

HEALTH CARE PROVIDER'S ATTITUDES AND PRACTICES REGARDING THE
PURPOSE AND USE OF ADVANCE DIRECTIVES IN A MILITARY HEALTH CARE
SETTING

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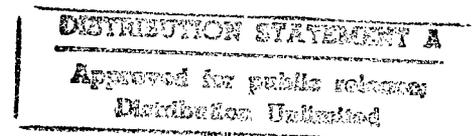
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ABSTRACT

This research study examined health care providers' attitudes and practices on the purpose and use of advance directives in a military health care setting. This research modified a study conducted by the End Of Life Study Group from the University of North Carolina - Chapel Hill. The literature has attributed low completion rates of advance directives to health care providers' erroneous beliefs that these documents are mainly for the terminally ill and elderly. Additionally, inadequate health care provider training and skills about advance directives have been cited for low completion rates. Family nurse practitioners (FNPs), in both civilian and military settings, receive training on ethical and moral implications of advanced nursing practice. These characteristics make the FNP an ideal candidate for promoting the purpose and use of advance directives. In this study, health care providers assigned to a mid-sized Air Force Base completed a modified research End-of-Life Study Group instrument. The End-of-Life Study Group instrument was modified to include demographic data and military terminology. Supporting evidence of the content validity was obtained via a review of the instrument by two experts. A content validity index on the modified instrument, rating the instrument of 1.0, indicating that the items were relevant to the study. The study consisted of 61 subjects. Data analysis utilized relative frequency scales and percentages. The results of the study revealed that health care providers in a military health care setting held the same attitudes and practice standards as their civilian counterparts. They believed that counseling should occur with any and all patients, yet limited their actual counseling to seriously, chronically, or terminally ill patients.

CINHAL Key Words

Advance Directives, Living Will, Autonomy, Informed Consent, End-of-Life, Ethics,
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CHAPTER ONE: INTRODUCTION

Historical Overview

An advance directive (AD) is defined by the United States Code Congressional and Administrative News (USCCAN) (1990) as “a written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State) and relating to the provision of such care when the individual is incapacitated” (p. 1388-115). The ideal AD states the person’s intention, is flexible in response to circumstances, is available when needed, and grants the patient the right to protect the health care provider (HCP) from liability (Palker & Nettles-Carlson, 1995). These documents, recognized under state law, are a written statement regarding what health care options a patient wishes when his or her cognitive ability is impaired (Doukas & Brody, 1992).

Advance directives can be expressed in many forms. The living will is a document indicating patient preferences concerning the administration of life-sustaining treatments in the event of a terminal illness, unconsciousness, or permanent vegetative state that would prevent the individual from expressing personal preferences. The Durable Power of Attorney for Health Care is a written statement for assigning a surrogate decision maker (proxy) to be the individual’s health care agent in the event of incapacity (Doukas & McCullough, 1991). Another form in which ADs can be expressed is a verbal agreement between patients and their HCP (American College of Physicians [ACP], 1992). For example, the State of Maryland recognizes an oral

statement to a attending physician about instructions on end-of-life care or proxy as an AD (Tussey, Taylor, Roszak, & Skinner, 1994).

Historically, health care centered around the principle of medical paternalism. That is, technical decisions regarding medical treatments and plan of care were made by the physician (Seigler, Pellegrino, & Singer, 1991). The twentieth century witnessed a rise in technological advances capable of keeping patients alive well beyond their functional capacity (Byock, 1995). There was a concomitant rise in consumerism. Patients demanded more involvement in health care decision making (Palker & Nettles-Carlson, 1995). Patients and families found themselves involved in vulnerable situations, where they were responsible for making health care decisions, especially in regard to end-of-life decisions.

Because of technological advances the process of death and dying has become more complex (Cranford, 1996). For example, the best paradigm for modern medicine is the persistent vegetative state (PVS). Patients with PVS have lost higher brain function, yet the brain stem continues respiratory and cardiac functions. Karen Ann Quinlan and Nancy Cruzan experienced a traumatic event that inflicted a loss of the higher brain function leaving them in a PVS. These women had no awareness of their condition and no ability to think, feel, or speak. Patients in PVS may live for years. Karen Ann Quinlan lived for ten years in PVS (Robinson, 1976). Nancy Cruzan lived for eight (Cranford, 1996). In 1994, there were an estimated 10,000 to 25,000 adults and 4000 to 10,000 children in a PVS (Singer, 1994). In the days before cardiopulmonary resuscitation and advance life support, neither of these patients would have survived their initial injury.

Patients and families began to resort to the legal system when they were unable to effectuate their wishes concerning end-of-life decision making through the health care system. Prior to 1985 the US Supreme court's involvement in the end-of-life decision making primarily focused on artificial nutrition and hydration in cases of irreversible cognitive impairment (Doukas & Brody, 1992). The much publicized case of Nancy Cruzan's parents' struggle to be recognized as surrogate decision makers on their daughter's behalf accelerated the national push for state recognition of patient preferences and living wills. These two landmark State and National Supreme Court cases, Quinlan and Cruzan, are reflective of the dilemmas patients and families faced with respect to end-of-life decision-making (Doukas & McCullough, 1991; Robinson, 1976). These precedent setting cases brought the ethical issues surrounding termination of medical interventions and end-of-life decisions to the public's attention.

In response to provider need for guidance, consumer pressure, and these two high profile legal cases, the 101st U.S. Congress enacted Public Law 101-508, The Patient Self Determination Act (PSDA) (Doukas & Brody, 1992; Doukas & McCullough, 1991; Emanuel & Emanuel, 1989; Palker & Nettles-Carlson, 1995). The PSDA addressed the health care facility's responsibility to: provide patients with written information concerning ADs, enact written policies for the HCP, or the organization, or both, respecting the patient implementation of ADs, include ADs in the patient's medical record, and provide staff education regarding ADs (USCCAN, 1990). The PSDA also addressed patient refusal of certain medical treatment options (Duffield & Podzamsky, 1996). This law additionally was designed to identify patients who had completed ADs and allow the patient the opportunity to make decisions related to life prolonging medical

care, typically in the form of preparing advance directives (Morrison, Olson, Mertz, & Meier, 1995). The PSDA has promoted the public awareness of ADs. It has also assisted in the identification of patients who have completed ADs (Doukas & Brody, 1992). The PSDA has been in effect for almost 6 years. Although it has raised awareness of ADs in both patients and HCPs, only 10 % of Americans have ADs (Johnston, Pfeifer, & McNutt, 1995).

Relevant Research Studies and Current Literature

Current Research

Hanson, Tulskey, and Danis (1997) performed a meta-analysis of research conducted between 1990 and 1996 in regard to the completion of ADs and on end-of-life decisions. All of the studies reviewed attempted to address patient preferences about ADs and patient completion rates of ADs or both. The investigators divided the results by targeted population. Sixteen studies were reviewed. Eight studies had patients as the targeted subjects, five studies targeted HCPs as the subjects, and three studies included both as subject groups. Eight studies addressed HCP attitudes and practices about ADs or end-of-life issues, or both. Of the eight studies that targeted HCPs five were directed at outpatient interventions. It is key to note that most of the patient-focused studies included a component of HCP education on the purpose and use of ADs, initiating and facilitating discussion, and outlining state policies. A meta-analysis of the data indicated that with appropriate interventions such as physician education and chart reminders, physicians and patients will increase their discussion and completion of ADs.

Hare and Nelson (1991) conducted a quasi-experimental study on completion rates for ADs. Twenty-two study physicians received training on the purpose and design

of the study, Minnesota state requirements for ADs, and information on initiating and facilitating conversations. The researchers divided 167 patients into three groups. The control group had no intervention; the second group was given a patient education handbook on ADs; the third group received the handbook and physician-initiated conversations on the purpose and use of ADs during subsequent appointments. The patient handbook included information on ADs and a standardized Minnesota State living will. Data collection spanned four months during which group three subjects averaged two physician-initiated discussions. The number of discussions ranged from one to seven. No subjects in either the control group or the handbook only group completed an AD during the study period. Eight of the 52 subjects (15 %) in the group receiving physician-initiated discussions completed ADs.

Schneiderman, Kronick, Kaplan, Anderson, and Langer (1992) investigated completion rates for ADs, the impact of ADs on medical interventions, and the cost of care at the end of life. They enrolled 204 patients with a 50 % predicted survival of five years. These patients were randomly assigned into two groups, a control group with no interventions prompting them to prepare ADs and a study group that received physician-initiated discussions about ADs and encouragement for their completion. The physicians in this study were given education booklets and received lectures on the purpose and use of ADs. The physicians were aware of each patient's status as a control or experimental subject, necessary for determining which patients required the interventions, but were blinded to the study's aim and purpose. One hundred and four of the 185 patients completed ADs and were enrolled into the next phase of the study.

The second phase of this research examined the financial impact of AD completion. The researchers found no significant difference between the health care costs of subjects with or without ADs. They also stated that all patients in the study, both the control and experimental subjects, felt that their preferences for care at the end-of-life were honored.

HCP Preferences in Regard to ADs

Two relevant studies on physician and nurse preferences for end-of-life care, life sustaining treatments, or both were done. The first study published was in 1993 by Gillick, Hesse, and Mazzapica. Their study examined 115 physicians' and 127 nurses' preferences for medical technology at the end-of-life. The subjects were asked to complete a medical directive indicating acceptance or rejection of 12 interventions in six hypothetical medical scenarios. The strong majority, 89 %, refused eleven of the twelve interventions in the scenario of irreversible coma or PVS. There were differences between the nurses and physicians. The nurses refused more interventions regardless of their invasiveness. Multiple analyses of variance failed to reveal any effect on refusal rates by specialty or personal involvement of decision making for a friend or family member.

The second study was done by Fischer, Alpert, Stoeckle, and Emanuel (1997). It examined physician preferences in terms of outcome goals for life sustaining treatments. They mailed 794 questionnaires and had 513 returned for a 72 % response rate. Their study showed that the respondents were more willing to undergo 'aggressive treatments' if the prognosis for cure was good. They would want an 'attempt at cure' when there was a high chance of a good outcome. The respondents tended to select 'comfort only'

options when they had to choose quality of life over longevity. Fischer et al. asked their subjects about the use of aggressive interventions if they had an acute life threatening illness in their current health. Fifty-two percent of the respondents chose to 'treat all' and 29 % of the respondents chose 'attempt to cure'.

Barriers to AD Completion

Morrison, Morrison, and Glickman (1994) conducted research on physician perceived barriers to assisting patients in the completion of ADs. Prior to conducting their survey they performed an extensive literature review to identify potential barriers. Their literature review identified five limitations: short appointment time periods, no mechanism for reimbursement of the office visit devoted to the discussions about ADs, the sensitivity that surrounds discussions about death and dying, the physician's belief that the discussion is not warranted, and physician's lack of knowledge and understanding regarding the use and purpose of ADs. The literature review also revealed that providing patients with informational booklets was not effective in promoting discussions about ADs and that physician-initiated discussions resulted in higher AD completion rates.

Morrison and co-investigators (1994) formulated their questionnaire based on this review of the literature. The researchers then sent questionnaires to 460 internal medicine residents and attending physicians. The return rate was 277 for a 60 % response rate. They found that two of the barriers to discussion of advance directives were physicians' erroneous beliefs that ADs are unnecessary for young healthy patients, and physicians' varying knowledge levels on how to formulate ADs. The researchers emphasized a need

to educate HCPs on the appropriateness of AD counseling with all patients, especially since the young and healthy are not immune to catastrophic illnesses or accidents.

Attitudes about ADs

Johnston et al. (1995) conducted a cross-sectional descriptive survey of 329 patients and 554 physicians. They sought to understand attitudes about the purpose and use of ADs, comparing responses between patients and HCPs. Their results revealed that fewer than half of the patients and more than 50 % of physicians believed that the age of the patient did not matter in the timing of initiating end-of-life discussions. The majority of physicians and patients believed the discussion should occur while the patient was healthy. Their research determined that 90 % of 329 patients were ready to discuss ADs.

The patients in this research study believed ADs should be addressed during a period of good health. The study results showed that 42 % of patients believed that the HCP should initiate the discussions, and 83 % of the 529 physicians felt it was the HCPs' responsibility to raise the issue. The majority of patients, 67 %, wanted the discussion of ADs spread over several visits (Johnson et al., 1995). These researchers concluded that there was a need for counseling relatively healthy patients regarding ADs in the outpatient setting. These findings mirror the recommendations of LaPuma and Schiedermayer (1989).

Timing of Counseling

Wanzer and colleagues (1989) advocated a proactive approach to counseling patients on ADs. They stated that HCPs are responsible for timely discussions with patients concerning life-sustaining procedures:

Many patients are aware of their rights to make decisions about their health care, including the refusal of life-sustaining measures, yet few actually execute living wills or appoint surrogates through a health care proxy. Although such documents can be very helpful in clarifying the patient wishes, they are too infrequently discussed in medical practice. Furthermore, at present, advance directives do not exert enough influence on either the patient's ability to control medical decision making at the end of life or the physician's behavior with respect to such issues in hospitals, emergency rooms, and nursing homes. There is an incredible gap between acceptance of this directive and its implementation (p. 845).

HCPs were urged to address ADs during routine, non-urgent patient appointments. These investigators determined that at this time the patient was emotionally prepared to consider all of his or her health care options.

