

Running Head: MEDICAL DIRECTIVE CHOICES

The Impact of a Videotaped Educational Tool
on Medical Directive Choices

Bonnie A. Rice

University of Tampa

THE IMPACT OF A VIDEOTAPED EDUCATIONAL TOOL
ON MEDICAL DIRECTIVE CHOICES

By

Bonnie A. Rice

Thesis

Submitted to the Faculty of

the Nursing Department of

The University of Tampa

in Partial Fulfillment of Requirements

for the Degree of

MASTER OF SCIENCE IN NURSING

July 29th, 1999

Thesis Committee, Chair
Nancy Ross, Ph.D.

Date

Thesis Committee Member
Pat Schultz, Ph.D.

Date

Thesis Committee Member
Karin Otto, Ph.D.

Date

Department Chair/Director
Nancy Ross, Ph.D.

Date

Dean of Graduate Studies

Date

The University of Tampa

Abstract

Agreement on the appropriateness of the use of medical technology should be the standard for healthcare providers and consumers. An inventory and dialogue regarding end-of-life decisions between providers and consumers prior to the onset of illness avoids the potential for confusion and prevents compromised care. This quantitative experimental study collected data regarding the impact of a videotaped teaching tool describing commonly used critical care interventions on a medical directive. The term medical directive describes an advance directive document with specific interventional preferences linked with potential patient outcomes. The educational packets were divided into experimental and control. The control packet contained a trifold with the medical directive, a letter of introduction, a demographic data questionnaire, a teaching brochure, and informed consent. The experimental packet also contained the educational videotape in addition to the other documents. 811 packets were distributed in the Tampa Bay/St. Petersburg area. 175 medical directives were returned (93 experimental & 72 control). The hypothesis tested was that the number of negative responses will be higher in the experimental group when predicted outcomes are poorer. The null hypothesis stated that the percentages of yes and no answers would be equal between the control and experimental groups. The overall differences in the percentages of affirmative answers in recovery scenario #1 and #2 (no disability and minor disability) revealed no statistical significance ($p=0.738$ & $p=0.408$ respectively). There were statistically significant differences (both $p<0.001$) between the control and experimental groups in recovery scenarios #3 and #4 (mod. disability and severe disability). This places the differences in responses in direct relationship to the potential outcomes. The most desired intervention in both control and experimental groups was antibiotics, and the least desired was endotracheal intubation. CPR was also consistently listed as more desirable in the control group than the experimental group. These data suggest additional education regarding critical care interventions may result in more informed decision-making.

Table of Contents

List of Tables.....
5

List of Figures.....
6

Chapter 1 Introduction.....
7

Chapter 2
Review of Literature.....
18
End-of-Life Healthcare Choices.....
18
Withdrawal of Life Support.....
21
Financial Impact of End-of-Life Care..... 22
Current Usage of Advance Directives.....
23
Patient Empowerment.....
25

Chapter 3
Methodology.....
31
Sample.....
31
Instrument Development.....
32
Procedure.....
33
Data
Analysis.....34

Chapter 4
Results.....
35
General Sample Characteristics.....
35
Descriptive Data.....
35

Hypothesis	
Testing.....	38
Secondary Analysis of Data.....	
40	
Chapter 5	
Discussion.....	
45	
Summary of Results.....	
45	
Explanation of Findings.....	
45	
Integration of Findings with Past Literature.....	
46	
Limitations.....	
47	
Implications for Practice and Suggestions for Further Research.....	47
Appendices	
Appendix A: Trifold with Medical Directive.....	
49	
Appendix B: Krames' Booklet.....	
50	
Appendix C: Letters for Permission	51
Appendix D: IRB Approval.....	52
Appendix E: Letters of Review.....	53
References.....	
54	

List of Tables

Table 1. Test for Equality of Two Proportions on Research Data..... 41

List of Figures

Figure 1.	Gender of Study Participants.....	37
Figure 2.	Marital Status of Study Participants.....	38
Figure 3.	Level of Education of Study Participants.....	38
Figure 4.	Age Distribution of Study Participants.....	39
Figure 5.	Percentage of Affirmative Answers to Interventions.....	40
Figure 6.	Percentage of Participants Under Medical Care.....	43
Figure 7.	Participants with Recent Illness in the Family.....	44

Chapter 1

Introduction

Healthcare consumers face a challenge when entering the healthcare arena. It is human nature to desire to live as long as possible. It is also human nature to desire to limit the potential suffering accompanying the actual process of dying. A large controlled trial of seriously ill hospitalized patients was undertaken by titled the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (Anonymous, 1995). The SUPPORT investigators reveal that out of 9105 study adults hospitalized with a life-threatening illness, more than one third spent at least ten days in Intensive Care. In interviews conducted after the study patients died, surrogates stated that 50% of all conscious patients died in moderate to severe pain. The original intention of life-sustaining critical care technology was to support viable patients through periods of physiologic crisis, rather than to prolong the process of dying. The SUPPORT trial indicates that not only does aggressive care "prolong dying, but is accompanied by significant emotional and financial expense" (Anonymous, 1995, p. 1591). Johns (1996) identifies the advent of life-sustaining technologies as a motivating factor in end-of-life discussion. This study determines the effect of a videotaped teaching tool in facilitating potential health care consumers to make informed choices about currently available technological interventions prior to the onset of any illness. This method allows decision-making to occur outside of a time of crisis and provide greater specificity for the providers, in the potential healthcare consumer's home environment.

