurse in the random sample will receive a packet in the mail that includes a self administered questionnaire (SAQ), "Your Views on Advance Directives". It is estimated to take approximately 10-15 minutes to complete. There will be no additional contact with the subjects.

3. **Methods and Procedures:** After receiving IRB approval, a request will be sent To the Department of Health Statistics for a randomly selected list of 400 Registered Nurses from among all of the licensed Registered Nurses in Tennessee. A packet will be mailed to each of the 400 randomly chosen Registered Nurses. Each packet will consist of a cover sheet, a questionnaire, "Your Views on Advance Directives", and a postage paid envelope for returning the questionnaires. The cover letter gives a description of the study, addresses confidentiality, identifies points of contact for questions regarding the study, and explains that participation is voluntary, with return of the questionnaire implying consent to participate. If subjects choose to, they will complete the questionnaire (10-15 minutes) and return it in the stamped addressed envelope provided. The questionnaire consists of one page of demographic data and two pages of questions with either Yes/No or 5-point Likert scale (Strongly Agree to Strongly Disagree) answers. There is no personal identifying information on the questionnaires. Each returned questionnaire will be coded and the codes will be used to enter data into the PI's personal password protected computer for analysis. During the study, the list of Registered Nurses and the returned questionnaires will be kept locked in a filing cabinet located in room 359 at UTK College of Nursing where only the PI and the committee chair will have access to it. After completion of data collection, the list of Registered Nurses and returned questionnaires will be destroyed. There should be no risk, stress, or discomfort from participating in this study. The address and phone number of the PI and committee chair is included on the cover letter should any questions arise. No references will be made in oral or written reports which could link subjects to this study. All reports from the study findings will be presented as grouped data so no individual can be identified.

4. **CATEGORY FOR EXEMPT RESEARCH PER 45 CFR 46: (2)**

- J. **CERTIFICATION:** The research described herein is in compliance with 45 CFR 46.101(b) and presents subjects with no more than minimal risk as defined by applicable regulations.

Principal Investigator Brenda J. Morgan Brenda J. Morgan 2-3-99
Name Signature Date

Student Advisor Debra C. Wallace Debra C. Wallace 2-3-99
Name Signature Date

Dept. Review
Comm. Chair Maureen Groer Maureen Groer 2/22/99
Name Signature Date

APPROVED:
Dept. Head Dean Joan Creasia Joan Creasia 2/23/99
Name Signature Date

INFORMATION SHEET

Advance Directive Choices Among Registered Nurses

You are invited to participate in a research study. The purpose of this study is to better understand the personal and professional choices Registered Nurses make regarding Advance Directives (ADs).

You are being asked to complete a questionnaire that will take approximately 10-15 minutes of your time. A postage-paid return envelope has been provided for your convenience. In order to analyze the data in a timely fashion, you are being asked to return the questionnaire as soon as possible. After returning the questionnaire, you will not be contacted again.

Your responses are very important. Results from this study may be used to assist nurses with more effective strategies for supporting patients when implementing Advance Directives.

The information in the study records will be kept confidential. Data will be stored securely and will be made available only to persons conducting the study. Each questionnaire will be coded and data will be entered into the computer for analysis by codes. No reference will be made in oral or written reports which could link you to the study. This study presents no risks to the participants. It includes no invasive interventions.

If you have questions at anytime about the study, you may contact the researcher through the University of Tennessee, (423) 974-4151 or e-mail: bmorgan5@utk.edu. The thesis chair, Dr. Debra Wallace, may be reached at (423) 974-7596. If you have any questions about your rights as a participant, contact the UTK Compliance Section of the Office of Research at (423) 974-3466.

Your participation in this study is voluntary, you may decline to participate without penalty.

Returning the completed questionnaire implies consent to participate.

Thank you for your participation,
Brenda J. Morgan, Graduate Student
University of Tennessee Knoxville, College of Nursing
Email: bmorgan5@utk.edu

APPENDIX D
REQUEST FOR SAMPLE NAMES AND ADDRESSES

THE UNIVERSITY OF TENNESSEE
KNOXVILLE



College of Nursing
Office of the Dean
1200 Volunteer Boulevard
Knoxville, Tennessee 37996-4180
(423) 974-7584
FAX (423) 974-3569

TO: Alice Jackson, Department of Health Statistics

FROM: Brenda J. Morgan, RN, BSN

SUBJECT: Written request for random sample

DATE: 24 February 1999

I am a graduate nursing student at the University Of Tennessee College of Nursing. In reference to our telephone conversation on 24 February 1999, this is the written request for a list of names to use in my thesis project, "Advance Directive Choices Among Registered Nurses". Please use the following information to obtain my random sample:

In the RN file, have the computer randomly select from all available active, licensed Registered Nurses currently residing and practicing in Tennessee, 400 names including addresses and zip codes.

I would like the list printed on address labels and have enclosed the additional \$15 (check enclosed for the total \$90). Also enclosed is a FEDEX postage paid return envelope. Thank you for your assistance.

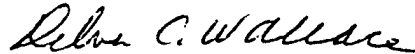
Sincerely,

A handwritten signature in cursive script that reads "Brenda J. Morgan".

Brenda J. Morgan, RN, BSN
223 Thelma Circle
Jacksboro, TN 37757
(423) 566-7423
bmorgan5@utk.edu

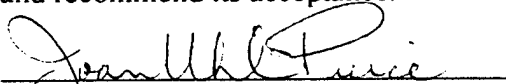
To the Graduate Council:

I am submitting herewith a thesis written by Brenda J. Morgan entitled "Advance Directive Choices Among Registered Nurses in Tennessee: Use of Johnson's Behavioral Systems Model." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science in Nursing, with a major in Nursing.

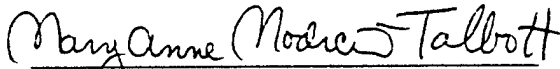


Debra C. Wallace, Major Professor

We have read this thesis
and recommend its acceptance:



Joan Uhl Pierce



Mary Anne Modrcin-Talbott

Accepted for the Council:



Associate Vice Chancellor and
Dean of The Graduate School