Clinical Ethics

The HCP's ability to address end-of-life issues is a significant component of clinical ethics. Leading physician ethicists La Puma and Schiedermayer (1989) stated "recognizing, addressing, and resolving minor ethical dilemmas in the outpatient setting may prevent the development of major, much more dramatic, ethical problems in the hospital" (p. 414). These authors believe the outpatient setting is an ideal environment for discussing end-of-life issues because outpatients are more independent and have more control over health care decisions than they do when they become inpatients. A prudent

way to practice clinical ethics involves the counseling of patients on life-sustaining treatments, promoting understanding regarding end-of-life decision making, and assisting the patient with the execution of ADs.

The American College of Physicians (ACP, 1992) recently revised their position statement on medical ethics. The changes were prompted by new health care regulations, advances in technology, changing societal mores, and moral conflicts related to health care issues. One significant change was the mandate that physicians raise the issue of ADs in the outpatient setting .

Relevance to Military Operations

Research regarding ADs is relevant to military HCPs for many reasons. Three factors make this issue a priority: a commitment to quality, the military member's risk of injury, and an emphasis on patient autonomy.

First, HCPs in the military are committed to providing patients with comprehensive health care from cradle to grave (Hunter, Smith, & Gordon, 1997; McGee & Hudak, 1995). The military HCP implement continuous quality improvement initiatives to improve patient access to care and satisfaction. The military medical treatment facilities are accredited by civilian regulatory agencies that help to ensure that HCPs maintain professional standards as defined by professional organizations (Joint Commission on Accreditation of Health Care Organizations [JCAHO], 1996).

Secondly, the military HCP must be aware of the need to counsel all patients on the preparation of ADs based on an inherent risk for injury. Age should not prevent them from broaching the subject. Military personnel are often deployed with little advanced notice to areas where they may encounter sudden devastating injury. In such situations

the activity duty member may be unable to communicate his or her wishes concerning advanced life support, artificial nutrition and hydration, or other life-sustaining measures (see Table 1). The risk for serious injury to military personnel is a current concern. Between 1988 and 1995, over 170 military personnel have died in combat operations and 4,000 died in non-combat line of duty accidents (Cowley & Parker, 1996).

Historically, soldiers were expected to die when injured due to lack of HCPs on the battlefield, lack of treatment options available, and death by secondary infection or malnourishment. Today's soldiers can be treated more successfully on the front line with sophisticated and portable medical equipment, infection control protocols and prevention methods, and faster evacuation from the field to more definitive care. These interventions may prolong the survivability of war, but quality of life may be impacted by a serious injury or being left in a PVS (Nuland, 1993).

Table 1

U.S. Estimates of Casualties of War in Past Conflicts

War	Deaths	Wounded	Total
Spanish-American	2,400	1,600	4,000
WW I	100,000	200,000	300,000
WW II	408,000	670,000	1,078,000
Korea	53,000	103,000	156,000
Vietnam	57,000	153,000	210,000
Gulf	79	No Record	No Record
Panama Invasion	500	No Record	No Record

Note. From An Encyclopedia of War and Ethics (p. 57),
by D. Wells, 1996, Westport CT: Greenwood Press.

Finally, under TRICARE, there is increasing emphasis on patient involvement in health care decision-making (Reigler, Takata, & Schultz, 1996). TRICARE, the military's version of an managed care organization, has broadened the medical focus of Department of Defense beneficiaries to include improved access to care, while providing cost effective treatment in a high quality managed care environment (Hunter et al., 1997).

Advanced Nursing Role

Family nurse practitioners (FNPs) are well suited to initiate conversations concerning end-of-life decision-making. First, as registered nurses, they typically have a great many clinical experiences to assist patients in the end-of-life decision process (Perrin, 1997; Thompson & Thompson, 1981). They are well prepared to discuss and describe the effects of medical interventions such as CPR, dialysis, ventilators, and other interventions intended to prolong life (Perrin, 1997). Additionally, they receive formal education and training on ethics and incorporation of ethical principles into practice (Fry, 1996). FNPs generally have long-term relationships with patients and their families.

Consequently, patients and families often feel at ease discussing sensitive topics with the nurse practitioner.

Statement of the Problem

Rising public awareness of health care issues, technological advancements, concerns about medical costs, and a focus on quality of life have increased the demand for patient autonomy in health care decision-making processes (Hanson et al., 1997). Additionally, research indicates that patients want to tailor end-of-life decisions based on their values and beliefs. Patients who execute ADs believe that they are putting their wishes in writing to prevent any unwanted medical interventions (Osman & Perlin, 1994). Technological advances in prolonging life without regard to the quality of that life have prompted an increased need for end-of-life care planning during the clinical encounter (Doukas & Reichel, 1993). Shrinking health care resources and extraordinary financial burden are two other reasons why ADs should be completed (Parker & Nettles-Carlson, 1995). Hanson and colleagues (1997) determined that, despite intensive educational interventions with patients and HCPs, there was a disparity between beliefs and actual clinical practices. This study focused on the HCPs' beliefs and attitudes.

Purpose of the Research

The purpose of this study was to describe the beliefs, attitudes, and practices of HCPs in a military health care system regarding the purpose and use of ADs.

Research Questions

The research questions were designed to reveal the attitudes and practices that HCPs in a military health care setting have about the purpose and use of ADs. The research questions were:

1. What beliefs do health care providers have regarding the purpose and use of ADs?
2. Have health care providers thought about and discussed their personal beliefs about end-of-life preferences with any one?
3. Have health care providers completed their own ADs?
4. Do health care providers initiate and facilitate conversations with their patients regarding the purpose and use of ADs?
5. Under what circumstances do health care providers discuss the purpose and use of ADs?
6. What patient education techniques and resources do health care providers employ?
7. Are health care providers comfortable with their skills and training in the arena of ADs?

Definition of Relevant Terms

Advance directive (AD). "A written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State) and relating to the provision of such care when the individual is incapacitated" (USCCAN, 1990, p. 1388-115).

Beneficence. "The principle of doing or producing good" (Mish & Gilman, 1991, p. 144).

Durable power of attorney for health care. A written statement for assigning a surrogate decision maker to be the individual's health care agent in the event of incapacity (Doukas & McCullough, 1991).

End-of-life issues. Medical treatments, or interventions, or both that are implemented when a person is reaching the end of life or is a victim of a catastrophic illness (Teno & Lynn, 1996).

Health care provider (HCP). Any physician, nurse practitioner, or physician assistant who provides health care services to a patient in a military health care system.

Informed consent. "Providing the information about the nature of a patient's medical condition, the objectives of the proposed treatments, treatment alternatives, possible outcomes, and the risks involved" (ACP, 1992, p.949). The doctrine of informed consent additionally involves the content of the information presented. Effective patient-HCP communication promotes better patient understanding of the proposed treatments and promotes patient satisfaction with the choice. This information is then used by the patient who should be the ultimate decision maker regarding his or her care.

Justice. The principle or ideal of a just dealing or right action. The morally correct distribution of benefits or burdens to society (ACP, 1992; Mish & Gilman, 1991).

Life-sustaining treatments. Any medical intervention, technology, procedure, or medication that is given to prolong life (Hastings Center, 1987). For the purpose of this research, life-sustaining treatments are limited to the use of cardiopulmonary resuscitation, mechanical ventilation, and tube feedings.

Living will. A document indicating patient preferences concerning the administration of life-sustaining treatments in the event of a terminal illness, unconsciousness, or permanent vegetative state that would prevent the individual from expressing preferences (Doukas & McCullough, 1991).

Nonmaleficence. The duty to do no harm to patients (Yeo & Molke, 1996). Nonmaleficence includes the obligation to protect the patient from danger, pain, and suffering.

CHAPTER TWO: LITERATURE REVIEW

Unfortunately, the PSDA has resolved few of the complex issues surrounding the purpose and use of ADs. Six years after the activation of the PSDA patients are still struggling for a voice in their end-of-life care. An advance care planning document with a focus on patient treatment preferences has eluded patients and HCPs alike. They have been difficult to formulate, communicate, and implement. The lack of completion of a comprehensive document has been blamed on numerous patient and HCP barriers. Facilitating patient completion of a value based AD based on the ethical principles of autonomy, informed consent, beneficence, and justice has not been a reality. Dr. Sarah Fry (1996) contends that utilization of a moral decision making process can be enhanced by using a systematical process of ethical analysis. Her model for moral decision making integrates the four key elements of personal values and beliefs, a professional code of ethics, moral concepts, and ethical principles. The first step of making a moral decision requires a study of the ethical or moral dilemma that one faces.

Barriers to Completion of ADs

Ross and West (1995) identified one major barrier to completion of ADs as:

The reliance on inpatient facilities to perform a service that perhaps should take place in an outpatient setting. The law provides little encouragement to prepare advance directives before the need arises. Furthermore, patients who are acutely ill may be unable to discuss treatment options (p. 356).

Studies have identified numerous reasons for the failure of AD completion in the inpatient setting. Meier and colleagues (1996) identified three reasons for low

completion rates: cognitive impairment of patient on admission; patients waited for the HCP to initiate the discussion' and inadequate public and professional education on the topic of ADs. Laster (1994) and Barrett (1994) reported that patients preferred that a family member make end-of-life decisions, yet the patient never discussed his or her preferences with the family. Also cited was the patient's preference of letting the physician make the decisions (Barrett, 1994; Virmani, Schneiderman, & Kaplan, 1994).

A variety of reasons were identified as potential causes for non-completion of ADs, regardless of the type of patient care setting. Concern regarding irrevocability was one reason patients do not complete ADs (Miles, Koepp, & Weber, 1996). The other reasons include fear, apathy, and the attitude that they are young and healthy. The belief that no one will honor the ADs and poor readability of the actual documents also play a role (Annas, 1995; Ott & Hardie, 1997). The lack of appointment time, or monetary reimbursement, or both, were identified as additional barriers (Hare & Nelson, 1991; Meier et al., 1996; Morrison et al., 1994; Sulmasy, Song, Marx, & Mitchell, 1996).

Facilitating Completion of ADs

Many researchers insist that the best way to facilitate completion of ADs is in the outpatient encounter with the primary care provider (Doukas & Brody, 1992; Duffield & Podzamsky, 1996; Sulmasy et al., 1996; Wanzer et al., 1989). These authors cited the following reasons for encouraging completion of ADs in the outpatient setting. One reason identified was that the primary HCP has a long term relationship with the patient (Duffield & Podzamsky, 1996; Miles et al., 1996). The role of the primary HCP as a patient advocate was cited by Doukas and Brody (1992). The inappropriateness of addressing these sensitive issues while the patient was sick and under severe stress was

cited by Sulmasy, Song, Marx, and Mitchell in 1996. Meir et al. (1996) stated most outpatients are typically well and have full cognitive ability to make decisions. Finally, the repeated exposure to the purpose and use of ADs enhances completion of a value based AD (Barrett, 1994; Laster, 1994).

Current literature and research support the need for the primary HCP to initiate end-of-life discussions and promote patient completion of a value based AD (ACP, 1992; Hare & Nelson, 1991; Sulmasy et al., 1996; Teno & Lynn, 1996; Thurber, 1996). Value based advance planning is a way for the patient to communicate his or her life long goals with emphasis on the health care decisions that impact the end-of-life (Doukas & McCullough, 1995; Teno & Lynn, 1996).

Doukas and McCullough (1991) support the need for obtaining a patient's value history. This history elicits values that are important in the event of a terminal illness or PVS (Doukas & Reichel, 1993). It opens a channel for HCP-patient conversation that encourages honest communication of the patient's condition and outcomes of therapy. This allows the patient to consider contingency plans that guide the HCP in defining and measuring patient preferences in certain scenarios. These scenarios should include patient preferences about cardiopulmonary resuscitation, ventilator support, and termination of life-sustaining treatments (Doukas & McCullough, 1991; Doukas & Reichel, 1993). Obtaining patient preferences on specific interventions gives the HCP more latitude with treatment options (Thurber, 1996). Thurber (1996) stated, "To this end, the use of value-focused advance directives would best serve the patient and physician goals" (p. 59).

Moral Decision Making Process

A systematic approach to the completion of a morally and ethically based AD is paramount (Sulmasy, FitzGerald, & Jaffin, 1993). This moral decision-making process enhances the validity of ADs by demonstrating that patient and HCP have reached the decision together (Danis, 1994). Seigler et al. (1991) endorsed the use of clinical ethics to provide HCPs with a conceptual moral-reasoning foundation to address ethical issues encountered in daily practice (Catalano, 1995; Doukas & McCullough, 1991). The process of moral decision-making is the theoretical foundation for this study and is based on several ethical principles.

Clinical Ethics

The process of making an ethically based decision is complex. Ethically based decisions regarding end-of-life care need to consider the patient's well being, for instance, benefiting more than burdening the patient (Hastings Center, 1987). Additionally, these decisions need to consider that patient's have the right to control decisions about his or her body and life. Together these provide for patient autonomy and beneficence. Combined with the HCPs' professional code of ethics, these actions affirm that the moral decision is made in a systematic, truthful manner that best suits the patient's and HCP's needs.

The American College of Physicians (1992) *Ethics Manual* states that current understanding of medical ethics is based on the fundamental principles of autonomy (self-determination), beneficence, nonmaleficence, and justice. One must recognize the need for truth telling, disclosure, and informed consent as additional considerations in

patient autonomy. In some cases moral ideas or principles conflict, creating an ethical dilemma (Yeo, 1996). The following discussion will address these ethical principles and their relevance to ADs.

Autonomy

Thompson and Thompson (1981) contend that autonomy and self-determination are major threads linking the ethical principles of beneficence, nonmaleficence, justice, truth telling, disclosure, and informed consent. The health care provider must recognize the patient as an autonomous agent who will make decisions based on his or her value and belief systems (ACP, 1992; Miller, 1981). The recognition of the patient as an autonomous decision maker is at the heart of the patient-HCP relationship.

“The physician-patient relationship always includes an important ethical dimension, no matter what setting or type of practice” (Sulmasy et al., 1993, p. 775). This relationship is founded on mutual trust and the respect for the patient’s values, beliefs, and view points (ACP, 1992; Seigler et al., 1991).

One of the significant changes in modern ethics is the locus of control for decision-making (Yeo & Molke, 1996). Under the locus of control approach, the patient is the primary decision maker and is considered an autonomous agent. Patient autonomy can be furthered by professional actions of the HCP. Actions, including acceptance of the patient’s individuality, full disclosure of information regarding procedures and treatment options, allowing time for deliberation and moral reflection, expressing compassion, awareness of the patient’s beliefs, values, and cultural diversity all support patient

autonomy (Miller, 1981). Open communication and acceptance of the patient's choices for end-of-life care facilitates informed decision-making, thus reinforcing autonomy. Patient autonomy is diminished when there are obstacles such as sickness or mental impairment blocking the capacity to logically consider treatment options (Osman & Perlin 1994).

Informed Consent

Informed consent goes beyond whether or not the patient gives permission for treatment. It focuses on the content of information the patient has available to make treatment decisions (ACP, 1992). Effective patient-HCP communication promotes better patient understanding of the proposed treatments and promotes patient satisfaction with the choice. The HCP is obligated to disclose all information in an unbiased, uncoerced, manner to prevent any swaying of the decision. Disclosure of information should be given in terms that the patient understands. The HCP must be sensitive to the patient's rights, values, and choices. Patient autonomy is reinforced when the patient, not the HCP, controls the information (Thompson & Thompson, 1981). This patient control reduces the chance of paternalism.

The principle of truth telling refers to the requirement of HCPs to honestly present the facts and not mislead the patient (Catalano, 1995). Truthfulness is expected in the patient-HCP relationship and is the key to formulating an ethically based practice. Medical paternalism may occur when the HCP wants to protect the patient from knowledge of the severity of his or her diagnosis or prevent the patient from selecting treatment options that are futile (Osman & Perlin, 1994).

Beneficence

Beneficence is defined as the “duty to promote good and prevent harm to patients” (ACP, 1992, p. 947). Preventing or removing some harm or directly acting to produce good all fall within the realm of beneficence (Yeo & Molke, 1996).

Beneficence requires HCPs to act in a way that benefits others. Sometimes the best treatment option may cause temporary harm to the patient, but will eventually produce a greater good in the course of the illness (Catalano, 1995). Opposition arises when the patient refuses a treatment and the HCP feels that the unwanted treatment will help the patient.

Nonmaleficence

The same training, skills, and powers that health professionals use to produce benefit can also produce harm. Nonmaleficence is the duty to do no harm to patients (Yeo & Molke, 1996). Nonmaleficence includes the obligation to protect the patient from danger, pain, and suffering (Osman & Perlin, 1994). Medically futile interventions may produce harm and prolong suffering (Danis, 1994). The HCP must take a proactive approach that describes to patients what these medical interventions are and their benefit to risk ratio. This may discourage the use of aggressive interventions in futile situations and negotiate for a better and more humane care option (Doukas & McCullough, 1995).

Justice

Medically futile interventions drain precious resources (Wear & Logue, 1995). The principle of distributive justice involves the delicate balance between medical need, cost effectiveness, and the larger impact on society. Justice is “the principle of dealing fairly and equitably with people” (Doukas & Reichel, 1993, p. 44). Justice in the medical

realm of ethics demands an individual's right to have access to health care they need on an equitable basis (Hastings Center, 1987). With the advent of managed care and inequitable insurance options many persons are limited in the amount and type of treatments they can afford. The managed care environment perpetuates the HCPs' need to balance patient treatments with incurred costs. The HCP also has a societal responsibility to use health related resources in a technically appropriate and efficient manner (Yeo, Moorhouse, & Donner, 1996).

"In ethical decision making, prevention takes the form of early action to record patient wishes and values, rather than waiting for a crisis with a newly incompetent patient whose wishes are unknown" (Doukas & Brody, 1992, p. 203). La Puma and Schiedermayer (1989) assert that outpatient completion of ADs allows the patient and family to assume responsibility for understanding end-of-life choices. The outpatient setting allows the HCP to continuously utilize a systematic process of inductive and deductive reasoning to facilitate making moral decisions (Catalano, 1995). These decisions are a mutual agreement between the HCP and patient.

Moral ideals or principles as we live them are sometimes vague or even confused (Yeo, 1996). Seigler and colleagues (1991) claim that the goal of clinical ethics is to improve the quality of patient care by analyzing and attempting to resolve ethical dilemmas that impact clinical practice. The daily use of clinical ethics is the standard of care. Patients and their situations are all different. There are many different moral decision-making frameworks that can be used to help patients reach a morally sound decision (Fry, 1996). Ethicists recognize that decision making is a complex process that has many components. These components consist of personal values and beliefs, codes

of ethics, moral concepts basic to the profession, and ethical principles (Fry, 1996; Hastings Center, 1987; Thompson & Thompson, 1981).

CHAPTER THREE: CONCEPTUAL FRAMEWORK

The conceptual framework for this research is founded on the ethical principles that are utilized when one makes a moral decision. Fry (1996) has outlined four components that contribute to a moral decision and sound action plan. She identifies these components as personal values and beliefs, ethical principles, ANA codes of ethics, and moral concepts of nursing. These four components are the key elements that are needed prior to implementing any formal moral decision making model.

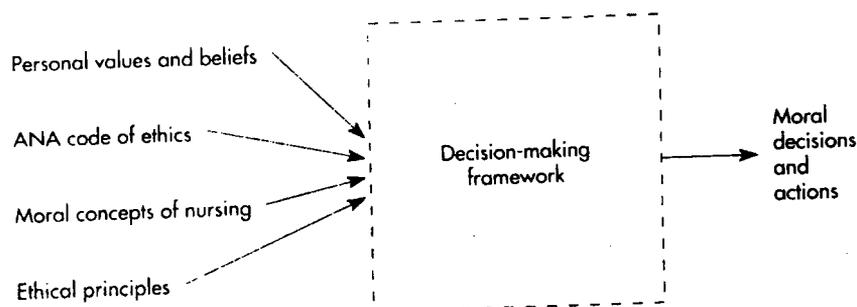


Figure 1.

Essentials of moral decisions and actions in nursing practice

Note. From Conceptual foundations in professional nursing practice (p.275)
by J. Creasa & B. Parker, 1996, St Louis: MO.

Personal values and beliefs are directed at both the patient and HCP. A value is defined as a worthwhile or desirable standard or quality that is incorporated into a person's belief system. These guide one's motivation and personal choices. Value identification through introspection and self-reflection are the first step in making ethical decisions.

The second step in moral decision making is to understand why these values are important to the individual and what their priority rankings are his or her belief system

(Fry, 1996). As discussed in the literature review consideration of the patient's right for value based decisions is essential for preparing for an AD. The HCP has equal rights to consider his or her own personal values and moral conscience (Hastings Center, 1987). The goal is for the HCP to be flexible enough to respect the patient's values without compromising professional standards.

The principles that form standards of practice come from the moral traditions of medicine and nursing (Hastings Center, 1987). The term *ethics* has numerous definitions. The definitions pertaining to moral decision making are: a set of moral principles or morals, a theory or system of moral principles or values, a philosophical mode of inquiry that helps one understand moral dimensions of human conduct, the principles of conduct governing an individual or group, or conforming to professional standards of conduct (Fry, 1996; Mish & Gilman, 1991).

Professional standards of conduct for advanced practice registered nurses are determined by the American Nurse's Association (1996). The ANA emphasizes that the advanced practice registered nurse (APRN) has an ethically based practice. The ANA (1996) has defined the role of clinical ethics for the APRN as:

The advanced practice registered nurse makes clinical and ethical decisions and takes action. The advanced practice registered nurse acknowledges the client's rights of self-determination, truthful disclosure, privacy, and confidentiality and respects the client's dignity and cultural beliefs. She or he serves as an advocate for the client and is obligated to demonstrate non-judgmental and non-discriminatory behaviors that are sensitive to client diversity. Advanced practice

registered nurses work to facilitate client decision making, promote ethical practice environments, and protect professional integrity (p. 5).

Health care providers have strict ethical obligations to the patient by virtue of their professional status and role (Hastings Center, 1987). Ethical obligations combined with professional moral concepts ensure patient autonomy is met (Catalano, 1995).

Basic moral concepts in nursing include advocacy, accountability, cooperation, caring, and fidelity (Fry, 1996). These core concepts are taught from the first day of nursing school and reinforced in daily practice. The ANA (1996) standards of practice incorporate these concepts into the role of the APRN.

The components that Fry (1996) addressed in the process of decision making are echoed by the American Medical Association (ACP, 1992), the American College of Physician Assistants (Osman, & Perlin, 1994), and the Hasting Center (1987). These professional organizations stress that all HCPs need to address their own personal beliefs and morals prior to engaging in moral decision making (ACP, 1992; Hastings Center, 1987; Perry & Breitner, 1982). Each organization has issued a position statement on the ethical principles and moral concepts required for the end-of-life decision making process.

Utilizing ethical moral decision-making models to resolve complex ethical dilemmas and to guide the patient and the HCP is an excellent way to promote a comprehensive plan of care and can prevent an erroneous decision (Catalano, 1995).

CHAPTER FOUR: METHODOLOGY

Methodology

This chapter describes the study methodology, research design, instrumentation, validity and reliability testing, sampling, and protection of human rights. The study population consisted of HCPs at a medium sized Air Force military medical treatment facility (MTF).

Study Design and Instrumentation

Descriptive research helps to identify trends and note discrepancies in current practice. A descriptive design was chosen for this study to help identify HCPs' beliefs and attitudes about ADs and then describe the use of ADs in their current practice. This descriptive study used a questionnaire to elicit responses describing HCPs attitudes, and practices regarding the purpose and use of ADs.

The interest in this topic was sparked by the researcher's personal experience with dying patients who had requested to have life sustaining interventions terminated. The research process started when the researcher requested the use of a research instrument used by Johnston et al. (1995) and the End of Life Study Group (see Appendix C). This instrument was used to collect data in a descriptive study that was published in the May 22, 1995, Archives of Internal Medicine. The title of the article was "The discussion about advance directives. Patient and physician opinions regarding when and how it should be conducted". The End of Life Study Group consisted of physicians holding faculty or fellow positions at the University of North Carolina - Chapel Hill from 1992 to 1994.

The questionnaire employed in this study was developed in three parts. First, Pfeifer et al. (1994), members of the End of Life Study Group, conducted a qualitative research study that surveyed physicians and patients on their beliefs, attitudes,

preferences, and expectations regarding the discussion of end-of-life medical care. Also identified were factors limiting the quality and frequency of these discussions. Johnston et al., (1995) analyzed these qualitative results and developed a quantitative questionnaire. The questionnaire consists of nominal and ordinal questions and Likert rating scale questions designed to elicit a respondent's attitudes and beliefs regarding the purpose and use of ADs. Finally, modifications were made by this researcher to capture specific data for this study. These modifications will be discussed later in this chapter.

The questionnaire contained five sections. Section I was designed to elicit data on demographics. Section II dealt with on personal practices. Section III described professional opinions and beliefs. Section IV centered around professional practices. Section V delineated professional skills and training.

The questionnaire utilized a mix of questions including nominal, forced choice with response sets, yes and no questions, and Likert rating scales. Nominal questions were in Section I, Items A through J. Forced choice questions were in Section III, Items A, B, E, and H, and Section IV, Items C, D, and E. Yes-No answer questions were in Section II, Items A, B, C, and D and Section V, Item B. Likert rating scale questions were in Section III, Items C, D, F, and G; Section IV, Items A and B; and Section V, Item A. Two forms of the Likert rating scale were used. One scale gave the subjects the choices of strongly agree, agree, not certain, disagree, and strongly disagree. The second scale gave the subjects the choices of never, rarely, sometimes, often, and very frequently.

“Researchers are encouraged to use questions in exactly the same form as those in previous studies to facilitate comparing results between studies” (Burns & Grove, 1993,

p. 370). The majority of the original questions were unchanged to preserve comparison with previous and future studies. One adaptation of the end-of-life tool involved expanding Section I questions on demographic data. The instrument modifications generated demographic information on the personal backgrounds of the HCPs. The background information included: age, licensure, (Physician, Nurse Practitioner, or Physician Assistant), clinical experience, and time in military or civil service. Another adaptation was changing the wording from physician to HCP and living will to advance directive.

The content portion of the questionnaire was adapted to obtain information on the unique position of HCPs in a military practice setting. Section III, Item H and Section IV, Items C and D were modified by changing the reference time points to military equivalent time points. Section V, Item A modifications included adding two additional choices on the HCP beliefs of not having adequate skills or the belief of not needing the skills to discuss ADs. Three questions were dropped because their focus was not within the scope of this study. One pertained to the management of disagreements between doctors and patients on the use of life-sustaining treatments. Another question pertained to the point when the discussion of ADs should occur in the provider-patient relationship. The final question concerned provider perceived barriers to discussions on life-sustaining treatments (Appendix B "Health Care Provider Questionnaire").

Validity Testing

Validity of an instrument is a determination of the degree to which the tool actually reflects the concept being studied (Burns & Grove, 1993). The validity of an instrument may vary from one sample to another or from one situation to another.

Estimates of the content validity of the End Of Life study group's questionnaire was accrued in three ways by the initial developers of the tool. First, the investigators conducted a qualitative research study to determine practicing physicians beliefs and practices regarding the purpose and use of ADs. Next, these researchers formulated a quantitative questionnaire based on the respondents' answers. Finally, a pilot study for content validity was completed (Johnston et al., 1995).

The thesis proposal and modified questionnaire used in this study were reviewed for military relevance, significance to military wartime readiness, and medical-legal implications by the chief legal advisor to the Air Force surgeon general, who concurred that this research had significance to military readiness and the deployment of troops. Two clinical experts then reviewed the modified questionnaire for content validity. The first medical expert was a senior military physician active in medical ethics and the use of ADs in military MTFs. The second expert was a military nurse practitioner with over 20 years experience. These reviewers were given a copy of the proposal, questionnaire, and a content validity index scoring tool. The reviewers rated each question in terms of content relevance using a 4-point scale. The questions were ranked on a scale ranging from 1 (not at all relevant) to 4 (very relevant). The content validity index, based on these results, was calculated to be 1.0. This score indicated that both reviewers rated all of the items as relevant or very relevant to the purpose of the study.

The only suggestion for revision was to the professional practice portion of the questionnaire. This suggestion resulted in the addition of a choice for subjects to select if they had never counseled patients about ADs.

Reliability

The original researchers conducted a pilot study to determine reliability of the questionnaire. This researcher did not perform a test-retest on the adapted questionnaire due to the time limitations of the study.

Research Approval

A complete copy of the study thesis proposal and modified instrument were submitted for research approval. Research approval was received by the thesis committee, the Institutional Review Board at the Uniformed Services University, and the Institutional Review Board at the MTF (see Appendix D and E).

Sampling Method

A convenience sampling method was used for this study. The potential number of sample participants were 150 military and civilian physicians, 11 nurse practitioners, and 15 physician assistants who were assigned to the MTF. The Air Force, the identified target population, currently consists of 3114 physicians, 210 nurse practitioners, and 416 physician assistants (Major Conrad, personal communication April 18, 1997).

The investigator traveled to the MTF and distributed the questionnaire packets at continuing education offerings, staff meetings, morning report, and inservice training. Each questionnaire was accompanied by a letter covering the purpose of the study, name of the researcher, university affiliation, directions for completion and return to the researcher. All questionnaires had a self-addressed, stamped envelope for return.

One hundred and forty-three questionnaires were distributed at the MTF. Twenty-seven questionnaires were returned to the investigator prior to leaving the MTF. An additional 34 questionnaires were returned via the mail for a completion rate of 43 %.

Ethical Considerations

Participation in this study was voluntary. A letter covering the purpose of the research, implications of the research and that completion of the questionnaire implies consent (see Appendix A).

At no point were participants identified by name. Completed questionnaires were returned to the researcher in sealed envelopes. Only the investigator was allowed access to the completed questionnaires. All participants were offered the opportunity to obtain completed results of this study.

Summary

The descriptive nature of the study allowed for identification of the beliefs, attitudes, and practices of HCPs. The questionnaire was lengthy and asked many questions about HCPs' opinions on the purpose and use of ADs. It asked the subjects about their personal and professional beliefs about ADs. These beliefs included who should be involved and what should be discussed. The questionnaire asked the subjects about their personal and professional practices such as if they had completed a living will for themselves and when and how they had discussed ADs with their patients. Finally, it asked if they were comfortable with their skills and training regarding ADs.

The research process continued with the data coding and entry of the subject responses. The data were entered and analyzed using the Statistical Packages for the Social Sciences (SPSS). Descriptive statistics including frequency, means, and ranges were generated to summarize the data.

The next chapter will present the data in raw numbers and text. Chapter Six will summarize the data compared to current literature available, make conclusions, and make recommendations for further research.

CHAPTER FIVE: ANALYSIS OF THE DATA

The ultimate goal of any research is to provide new knowledge, insights, and perspectives. The purpose of this study was to describe HCPs beliefs, attitudes, and practices regarding the purpose and use of ADs. This chapter will present the findings obtained from the data collection. The data will be presented in narrative and graphical format.

Return Rate

The data were obtained by distributing 143 questionnaires. Sixty-one were returned for a response rate of 43 %, an acceptable return rate for mailed questionnaires. Typically mailed questionnaires have a 25-30 % return rate (Burns & Grove, 1993). Not one of the questionnaires was excluded from the study, but some subjects selected multiple answers and some subjects opted not to answer certain items of the instrument. The item where multiple answers were selected were scored like an item with no response. This accounted for the varying response rates for specific items. No questionnaires were received after the established deadline.

Demographic Information

The demographic data are summarized in Table 2. Subject composition is summarized in Table 3. Number of years in practice is summarized in Table 4.

Table 2

Subject Demographics

Demographics	
GENDER	Percentage
Male	77 %
Female	23 %
AGE	Years Old
Range	24-56 years old
Mean	35 years old
ETHNICITY	Percentage
Caucasian	89 %
Asian	7 %
Other	4 %
MEDICAL SPECIALTY	Percentage
Internal Medicine	31 %
Family Practice	14 %
Emergency Medicine	12 %
Obstetrics and Gynecology	10 %
Medical Students	10 %
Orthopedics	8 %
Acute Care	3 %
Other: women's health, anesthesia, general surgery	12 %
HIGHEST EDUCATION	Percentage
Medical Degree	74 %
Bachelors Degree	16 %
Masters Degree	5 %
Doctoral Degree	5 %

Table 3

Percentage of Subjects to Medical Treatment Facility Population

	Sample N = 61	Percentage
Physicians	48	80 %
Nurse Practitioner	2	3 %
Physicians Assistants	4	7 %
Medical Students	11	Unknown

Table 4

Number of Years in Practice Settings

Practice setting	N	Mean	Range
Current Practice	61	4 years	< 1 year - 30 years
Health Care Related Positions	61	9.5 years	1 year - 30 years
Armed Service	52	7 years	< 1 year - 23 years
Civil Service	9	1.5 years	< 1 year - 23 years

Note. Current practice defined as clinic or unit assigned. Health care related position defined as any paid or volunteer work in medical field. Armed Services defined as a member of the uniformed services serving the US government. Civil service defined as any position held in a US government medical treatment facility.

Research Question One

What beliefs do health care providers have regarding the purpose and use of ADs?

Section III Professional Opinions and Beliefs, Items A, B, C, D, E, F, G, and H pertained to this research question in that these sections described the subjects' professional beliefs about the purpose and use of ADs and about discussions and decisions concerning the use of life-sustaining treatments.

Item A asked the subjects who they believed should first start the discussion about life-sustaining treatments. Eighty-two percent answered that HCPs should bring it up first, but that patients could if they desired. Twelve percent answered that patients should bring it up first, but HCPs could if they so desired. Two percent answered that the HCPs should always bring it up first. Five percent were undecided. There were no responses for the choice of 'patients should always bring it up first'.

Item B asked the subjects their beliefs on who should be the primary decision maker with respect to the use or withdrawal of life-sustaining treatments for competent patients who can communicate. Eighteen percent answered that both the patient and HCP are equally responsible. Eighty percent answered that the patient is primarily responsible. Two percent answered that the HCP is primarily responsible. None of the subjects answered that the family is primarily responsible.

Item C asked the subjects who they believed, in addition to the HCP and patient, should be involved in the discussion about the use of life-sustaining treatments. See Table 5 for a summary of results .

Table 5

Who Should be Included in The Discussion about the use of Life-Sustaining Treatments

Who should be included in the discussion	N	Mean	Standard Deviation
Spouse/Significant Other should definitely be involved	59	1.4	0.62
Family should definitely be involved	60	1.9	0.77
Lawyer should definitely be involved	59	3.34	1.27
Clergy should definitely be involved	59	2.58	0.95

Note. Yes = 1; No = 2; Not Certain = 3; Not Applicable = 4.

Item D asked the subjects to indicate their extent of agreement on specific statements about ADs. The extent of agreement was determined by using a five point Likert scale indicating (1) strongly agree, (2) agree, (3) not certain, (4) disagree, and (5) strongly disagree. The results are summarized in Table 6 for the 61 respondents.

Table 6

Opinions Regarding Advance Directives

Statements about advance directives	Mean	Standard Deviation
Are very useful in stimulating discussion between patients and Health Care Providers about the use of life-sustaining treatments	1.66	0.7
Should be re-evaluated during serious illness	1.7	0.74
Help patients make decisions about life-sustaining treatments	1.87	0.78
Increase patient understanding of life-sustaining treatments	2.11	0.78
Adequately convey patients' wishes about the use of life-sustaining treatments	2.59	1.05
Are not useful because patients frequently change their minds during serious illness	3.57	0.81
Hinder patients' ability to change their minds about life-sustaining treatments	3.69	0.89
Hinder future discussion about life-sustaining treatments	3.69	0.94
Are legal documents and they protect you from malpractice	3.87	0.97
Make future discussions unnecessary	4.2	0.6

Note. Likert rating scale: strongly agree (1), agree (2), not certain (3), disagree (4), and strongly disagree (5).

Item E asked the subjects to select a statement that best described their beliefs about discussing life-sustaining treatments and making a decision. Forty-eight percent

answered that the health care provider should provide the facts about life-sustaining treatment and make a recommendation so that the patient could decide. Forty-eight percent answered that the HCP should give all the facts about life-sustaining treatments, make no recommendations, and let the patient decide. Four percent answered other.

Item F asked the subjects to rate their degree of agreement with the importance of specific types of information used in facilitating patient decisions about life-sustaining treatments. See Table 7 for a summary of results from the 61 respondents.

Table 7

Types of Information Health Care Providers Utilized to Make Decisions about Life-Sustaining Treatments

Types of information	Mean	Standard Deviation
The chance of surviving and fully recovering	1.28	0.49
The possible effects that life-sustaining treatments might have on the patient's quality of life	1.28	0.45
A description of what life-sustaining treatments are	1.3	0.46
The chance of surviving but not fully recovering (e.g., staying in a coma)	1.33	0.54
The patient's state of health at the time of the discussion	1.44	0.59
The possible effects that the life-sustaining treatments might have on the patient's family (e.g., cost, physical suffering)	1.66	0.73

Note. Likert rating scale: strongly agree (1), agree (2), not certain (3), disagree (4), and strongly disagree (5).

Item G asked the subjects their belief under what circumstances HCPs should discuss the use of life-sustaining treatments with their patients. See Table 8 for a summary of results from the 61 respondents.

Table 8

What Circumstances Should Health Care Providers Discuss the use of Life-Sustaining Treatments

Circumstances that HCP believe AD discussions should occur	Mean	Standard Deviation
When a serious chronic disease is diagnosed	1.87	0.92
When a patient is critically ill	1.92	0.86
Later in the course of managing a fatal disease	2.02	1.13
When a fatal disease is first diagnosed	2.08	1.19
Prior to a deployment	2.28	1.08
During a routine appointment with no active medical problems	2.32	0.91
During a retirement physical	2.49	1.04
During any appointment that the patient comes to see you	2.98	1.08

Note. Likert rating scale: strongly agree (1), agree (2), not certain (3), disagree (4), and strongly disagree (5).

Item H asked the subjects their beliefs on what time period should health patients and their HCPs start discussing whether or not to use life-sustaining treatments. Eighty-three percent answered 'any time'. Ten percent answered on yearly physical exams. Seven percent of the subjects answered 'other'.

Research Question Two

Have health care providers thought about and discussed their personal beliefs about end-of-life preferences with any one?

Section II Personal Practices, Items A, B, and C pertain to the research question in that it asked the subjects about their personal preferences and practices about the use of life-sustaining treatments for themselves. Item A asked the subjects if they ever thought about their own preferences to the initiation or withholding of life-sustaining treatments if needed. Ninety-three percent of the subjects answered yes.

Item B asked the subjects the specific question “In your current health, if you had a cardiac arrest, would you want life-sustaining treatments attempted?” All but one subject answered yes.

Item C asked the subjects with whom had they discussed their preferences on the use of life-sustaining treatments. See Table 9 for a summary of results from the 61 respondents.

Table 9

Health Care Providers Discussion of their Personal Preferences.

With whom had the subjects discussed their end-of-life preferences	Percentage
Spouse/significant other	64 %
Friends	53 %
Family	49 %
Health Care Provider	12 %
Other	13 %

Research Question Three

Have health care providers completed their own ADs?

Section II Personal Practices, Item D pertained to the research question in that it asked the subjects if they ever had signed a living will or durable power of attorney for health care for themselves. Eighty-two percent answered no.

Research Question Four

Do health care providers initiate and facilitate conversations with their patients regarding the purpose and use of ADs?

Section IV Professional Practices, Items A and B pertained to the research question in that it asked the subjects about their actual professional practices for the discussion on the purpose and use of ADs. Twenty-one percent answered that they had never discussed ADs or life-sustaining treatments.

Item A asked the subjects the frequency they utilized specific methods in initiating discussions about life-sustaining treatments. See Table 10 for a summary of results from the respondents.

Table 10

Methods for Initiating Discussions about Life-Sustaining Treatments

Methods of initiating discussions	N	Mean	Standard Deviation
I imply a sense of urgency and need to decide, and ask the patient to make a decision	47	1.96	0.78
I offer an opinion of what the patient should do	48	2.23	0.9
I give all of the facts and await the patient's decision/response	48	2.91	0.92
I introduce the issues, ask the patient to discuss the situation with their family, and then discuss at later visits	45	3.49	0.92
I ask the patient if they have a Living Will or Durable Power of Attorney for Health Care	48	3.56	0.92

Note. Likert rating scale: never (1), rarely (2), sometimes (3), often (4), and very frequently (5).

Item B asked the subjects the type and amount of information they discuss on life-sustaining treatments. See Table 11 for a summary of results from the respondents.

Table 11

Description of Life-Sustaining Treatments

How HCP describe life sustaining treatments	N	Mean	Standard Deviation
Always give detailed descriptions of life-sustaining treatments	45	2.47	1.01
Only provide details at patient's request	43	3.16	1.02
Use stories about similar patients	43	3.33	1.04
Vary detailed descriptions in order to influence decisions that I feel are appropriate	44	3.52	0.99

Note. Likert rating scale: strongly agree (1), agree (2), not certain (3), disagree (4), and strongly disagree (5).

Research Question Five

Under what circumstances do health care providers discuss the purpose and use of ADs?

Section IV Professional Practice, Items C and D pertain to the research question in that they asked the subjects about their professional practices on the purpose and use of ADs and circumstances of counseling on life-sustaining treatments. Twenty-one percent answered that they had never discussed ADs or life-sustaining treatments.

Item C asked the subjects to select any or all of the circumstances in which they discuss the use of life-sustaining treatments with their patients. See Table 12 for a summary of results from the 59 respondents.

Table 12

Circumstances that Health Care Providers Discuss the use of Life-Sustaining Treatments

Circumstances that HCP discuss ADs	Percentage
When a serious chronic disease is diagnosed	66 %
When a patient is critically ill	63 %
Later in the course of managing a fatal disease	60 %
When a fatal disease is first diagnosed	55 %
During any appointment that the patient comes to see you	29 %
During a routine appointment with no active medical problems	23 %
During a retirement physical	12 %

Note. The subjects could select any or all of the choices that applied.

Item D asked the subjects at what time do they discuss the use of life-sustaining treatments with their healthy patients. Forty-three percent answered “when the patients bring it up”. Twenty-six percent answered that they would discuss it at any time. Nineteen percent answered “never”. Nine percent were undecided. Two percent answered it should be discussed on yearly physical exams. Two percent answered “other”.

Research Question Six

What patient education techniques and resources do health care providers employ?

Section IV Professional Practices, Item E pertained to the research question in that they asked the subjects about their professional practices on which patient education

resources they utilize. Twenty-one percent answered that they had never discussed ADs or life-sustaining treatments.

Item E asked the subjects to select any or all of the specific patient resources available on the use of life-sustaining treatments. See Table 13 for a summary of results from the 54 respondents.

Table 13

Resources Available to your Patients Regarding Decisions for Life-Sustaining Treatments

Resources health care providers use	Percentage
Conversations with their health care provider	79 %
Conversations with admitting personnel at the time of hospital admission	53 %
Routine literature given to the patient at the time of hospital admission	52 %
Conversations with nurses	42 %
Waiting room literature	23 %
Specific education programs about end of life issues and advance directives	20 %

Note. The subjects could select any or all of the choices that applied.

Research Question Seven

Are health care providers comfortable with their skills and training in the arena of ADs?

Section V Professional Skills and Training, Items A and B pertain to the research question in that they asked the subjects about their skills and training on the purpose and use of ADs and discussions about life-sustaining treatments. Item A asked the subjects to rate their extent of agreement with specific statements about their skill and training levels. See Table 14 for a summary of results from the respondents.

Table 14

Practitioner Skills and Training

Practitioner skills and training	N	Mean	Standard Deviation
I have adequate skills to discuss end of life issues with patients	61	1.93	0.98
I received training in this area during school	61	2.82	1.22
I received helpful training in this area while in my current practice	59	3.02	1.14
I do not have adequate skills to discuss end of life issues with patients	61	3.95	0.97
I feel that I do not need the skills to discuss end of life issues with patients	60	4.45	0.77

Note. Likert rating scale: strongly agree (1), agree (2), not certain (3), disagree (4), and strongly disagree (5).

Item B asked the subjects if they believe that HCPs should receive training on facilitating end-of-life discussions and the use or withdrawal of life-sustaining treatments as a part of their formal education. Ninety-eight percent agreed that they should.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

Research provides a means for new understanding of a phenomenon. This chapter will present the findings associated with this study and will provide interpretation of these findings. Problems, limitations, implications of this study, and suggestions for further research will also be explored.

In recent decades there has been enormous amount of literature about ADs and end-of-life planning. This study was prompted by research done in 1993 by Johnston et al. (1995) that examined the perceptions of HCPs and patients on what should be included in the discussions about ADs. They compared HCP's and patient's perceptions on the timing, components, and barriers to discussions. This study modified the HCP portion of their research.

The purpose of this descriptive study was to identify HCPs attitudes and practices on the purpose and use of ADs. The conceptual framework for this study stated that there are four key elements required for moral decision making. These elements were personal values and beliefs, a professional code of ethics, moral concepts, and ethical principles. The research questions of this study were designed to describe if HCPs in a military health care setting had any or all of these elements for moral decision making process in regards to the purpose and use of ADs.

Analysis of the Sample Population

The study subject composition was disproportional to the given sample population. The study MD subject composition was 80 %, which is 31 % of the MTF practicing MD population. The study PA subject composition was 7 %, which

significantly less than the proportion of 36 % of the MTF practicing PA population. The study NP subject composition was 3 %, which was half of the 6% of the MTF practicing NP population. For this reason no attempt was made to describe differences in demographics or subjects responses among the sub-groups of providers. No generalizations could be made about the larger Air Force population from the responses of the subjects.

The specialties of the subjects had a wide range. Internal medicine had the highest response of 31 % followed by family practice at 13 %. Most of the current research has sampled these specialty fields. Other specialties represented in the sample consisted of emergency medicine, obstetrics and gynecology, orthopedics, acute care, anesthesia, and general surgery (see Table 2 for the summary of the subject specialties). The diversity of subjects' practicing specialties added to the validity of the study.

Research Question One

What beliefs do health care providers have regarding the purpose and use of ADs?

Research question one identified who the subject's believed was responsible for initiating the discussions about life-sustaining treatments. The results are summarized in Table 15.

Table 15

Initiation of the Discussion on Advance Directives

Who is responsible to initiate the discussion	This study	Johnston, Pfeifer, McNutt
HCP should bring it up first, but patients can if they desire	82 %	80 %
Patients should bring it up first, but HCP may if they desire	12 %	15 %
Health Care Providers always bring it up first	2 %	4 %
Patients should always bring it up first	0 %	0 %

Note. Results from Johnston, S., Pfeifer, M., & McNutt, R. (1995). The discussion about advance directives. Archives of Internal Medicine, 155(10), 1025-1030.

This study results closely matched the results from Johnston, Pfeifer, and McNutt's (1995) research. Eighty-two percent believed that the HCP should always initiate the conversations about ADs. Morrison et al. (1994) noted that the patient is waiting for HCP to initiate the communication process. They also noted that physician-initiated discussions about end-of-life preferences are more effective than patient-initiated discussions in the completion of ADs.

A relatively small number of the subjects felt it was the patients' responsibility to initiate the conversation. Interestingly, neither of the two studies had subjects who believed that it was solely the patient's responsibility to initiate the discussion.

Research question one sought to identify who subjects believed should make the final decisions about life-sustaining treatments for the competent patient. Eighty percent answered that the patient is solely responsible. Ross and West (1995) supported the premise of patient as primary decision maker thus facilitating autonomy and self determination. Francy's (1990) study supported the notion that the patient must be the

primary decision maker concerning care and not be judged for his or her decisions even if they are contrary to the beliefs and values of others. Eighteen percent felt that there is an equal responsibility between patient and HCP. This belief may have been rooted in the ethical principle of informed consent (ACP, 1992; Miller, 1981). When the HCP fully informs the patient of the treatment plans, benefits, and risks, there is an equal decision making between patient and HCP (Weg, 1994). None of the subjects believed it was the responsibility of the family to make the decision for a competent patient. The ACP ethics manual clearly stated that "all adult patients are considered competent to make decisions about medical care unless the court declares otherwise" (ACP, 1992, p. 949).

The results of research question one described who the subjects believed should be involved in the decision making process. Johnston and colleagues (1995) research also examined this belief. The results are compared in Table 16.

Table 16

Who Should be Involved in the Decision Making

Who should be involved in the decision making process	This study	Johnston, Pfeifer, McNutt
Spouse/significant other	96 %	95 %
Family members	72 %	70 %
Clergy	49 %	5 %
Lawyer	24 %	36 %

Note. Results from Johnston, S., Pfeifer, M., & McNutt, R. (1995). The discussion about advance directives. Archives of Internal Medicine, 155(10), 1025-1030.

Additionally, the ACP (1992) outlined the HCP role in providing patient counseling about ADs. Physicians should raise the issue of ADs routinely with

competent adult patients in outpatient visits and encourage them to provide opportunity to discuss their preferences with their surrogate and family members. Both studies and current literature supported the belief that the spouse and family members need to be involved. Miles et al. (1996) and Laster (1994) stated that between 85 and 90 % of the time when a patient was incapacitated, the proxy decision making responsibility fell to these two groups of individuals. Involving the proxy, or family, or both, keeps confused kin from making a decision against the patient's wishes (Humphry, 1991).

These two studies were closely matched in subject responses with the exception clergy involvement . The study subjects believed in less involvement. This may have been because the mobility of the military population inhibits long term bonds with religious leaders.

Research question one described the subjects' beliefs regarding specific statements pertaining to ADs. The items scored as strongly agree or agreeing were rated as agree with the statement. The items scored as strongly disagree or disagreeing were rated as disagree with the statement. See Tables 17 through 19 for the summation of the results.

Table 17

Agreement with Statements

Advance directives:	Agreement with Statement
Should be re-evaluated during serious illness	91 %
Are very useful in stimulating discussion between patients and Health Care Providers about the use of life-sustaining treatments	90 %
Help patients make decisions about life-sustaining treatments	82 %
Increase patient understanding of life-sustaining treatments	80 %

Note. Responses marked as strongly agree and agree are indicated as agreement with the statement.

The agreement with statements about usefulness of ADs in stimulating discussions and helping patients make the decision was extensively covered in the literature. "Advance planning catalyzes important, memorable, and therapeutic discussions between patients, providers, and family members about emotionally and conceptually difficult issues" (Miles et al., 1996, p. 1066). Virmani et al. (1991) agreed that patients who have executed ADs report a higher discussion rate with their HCP, although these discussions were devoted more towards general attitudes and feelings versus actual decision making.

Table 18

Disagreement with Statements

Advance directives:	Disagree with Statement
Make future discussions unnecessary	94 %
Hinder future discussion about life-sustaining treatments	65 %

Note. Responses marked as strongly disagree and disagree indicated as disagreement with the statement.

Disagreement with the negative statements about ADs, such as ADs hindering future discussions, or hindering the patients' ability to change their minds, or both, had numerous citations in the literature. Miles et al. (1996) cited one of the barriers to patient completion is their fear or irrevocability of previous ADs. Doukas and McCullough (1995) counter argue by pointing out that prevention by early action in recording patient wishes and values was the best way to facilitate open communication.

Some of the statements had mixed responses. Mixed responses for the purpose of this research was any area that had a minimum of 25 % of the subjects selecting not certain as their response. See Table 19 for the summary of the results .

Table 19

Mixed Responses about Advance Directives

Advance directives:	Agree	Not Certain	Disagree
Adequately convey patients' wishes about the use of life-sustaining treatments	48 %	28 %	25 %
Hinder patients' ability to change their minds about life-sustaining treatments	12 %	25 %	64 %
Are not useful because patients frequently change their minds during serious illness	9 %	33 %	59 %
Are legal documents and they protect you from malpractice	10 %	25 %	66 %

Note. Items rated as strongly agree or agree were rated as agree. Items rated as not certain were rated as not certain. Items rated as disagree or strongly disagree were rated as disagree.

Interestingly enough, the topics that brought mixed responses were also debated by the prominent scholars. The questionability of the ADs as legal documents has been argued in many journals. Yet, the PSDA clearly defined an advance directive as “a written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State) and relating to the provision of such care when the individual is incapacitated” (USCCAN, 1990, p. 1388-115). Humphry (1991), president of the Euthanasia Society, recognized that ADs protect the HCP from potential lawsuits by family members. Eliasson, Howard, Torrington, Dillard, and Phillips (1997) noted in their research within a military MTF, that there was a potential for staff members to aggressively pursue DNR orders because of the lack of concern for malpractice. This may have also been true for this study's subjects.

Virmani et al. (1994) stated that ADs were flawed instruments to convey patient wishes to HCPs. Many authors call for using ADs as guidelines to determine what patients would desire, but not as hard and fast treatment protocols (Doukas & McCullough, 1991).

Hanson and colleagues (1997) addressed the issue of the stability of patient preferences, especially in periods of illness. Their research showed that 80 % of older adult patients had stable preferences. Emanuel, Emanuel, Stoeckle, Hummel, and Barry (1994) also demonstrated through their research that patient treatment decisions remained stable. The stability of their decisions improved after reviewing these decisions with their HCP. Their research showed that a recent hospitalization actually strengthened the patient's choices for care.

Research question one described how the subjects believe the information on end-of-life care and life-sustaining treatment should be presented to the patient. Forty-eight percent answered that the HCP should give all the facts about life-sustaining treatments, make no recommendations, and let the patient decide. Many authors supported this belief as true patient self-determination through respecting patient autonomy in the decision making process. Francy (1990) stated the dying persons can expect to be given all necessary information, to have all questions answered, and never to be deceived.

Forty-eight percent responded that all the facts should be given, the HCP should make recommendations, and then the patient must make the decision. Some authors stated that this choice perpetuates paternalism. Other authors argued that this belief is rooted in informed consent (Layson et al., 1994; Miller, 1981). Layson and colleagues (1994) research on discussions about ADs revealed that 50 % of the HCPs studied

admitted to swaying the patient's decision by the manner in which they conducted the counseling on life-sustaining treatments. Hanson et al. (1997) raised the concern that even after face-to-face discussions the HCP's understanding of patient preferences was poor. These authors attributed such findings to the HCP's focus on the description of the treatments rather than listening to patients' preferences. Eliasson, Howard, Torrington, Dillard, and Phillips (1997) stated "The manner in which physicians discuss end-of-life decisions with patients will influence the patient's or family's likelihood of accepting a DNR order" (p.1110).

Research question one identified the subjects' beliefs of which key components of life-sustaining treatments should be discussed. See Table 20 for the summary of the results.

Table 20

Key Components of Discussions

Importance of key component of discussions	Agree with the statement
A description of what life-sustaining treatments are	100 %
The possible effects that life-sustaining treatments might have on the patient's quality of life	100 %
The chance of surviving but not fully recovering (e.g., staying in a coma)	97 %
The chance of surviving and fully recovering	96 %
The patient's state of health at the time of the discussion	95 %
The possible effects that the life-sustaining treatments might have on the patient's family (e.g., cost, physical suffering)	89 %

Note. Responses marked as strongly agree and agree are indicated as agreement with the statement.

The study HCPs rated the individual choices higher than the study done by Johnston et al. (1995). Johnston and colleagues' study revealed that 61 % of physicians

agreed that detailed descriptions should be provided and 60 % of patients concurred that this was a high priority to them.

There was a plethora of literature about what are considered to be the best discussion techniques to facilitate informed decision making, completion of a comprehensive AD, and maintaining patient autonomy. Weg (1994) stated, "Health care providers have the obligation to counsel patient on the seriousness of their condition. These are patients with serious and chronic diseases but not in acute distress, he or she is more capable of analyzing our advice and seeking that his or her family or appropriate other" (p.1646). Ogg (1989) echoed these sentiments for the dying patient. She stated that they are entitled to information regarding all treatment options so that they can make informed choices about their health care options.

The importance of truthful disclosure, informed consent, and end-of-life care was stressed in the ACP (1992) ethics guidelines. The ACP stated, "The physician is obligated to ensure that the patient or, where appropriate, the surrogate be adequately informed about the nature of the patient's medical condition, the objectives of the proposed treatments, the treatment alternatives, possible outcomes, and the risks involved" (1992, p.949).

Research question one identified the subjects' belief on what circumstances should occur before the HCP and patient discuss life-sustaining treatments. See Table 21 for the summary of the results.

Table 21

Circumstances Requiring a Discussion on Advance Directives

Circumstances when the discussion should occur	Agreement with statement
When a patient is critically ill	84 %
When a serious chronic disease is diagnosed	83 %
Later in the course of managing a fatal disease	74 %
When a fatal disease is first diagnosed	69 %
Prior to a deployment	66 %
During a retirement physical exam	66 %
During a routine appointment with no active medical problems	65 %
During any appointment the patient comes to see you	35 %

Note. Responses marked as strongly agree and agree are indicated as agreement with the statement.

This study showed that the subjects agreed with the statement that they should discuss ADs and life-sustaining treatments with patients who are chronically, critically, or terminally ill. Most prominent authorities in the area of end-of-life care planning and medical ethics felt that waiting until the patient was critically ill was a poor choice of timing because the patient's increased stress or deteriorating medical condition impairs them from making a fully informed choice (Sulmasy et al., 1996; Wanzer et al., 1989). Additionally, several authors thought that the best time to address ADs and end-of-life issues for chronically or terminally ill patients was in the outpatient setting (Doukas & Reichel, 1993; Meir et al., 1996; Wanzer et al., 1989).

Research question one identified the time when the subjects believed the HCP and healthy patients should discuss ADs. All of the subjects indicated their belief that counseling should occur with healthy patients. Eighty-three percent answered 'any time'. Ten percent answered on yearly physical exams. Seven percent answered 'other', these subjects wrote such responses as "when the provider-patient relationship has been established". That all of the subjects believed it was prudent to discuss ADs with healthy

patients was encouraging. Wanzer et al. (1989), La Puma and Schiedermayer (1989), and Doukas and McCullough (1995) all supported the counseling of healthy patients. Layson et al. (1994) stated that 70 to 92 % of elderly outpatients thought the discussion should occur when they are healthy.

Some of the statements elicited mixed responses. Mixed responses for the purpose of this research have occurred when any area had a minimum of 25 % of the subjects selecting not certain as a response. See Table 22 for the summary of the results.

Table 22

Circumstances for Healthy Patients to Discuss Advance Directives

Circumstances for discussion with healthy patients	Agree	Not Certain	Disagree
During any appointment that the patient comes to see you	35	30	35
During a retirement physical	58	26	17

Note. Items rated as strongly agree or agree were rated as agree. Items rated as not certain were rated as not certain. Items rated as disagree or strongly disagree were rated as disagree.

Summary

Research question one asked, "What beliefs do health care providers have regarding the purpose and use of ADs?. This study explored the beliefs of HCPs on the purpose, rationale for use, methods for discussion, and timing of AD counseling. Fry's conceptual framework linked the four key elements of personal values and beliefs, professional code of ethics, moral concepts, and ethical principles to moral decision making (Fry, 1996). Question one of this study explored the study's HCPs' professional and personal values and beliefs on these four key elements.

The results of question one demonstrated that study HCPs believed in their commitment and obligation to their respective professional organization's standards of care and scope of practice. This was ascertained by their agreement with facilitating patient autonomy and informed decision making through truthful disclosure. These key ethical principles are pivotal for comprehensive treatment plans, realistic goals, and outcomes that are required for moral decision making in end-of-life care planning.

Research Question Two

Have health care providers thought about and discussed their personal beliefs about end-of-life preferences with any one?

The instrument had three response sets that answered research question two. The first item elicited the subject's response as to whether they had ever thought about their own preferences regarding the initiation or withholding of life-sustaining treatments. The second item asked with whom had they discussed their preferences on the use of life-sustaining treatments. The final item on the instrument asked the subjects the specific question 'In your current health, if you had a cardiac arrest, would you want life-sustaining treatments attempted?.'

Ninety-three percent had thought about their own preferences for life-sustaining treatments. (See Table 23 for the breakdown of with whom they had discussed their preferences.) All but one subject wanted the use of CPR in the event of a cardiac arrest.

Table 23

Health Care Provider Discussion of Personal Preferences

With whom had the subjects discussed their end-of-life preferences	Percentage
Spouse/significant other	64 %
Friends	53 %
Family	49 %
Health Care Provider	12 %
Other	13 %

Two studies were done specifically examining the HCP preferences for end-of-life care. Both studies indicated that the health condition of the patient and the projected quality of life were important considerations. Gillick et al. (1993) researched the preferences physicians and nurses would want for themselves. Their results showed an overwhelming 93 % refusal rate for life-sustaining treatments if they were terminally ill, in a PVS, or mentally incapacitated. Fischer and co-researchers (1997) examined the preferences of 513 physicians on the use of aggressive interventions if they had an acute life threatening illness in their current health. Fifty-two percent selected aggressive interventions if they had a good prognosis. Basta (1996) surveyed 200 nurses of whom 98 % did not want to be resuscitated if the chance of recovery and independence was less than 5 % and none wanted CPR if the chance was less than 1 %.

The study subjects were more willing to undergo aggressive interventions in their current health. This may have been related to the young age of the sample. The age range of the study population was from 24 to 56 years old, with a mean of age 35.

Summary

Research question two examined whether the HCP had thought about their personal preferences for end-of-life care. The process of introspectively determining which choices one may want at the end-of-life requires one to determine his or her own personal values. Determination of these values facilitates identification of the meaning of the value to the individual. This process was a key element of personal values and beliefs in Fry's (1996) conceptual framework for moral decision making.

Research Question Three

Have health care providers completed their own ADs?

Eighteen percent of the study subjects had completed ADs. Johnston et al. (1995) research indicated a 10 % completion rate. The higher completion rate may be indicative of the subject's being more aware of the potential for catastrophic illness or injury as member of the armed services. Mertz (1990) reported that in a combat situation there is a 3 % per day casualty rate. Another reason may have been that the HCPs in a military setting frequently take care of veterans who have suffered devastating injuries. Nuland (1993) points out veterans of battles seem to lose something of their wholeness and profess a desire to have died on the battlefield. Additionally, the preparation of living wills and durable power of attorney are provided as a free service to military personnel. These documents are recognized as transferable to all states if prepared by a military legal office. Any or all of these reasons could have been responsible for the higher completion rates.

Summary

The subjects who have completed ADs have exercised their own autonomy by putting their wishes into writing. Those individuals may be more able to understand patient desires and feel more comfortable helping their patients reach autonomy. This was another key element of the moral-decision making framework defined by Fry (1996).

Research Question Four

Do health care providers initiate and facilitate conversations with their patients regarding the purpose and use of ADs?

The research question identified subjects who currently address ADs in their daily practice. Twenty-one percent answered that they had never discussed ADs or life-sustaining treatments. The following data presented was representative of the 79 % who currently address ADs in their daily practice.

Table 24

Methods Used to Initiate Discussions

Methods used to initiate discussions	Freq	Sometimes	Never
I ask the patient if they have a Living Will of Durable Power of Attorney	56 %	29 %	15 %
I introduce the issues, ask patient to discuss the situation with their family, and discuss at later visits	53 %	28 %	19 %
I give all of the facts and await the patient's decision or response	25 %	42 %	33 %
I offer an opinion of what to do	6 %	29 %	65 %
I imply a sense of urgency and need to decide, and ask the patient to make a decision	2 %	21 %	77 %

Note. Items rated as often and/or very frequently were rated as very frequently (Freq). Items rated as sometimes was rated as sometimes. Items rated as never or rarely were rated as never.

Research indicates that discussions about end-of-life issues occur 40 % more often if the patient already has an AD (Miles et al., 1996). Authorities have supported discussing ADs over several visits and having periodic reviews to see if changes in health status alter their treatment preferences (Doukas & McCullough, 1995). The study subjects indicated that 56 % of the time they ask the patient if they have an AD and 53 % indicated they discuss the AD over several visits. Johnston and colleagues (1995) research showed that patients favored this technique 67 % of the time.

In the present research, the subjects had mixed responses for the item 'I give all of the facts and await the patient's decision'. It was hard to distinguish if the 'give all of the facts' or if 'wait for a decision' is the point of disagreement. An overwhelming 77 % of subjects answered that they do not pressure or rush the patient into a decision. Sixty-five percent stated that they never offer an opinion to the patient. Luce (1992) stated that clinicians should agree on treatment options based on specific data, diagnostic indices, and clinical experience. All of this data should be honestly presented to the patient and the HCP then can make recommendations if the patient desires him or her to do so. The study subjects indicated they utilize these methods to facilitate discussions. This practice maintains respect for patient autonomy.

Research question four described the rate of agreement or disagreement on how the subjects present the information they discuss on life-sustaining treatments. See Table 25 for the summary of the results.

Table 25

Health Care Provider Presentation of Life-Sustaining Treatments to Patients

Presentation of life sustaining treatments	Agree	Not Certain	Disagree
Always give detailed descriptions of life-sustaining treatments	60 %	18 %	22 %
Only provide details at patient's request	33 %	16 %	51 %
Use stories about similar patients	28 %	19 %	53 %
Vary detailed descriptions in order to influence decisions that I feel are appropriate	18 %	23 %	59 %

Note. Items rated as strongly agree or agree were rated as agree. Items rated as not certain were rated as not certain. Items rated as disagree or strongly disagree were rated as disagree.

Research question one addressed the importance of the way a HCP presented the information discussed about ADs and life-sustaining treatments. Research question four examined the actual professional practices of the subjects regarding the issues outlined in Table 25. The subjects agreed that it was important to present all of the facts, but contended that they do their best not to sway the patient with respect to treatment choices.

Summary

Research question four examined the professional practice that HCPs utilized in the discussion of ADs. These subjects indicated that through their professional practice methods in the discussion of ADs, they maintain a commitment to patient autonomy. This was demonstrated by the subject's adherence to the professional guidelines placed

upon them by their professional organizations. These were two of the four key elements required for a moral decision making process.

Research Question Five

Under what circumstances do health care providers discuss the purpose and use of ADs?

“The timing of the discussion is critical: too early may be perceived as threatening and too late may be disastrous” (Tunzi, Wollitzer, & Blossom, 1988, p. 572). The subjects selected specific circumstances when they discuss ADs see Table 26 for the summary of the results.

Table 26

Circumstances when Discussions of Advance Directives Occur

Circumstances when discussions of ADs occur	Number of Subjects From N = 59	Percentage
When a serious chronic disease is diagnosed	39	66 %
When a patient is critically ill	37	63 %
Later in the course of managing a fatal disease	35	60 %
When a fatal disease is first diagnosed	32	55 %
During any appointment that the patient comes to see you	17	29 %
During a routine appointment with no active medical problems	14	23 %
During a retirement physical	7	12 %

Over half of the subjects of this study stated that they discussed ADs with patients who have serious chronic medical condition, terminal illness, or fatal disease. Only 14 subjects discussed ADs when patients came to see them no matter the reason for the appointment. Only seven subjects stated that they discussed ADs during a retirement physical exam.

Research question one examined what the current literature recognized as prudent points in time to initiate and facilitate the discussion of ADs. The study subjects results were mirrored in the literature, HCPs tried to address ADs in sick and debilitated patients, but found it hard to address these sensitive issues in the outpatient setting with healthy individuals. The ACP (1992) position statement on clinical ethics recommends that HCPs discuss resuscitative measures with seriously ill patients. They noted that these discussions often lead to a comprehensive plan of care.

Research question five also described when HCPs discuss ADs with healthy patients. Forty-three percent answered that they did when the patients bring it up. Twenty-six percent discussed ADs at any time a patient comes to see them. Nineteen percent answered that they had never discussed ADs. As discussed in research question one, patients wait for the HCP to initiate the discussion. From these responses it can be understood that the study HCPs do not initiate conversations on the use and purpose of ADs as much as they believed they should.

Summary

The results of research question five reflected the actual process of moral decision making. The study subjects were comfortable with initiating and facilitating discussions with seriously and terminally ill patients. They followed the recommendations set by the American College of Physicians (1992) about discussing life sustaining treatments for these patient populations. The study subjects stated in research question one that they believed the discussion of ADs should occur with healthy patients but research question five identified in actual practice the lack of discussion occurring on ADs. This same gap was noted by Hanson and colleagues (1997).

Research Question Six

What patient education techniques and resources do health care providers employ?

Research question six examined the resources that HCP utilize for the education of patients on the purpose and use of ADs. Table 27 summarizes the patient education resources utilized by the subjects.

Table 27

Resources Available to Patients

Resources the subjects used	Percentage
Conversations with their Health Care Provider	79 %
Conversations with admitting personnel at the time of hospital admission	53 %
Routine literature given to the patient at the time of hospital admission	52 %
Conversations with nurses	42 %
Waiting room literature	23 %
Specific education programs about end of life issues and advance directives	20 %

Note. The subjects could chose any or all that applied.

Morrison and colleagues (1994) concluded that patients had a higher completion rate if the HCP counseled them about ADs. Ironically, many HCPs have relinquished the task of counseling patients to other hospital staff. The Joint Commission for the Accreditation for Hospitals has clearly outlined the role of the health care facility and the HCP in addressing ADs with special emphasis on the role of patient and family

involvement (JCAHO, 1996). Most hospitals have interpreted the JCAHO standards and PSDA guidelines of implementation as asking patients upon admission if they have an AD. If they do not have an AD, they offer patients assistance in the preparation of one. The admission patient representative was noted as being the most frequent point of contact for this task, although research showed that patients feel uneasy about being approached by someone other than their primary HCP (Doukas & Reichel, 1993; Ross & West, 1995).

Meir and colleagues (1996) demonstrated that a multi-disciplinary approach to patient education yields the highest completion AD rate. Teno and Lynn (1996) advocate that the patient be exposed to ADs in numerous settings including during the outpatient visit, the admission procedures, the nursing staff admission interview, and follow up after hospital discharge during the outpatient hospital visit.

Authorities advocated the use of numerous different patient teaching techniques. Johnston and colleagues (1995) research identified that patients preferred written material and videos that include a brief description of what life sustaining treatments are and how to draft an AD.

Summary

All of the HCP professional organizations delineate the role of patient teaching in the HCP-patient relationship. Patient education is an integral part of the clinical encounter. This professional standard is based on informed consent and truth telling. The study HCPs stated they utilized numerous techniques and resources, demonstrating their commitment to professional standards and codes of ethics.

Research Question Seven

Are health care providers comfortable with their skills and training in the arena of ADs?

Research question seven described the subject's comfort level with their skills and training on counseling patients about the purpose and use of ADs. Table 28 summarizes the study results.

Table 28

Practitioner Skills and Training

HCP beliefs about their skills and training	Agree	Not Certain	Disagree
I have adequate skills to discuss end of life issues with patients	73 %	20 %	7 %
I received training in this area during school	49 %	11 %	40 %
I received helpful training in this area while in my current practice	40 %	14 %	46 %
I do not have adequate skills to discuss end of life issues with patients	9 %	20 %	71 %
I feel that I do not need the skills to discuss end of life issues with patients	3 %	7 %	90 %

Note. Items rated as strongly agree or agree are rated as agree. Items rated as not certain are rated as not certain. Items rated as disagree or strongly disagree are rated as disagree.

Most of the study subjects felt comfortable with their skills and noted that they felt these skills were valuable in their clinical practice. Tunzi and colleagues (1988) research demonstrated that HCPs who participated in ethics training were more likely to

discuss life-sustaining treatments with patients. Ninety-eight percent believed that HCPs should receive training on facilitating end-of-life discussions and the use or withdrawal of life-sustaining treatments as a part of their formal education.

The early 1990s saw a strong professional movement to incorporate clinical ethics skills into the residency programs across the United States (Seigler et al., 1991). This movement was started because many residents felt uncomfortable with their skills and training.

Summary

Research question seven examined the subjects beliefs regarding possession of the skills and training required to counsel patients on ADs. Continuing education is an element needed for personal growth and professional advancement. The subjects indicated that they were comfortable with their skills even if they did not receive training during their professional schooling. All believed that these skills need to be taught in basic schooling.

Implications of the Study

The results of the study demonstrated that HCPs in a military setting are not much different than their civilian counterparts. The study subject responses and data conclusions were supported by previous research studies done on the subject of ADs. The study subjects demonstrated that they utilize a personal value and belief system to formulate their opinions on the purpose of ADs, the implications for use, who should have an AD, how to counsel patients on ADs, and their own need to have an AD. They adhered to a recognized professional organizations code of ethics by facilitating patient

autonomy and self determination through counseling on life-sustaining treatments, end-of-life care, and ADs. They also conformed to moral concepts such as advocacy, accountability, fidelity, and caring through open and honest communications with their patients. Further, the subjects practiced truth telling and informed consent when addressing sensitive issues with their dying patients. The study showed that HCPs had the four required key elements outlined by Fry (1996) for facilitating the process of making a moral decision.

Limitations of the Study

Any research study may be hampered by problems and limitations. This study was no different. This study used a modified instrument with a different population. Although estimates of content validity were obtained, estimates of reliability such as test-retest reliability were not obtained. The questionnaire was lengthy and took almost 15 minutes to complete. The final weakness in the instrument was that those who had never counseled patient should have been given permission to omit the section of questions pertaining to professional practices.

The generalizability of the study should be used with some caution. The sample was consisted of a unique population and generalizability may be limited to medium sized MTFs that have residency programs. The smaller military health care settings may vary in responses depending on the type of patients treated within their catchment area.

Recommendations for Further Research

1. Modify the instrument to permit the subjects to omit the section on professional practices if they have never counseled patients on ADs.

2. Obtain estimates of reliability on the modified instrument when using a different population or setting.
3. Compare the section on beliefs to the section on professional practices to determine if there is a correlation between subject beliefs and actual practice.
4. Repeat this research with a focus on military HCPs but not civilian HCPs.
5. Replicate this research in another branch of the Armed Services.

Conclusions of the study

There has been a nationwide push for HCPs to recognize patient's rights in regards to the end-of-life care. This study investigated the attitudes and practices of HCPs in a military setting on the purpose and use of ADs. The descriptive nature of this study allowed the investigator to compare and contrast the data results with topics in the current literature. There is still much to learn regarding the gap between the need to prepare ADs, to complete an AD, and to implement patient preferences at the end of life. New studies may gain insight as to why these gaps exist.

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APPENDIX A

Cover Letter and Consent Form

1. Title of Research: Military Health Care Providers' Attitudes and Practices Regarding the Use of Advance Directives
2. Investigator: Bridget L. Larew, Maj, USAF, NC
Uniformed Services University of the Health Sciences
Graduate School of Nursing
301-989-9165 (home)
3. Purpose of the Study: The purpose of this research study is to determine health care provider's beliefs and practices concerning the end-of-life decisions and advance directives.
4. Procedure: Each participant will be asked to complete the accompanying questionnaire. Please return it in the attached envelope and place in a mail box.
5. Risk/Benefit: This study involves no physical risks or discomfort to you. Should you have any questions concerning the nature of the study, please do not hesitate to call the investigator. While this study may not help you personally, it may provide information that will help other health care providers to provide education concerning advance directives and end-of life decision making.
6. Confidentiality: Any information obtained from this study will be treated in a confidential manner. Participants will remain anonymous throughout the study.
7. Right to Withdraw: Your cooperation is completely voluntary. You have the right not to answer any or all of the questions.
8. Cost: There is no cost to you, nor will you be reimbursed for your participation in the study.
9. Information from the Investigator: Please feel free to contact the investigator should you have any questions concerning this study.
10. Consent: To maintain anonymity, completion of the questionnaire implies consent to participate in the study.

Thank you very much for your cooperation

APPENDIX B
Health Care Provider Questionnaire

Health Care Provider Questionnaire

I am investigating how Health Care Providers (Physicians, Nurse Practitioners, and Physician Assistants) address end-of-life issues (Medical treatments and/or interventions that are implemented when a person is reaching the end of life or is a victim of a catastrophic illness) especially about life-sustaining treatments. Life-sustaining treatments for this survey may include CPR, mechanical ventilation, tube feedings, and other related interventions.

I. Demographics:

Please provide the following information about yourself.

A. Date of Birth: _____

B. Sex: (*circle one*)

1. Male 2. Female

C. Race: (*circle one*)

1. Asian

2. Black

3. Hispanic

4. White

88. Other: please specify: _____

D. Status: (*circle one*)

1. Practicing Physician:

2. Medical Student: Please specify year: _____

3. Nurse Practitioner

4. Physician's Assistant

E. Specialty:

1. Internal Medicine
2. Family Practice
3. Acute Care
4. Flight Medicine
88. Other: please specify: _____

F. Highest Education Completed: in current specialty (*circle one*)

1. Diploma
2. Associate degree
3. Bachelor's degree
4. Master's degree
5. Medical Degree
6. Doctoral Degree (e.g., Ph.D.)
88. Other: please specify: _____

For the following questions please round up to nearest year:

- G. Number of Years in Practice at current position: _____
- H. Number of Years in Health Care Related positions: _____
- I. Number of Years in Armed Service: _____
- J. Number of years in Civil Service: _____

II. Personal Practices

A. Have you ever thought about whether you would want to have life-sustaining treatments attempted on yourself if needed? *(circle one)*

- 1. Yes
- 2. No

B. In your current health, if you had a cardiac arrest, would you want life-sustaining treatments attempted? *(circle one)*

- 1. Yes
- 2. No

C. Have you ever discussed the use of life-sustaining treatments for yourself with your : *(circle only one number per line)*

	<u>YES</u>	<u>NO</u>	<u>UN-CERTAIN</u>	<u>N/A</u>
1. Spouse/ Significant other	1	2	3	4
2. Family	1	2	3	4
3. Friends	1	2	3	4
4. Health Care Provider	1	2	3	4
88. Other: please Specify:	1	2	3	4

D. Have you ever signed a Living Will or Durable Power of Attorney for Health Care for yourself?

- 1. Yes
- 2. No

III. Professional Opinions/ Beliefs

A. Who do you believe should first start the discussion about life-sustaining treatments -- the patient or the Health Care Provider? *(circle only one answer)*

1. Health Care Providers should always bring it up first
2. Health Care Providers should bring it up first, but patients can if they desire
3. Patients should bring it up first, but Health Care Providers can if they desire
4. Patients should always bring it up first
99. Undecided

B. For patients who can communicate, who do you think has primary responsibility for making the final decision about whether or not to use life-sustaining treatments? *(circle only one answer)*

1. Patient is primarily responsible
2. Family is primarily responsible
3. Health Care Provider is primarily responsible
4. Both the patient and Health Care Provider are equally responsible
99. Undecided

C. Once initiated, who in addition to the Health Care Provider and patient should be involved in the discussion about the use of life-sustaining treatments? (*circle only one answer per line*)

	<u>Strongly Agree</u>	<u>Agree</u>	<u>Not Certain</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
1. Spouse/Significant Other should definitely be involved	1	2	3	4	5
2. Family should definitely be involved	1	2	3	4	5
3. Lawyer should definitely be involved	1	2	3	4	5
4. Clergy should definitely be involved	1	2	3	4	5
88. Other: please specify:	1	2	3	4	5

D. Please indicate your opinion about the following statements regarding Advance Directives: (*circle only one number per line*)

<u>Advance Directives:</u>	<u>Strongly Agree</u>	<u>Agree</u>	<u>Not Certain</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
1. Are very useful in stimulating discussion between patients and Health Care Providers about the use of life-sustaining treatments	1	2	3	4	5
2. Help patients make decisions about life-sustaining treatments	1	2	3	4	5
3. Adequately convey patients' wishes about the use of life-sustaining treatments	1	2	3	4	5
4. Hinder future discussion about life-sustaining treatments	1	2	3	4	5

Advance Directives:	<u>Strongly Agree</u>	<u>Agree</u>	<u>Not Certain</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
5. Increase patient understanding of life-sustaining treatments	1	2	3	4	5
6. Hinder patients' ability to change their minds about life-sustaining treatments	1	2	3	4	5
7. Make future discussions unnecessary	1	2	3	4	5
8. Should be re-evaluated during serious illness	1	2	3	4	5
9. Are not useful because patients frequently change their minds during serious illness	1	2	3	4	5
10. Are legal documents and they protect you from malpractice	1	2	3	4	5

E. Which of the following statements best describes your feelings about discussing life-sustaining treatments and making a decision? (*circle one answer*)

1. A discussion is not necessary, the Health Care Provider makes the decisions
 2. The Health Care Provider should give all of the facts about life-sustaining treatment and make a recommendation, so the patient can decide
 3. The Health Care Provider should provide the facts about life-sustaining treatment, but no recommendation, so the patient can decide
 4. A discussion is not necessary, the patient makes the decision
88. Other: please specify: _____
99. Undecided

F. How important are the following types of information when Health Care Providers and their patients make decisions about life-sustaining treatments? (*circle only one number per line*)

Information presented	<u>Strongly</u> <u>Agree</u>	<u>Agree</u>	<u>Not</u> <u>Certain</u>	<u>Disagree</u>	<u>Strongly</u> <u>Disagree</u>
1. A description of what life-sustaining treatments are	1	2	3	4	5
2. The patient's state of health at the time of the discussion	1	2	3	4	5
3. The chance of surviving and fully recovering	1	2	3	4	5
4. The chance of surviving but not fully recovering (e.g., staying in a coma)	1	2	3	4	5
5. The possible effects that life-sustaining treatments might have on the patient's quality of life	1	2	3	4	5
6. The possible effects that the life-sustaining treatments might have on the patient's family (e.g., cost, physical suffering)	1	2	3	4	5

G. Under what circumstances should Health Care Providers discuss the use of life-sustaining treatments with their patients? *(circle only one number per line)*

When should the discussions about life-sustaining treatments occur:	<u>Strongly</u> <u>Agree</u>	<u>Agree</u>	<u>Not</u> <u>Certain</u>	<u>Disagree</u>	<u>Strongly</u> <u>Disagree</u>
1. During a routine appointment with no active medical problems	1	2	3	4	5
2. When a serious chronic disease is diagnosed	1	2	3	4	5
3. When a fatal disease is first diagnosed	1	2	3	4	5
4. Later in the course of managing a fatal disease	1	2	3	4	5
5. During any appointment that the patient comes to see you	1	2	3	4	5
6. When a patient is critically ill	1	2	3	4	5
7. During a retirement physical	1	2	3	4	5
8. Prior to a deployment	1	2	3	4	5

H. In general, at what time period should healthy patients and their Health Care Providers start discussing whether or not to use life-sustaining treatments? *(circle one answer only)*

1. Any time
2. On yearly physical exams starting at age (please specify) _____
3. Prior to a deployment
4. On their retirement physical
5. Never
88. Other: please specify _____

IV. Professional Practices

A. How often do you begin discussions about life-sustaining treatments in the following ways? (*circle only one number per line*)

	<u>Never</u>	<u>Rarely</u>	<u>Sometimes</u>	<u>Often</u>	<u>Very</u> <u>Frequently</u>
1. I give all of the facts and await the patient's decision/response	1	2	3	4	5
2. I introduce the issues, ask the patient to discuss the situation with their family, and then discuss at later visits	1	2	3	4	5
3. I offer an opinion of what the patient should do	1	2	3	4	5
4. I imply a sense of urgency and need to decide, and ask the patient to make a decision	1	2	3	4	5
5. I ask the patient if they have a Living Will or Durable Power of Attorney for Health Care	1	2	3	4	5
6. I have never discussed advance directives with any of my patients (<i>circle entire box</i>)					

B. Health Care Providers vary their methods for discussing life-sustaining treatments based on individual characteristics of patients and their families. In general, however, how do you describe life-sustaining treatments to patients? (*circle only one per line*)

	<u>Strongly Agree</u>	<u>Agree</u>	<u>Not Certain</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
1. Always give detailed descriptions of life-sustaining treatments	1	2	3	4	5
2. Only provide details at patient's request	1	2	3	4	5
3. Vary detailed descriptions in order to influence decisions that I feel are appropriate	1	2	3	4	5
4. Use stories about similar patients	1	2	3	4	5
88. Other: please specify:	1	2	3	4	5
5. I have never discussed advance directives (<i>circle entire box</i>)					

C. Under what circumstances do you discuss the use of life-sustaining treatments with your patients? (*circle any item that applies*)

- | | |
|---|---|
| 1. During a routine appointment with no active medical problems | 5. During any appointment that the patient comes to see you |
| 2. When a serious chronic disease is diagnosed | 6. When a patient is critically ill |
| 3. When a fatal disease is first diagnosed | 7. During a retirement physical |
| 4. Later in the course of managing a fatal disease | 8. Prior to a deployment |
| | 88. Other: Please specify: _____ |

D. In general, at what time period do you discuss with your healthy patients about the use of life-sustaining treatments? (*circle one answer only*)

1. Any time
2. On yearly physical exams starting at age (please specify) _____
3. Prior to a deployment
4. On their retirement physical
5. Never
6. When they bring it up
88. Other: please specify _____
99. Undecided

E. What resources are available to your patients regarding decisions related to the purpose and need for life-sustaining treatments: (*circle any that apply*)

1. Waiting room literature
2. Routine literature given to the patient at the time of hospital admission
3. Conversations with admitting personnel at the time of hospital admission
4. Conversations with their Health Care Provider
5. Specific education programs about end of life issues and advance directives
6. Conversations with nurses
88. Other: please specify: _____

V. Professional Skills and Training

A. Please indicate your agreement with the following statements. *(circle one number per line)*

Please indicate your agreement with the following statements.	<u>Strongly Agree</u>	<u>Agree</u>	<u>Not Certain</u>	<u>Disagree</u>	<u>Strongly Disagree</u>
1. I have adequate skills to discuss end of life issues with patients	1	2	3	4	5
2. I received training in this area during school	1	2	3	4	5
3. I received helpful training in this area while in my current practice	1	2	3	4	5

B. Do you think that Health Care Providers should receive training in discussing life-sustaining issues as a part of their formal education (e.g., Medical school, Masters of Nursing, and BS for Physician's Assistants)?

1. Yes
2. No

APPENDIX C

Letters of Confirmation

The University of Kansas Medical Center School of Medicine-Wichita

Internal Medicine

January 7, 1997

Bridget Larew, Capt., USAF, NC
331 Scott Drive
Silver Spring, Maryland 20904

Dear Captain Larew:

I am enclosing copies of the two provider questionnaires used in our study. The members of the End of Life Study Group are happy to allow you to use the questionnaires. We would only ask that our group be credited for the development of the questionnaires on your thesis and in any publications.

The process we used to develop the instrument is summarized in the Method section of the *Archives of Internal Medicine* article. If you have any further questions after reviewing the questionnaires, please let me know.

Sincerely,



Sarah Coate Johnston, M.D.
Associate Professor

SCJ:sb

Enclosures: 2 questionnaires

APPENDIX D

Letter of Facility Institutional Review Board Approval



DEPARTMENT OF THE AIR FORCE

HEADQUARTERS AIR FORCE MATERIAL COMMAND
WRIGHT-PATTERSON AIR FORCE BASE, OHIO

21 May 1997

MEMORANDUM FOR CAPT BRIDGET L. LAREW

FROM: 74th Medical Group/SGHT
Clinical Investigations
4881 Sugar Maple Drive
Wright-Patterson AFB OH 45433-5300

SUBJECT: Proposed Protocol

1. The protocol you submitted, "Preventative Ethics in the Outpatient Setting: Health Care Providers' Attitudes and Practices Regarding the Use of Advanced Directives," was reviewed via expedited review by the Chair of the Institutional Review Board (IRB) of Wright-Patterson Medical Center on 21 May 1997 and has been assigned file number #97-X06. Your protocol was determined to be exempt and has been approved.
2. Progress reports will be due annually. You will receive a reminder 30 days in advance when your report is due. If you complete your study prior to May 1998 a final report may be completed. I have attached a blank form for your progress/final report.
3. Any unanticipated major adverse reactions or other medical misadventures must be reported immediately to the department chairperson, the Chief of Medical Staff, the Clinical Investigations Coordinator and ultimately the commander IAW AFI 40-403. Such events will also need to be summarized in the subsequent progress report.
4. If you anticipate separating from the Air Force or changing assignments before the protocol is completed, you must notify the Clinical Investigations Office as soon as this is known. You will be required to either formally close the protocol, or to have another investigator take over the study. The latter process requires nomination by the department chairperson, submission of a curriculum vitae, and approval by the Institutional Review Board.
5. Please indorse below and return to Clinical Investigations (SGHT). I hope that your study will prove to be a worthwhile experience for you. Let us know if there is any way we can assist you.


DEBBIE BACHMAN
Clinical Investigations Coordinator

1st IND

TO: SGHT/Clinical Investigations

Noted/Acknowledged

Principle Investigator

Date

22 May 97

MEMORANDUM FOR CAPT BRIDGET L. LAREW

FROM: MAJ COLLINS/NURSING RESEARCH FUNCTION

SUBJECT: Research Proposal

1. The nursing research committee met on 20 May 1997 and reviewed your proposal. You have an excellent proposal that was truly a pleasure to review.

2. The following are recommendations and/or questions the committee brought forward. We realize your committee has already reviewed and accepted your proposal as is, so our recommendations for change are strictly voluntary on your part.

a. The Framework you chose applies specifically to nursing. Since you are including PAs and Physicians in your study, you may want to modify the Framework so it is more generic/inclusive.

b. Suggestions were made to cite a "medical center in the midwest" for data collection rather than name a specific facility. Especially when submitting your study for publication, it is important to use an area for data collection rather than a specific facility.

c. Are you including Air Force providers who are active duty only for data collection? We have providers from other branches of service, as well as civilians seeing patients. They would attend your CME presentation. How do you plan to eliminate them? If you want to include all providers seeing patients in this facility, you would need to spell it out in your instrument for data collection.

d. It was also recommended that you break down physicians into level of Medical Degree, i.e.: 1st yr resident, 2nd yr resident, 3rd yr resident, 4th yr resident, and Attending.

e. Editorial input was provided by several members reviewing your proposal. I am including their suggestions on the copy I am returning to you. It is your prerogative to input these suggestions into your revision.

f. I forwarded your study to the IRB and it met with approval as an "Exempt" study. The letter approving your study and requirements for this facility are included in this packet.

3. If there are questions about any of the above, please let me know. I will be your contact person and am happy to assist you in any way necessary. My telephone number at work is (937)257-9207, and at home (937)320-0929. Let me know if you need anything. Again, congratulations for your tremendous efforts and good luck to you!


THERESA L. COLLINS, Maj, USAF, NC
Nursing Research Function

APPENDIX E

Letter of Uniformed Service University of the Health Sciences Institutional Review

Board Approval



UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES

4301 JONES BRIDGE ROAD
BETHESDA, MARYLAND 20814-4799



August 7, 1997

MEMORANDUM FOR BRIDGET LAREW, GRADUATE SCHOOL OF NURSING

SUBJECT: IRB Approval of Protocol T06141-01 for Human Subject Use

Your research protocol entitled *Preventive Ethics in the Outpatient Setting: Health Care Providers' Attitudes and Practices Regarding the Use of Advanced Directives*, was reviewed and approved for execution on 8/1/97 as an exempt human subject use study under the provisions of 32 CFR 219.101 (b) (2).

The purpose of this study is to describe the beliefs, attitudes, and practices of health care providers in a military health care system regarding the purpose and use of Advanced Directives (ADs) for end of life decisions. The IRB understands that this protocol uses a survey instrument in which there are no identifiers recorded with responses to questions. It has already received approval from the IRB at Wright-Patterson where the study will be conducted.

Please notify this office of any amendments you wish to propose and of any unexpected incidents regarding the protection of human subject which may occur in the conduct of this project. If you have any questions regarding human volunteers, please call me at 301-295-3303.

Michael J. McCreery, Ph.D.
LTC, MS, USA
Director, Research Programs and
Executive Secretary, IRB

Cc:
Director, Grants Administration