Advances in life-sustaining equipment mandate increased education for potential clients, promoting the process of informed consent. Gillick (1995) defines informed consent as "the prevailing model for medical decision-

making"(p. 621). He states that as patients become acutely ill and are diagnosed, they are informed of their prognosis and all available treatment. After discussing the risks and benefits of treatment with the physician, the "patient must make a selection, perhaps guided by a specific recommendation by their physician" (Gillick, 1995, p. 621). Florida Statute 765 (1993) defines informed consent as:

consent voluntarily given by a person after a sufficient explanation and disclosure of the subject matter involved to enable that person to have a general understanding of the procedure and the medically acceptable alternative procedures and to make a knowing healthcare decision (p.1432).

Healthcare consumer decisions involving life and death situations often occur in a time of crisis. Gillick (1995) also notes that "in a medical crisis, patients may be technically decision-capable but sufficiently distraught that decision-making is not optimal" (p. 621). An examination of one's values and beliefs is best made in the absence of crisis . The SUPPORT principal investigators (Anonymous, 1995) agree with the finding that communication regarding advance directives is often absent or occurs only in times of crisis.

Health care consumers must examine their attitudes related to the use of medical technology in critical care units in situations where the client's outcome is less than optimal. Healthcare providers have an "inherent ethical obligation to respect the sanctity of life" (American Dietetic Society, 1992, p.999). The American Dietetic Society (1992), in addressing the feeding of individuals in a vegetative state, takes the following position:

Moral principles guiding healthcare providers are beneficence, autonomy, and justice. Technological and medical advances have created a conflict between application of these

moral principles and the use of certain types of treatment. The decision of which moral principle takes precedence in what situation creates the conflict (American Dietetic Society, 1992, p.996).

Coppa (1996) outlines four moral principles to be considered when withdrawing life support. The four moral principles are autonomy, nonmaleficence, beneficence and justice. Coppa states "Autonomy (in this setting) should give the patient or surrogate the ability to decide how much or how little care is appropriate" (1996, p.19). Beneficence and nonmaleficence are closely interrelated in healthcare decisions and can be confused. For example, Coppa states that the motive behind removal of a feeding tube may represent beneficence or nonmaleficence. The action is beneficent if it reflects the desire to prevent suffering. The action is nonmaleficent if the motive is to save the patient, even from the eventuality of death. Coppa further implies that the principle of justice in terms of allocating medical resources "gives medicine the responsibility to be aware of greater social concerns" (p. 19). This comment brings into the dilemma the lack of infinite healthcare resources. Coppa notes that currently any person who is terminally ill can access healthcare resources despite the projected outcomes. This has been the basis for guaranteed access to healthcare in the United States.

Agreement between health care providers and consumers on the appropriateness of the use of medical technology should be the standard. A prior inventory and dialogue regarding values involving end-of-life decisions avoids compromised quality or access to critical care services. According to Johnson (1996), physicians balance the ethical principle of patient autonomy with other principles such as appropriate withholding of care in the setting of futility. Physicians should utilize all medical treatment deemed potentially beneficial for,

and desired by their patients. Physicians also have an obligation to educate the clients and their families about the temporal benefits of such treatments given a potentially poor outcome. The desired treatment outcome can only be deemed acceptable by the individual healthcare consumer, not the physician alone.

Heffner, Fahy, and Barbieri (1996) call for increased patient education about advance directives and expanded dialogue between patients and their physicians regarding advance directives. DesRosiers and Navin (1997) note that patients are comfortable discussing advance directives with nurses. The proposed study addresses the issue of increased education on advance directives, however, removes the education from the acute care setting. Discussions involving life and death decisions should not wait until one is sick and the family is in crisis. Advance directive education offered prior to any illness would allow the individual to conduct a values inventory to decide what is most important to one's life. Healthcare choices would be based on careful consideration without the influence of pain or illness.

The research hypothesis of this study is that the healthcare consumer, when provided education outlining critical care interventions and their purposes, will choose to reduce medical interventions in situations where poor outcomes are predicted. The proposed research addresses several other issues included in the literature including education related to critical care interventions in relation to the advance directive, education provided by videotape in the home setting, and education created utilizing a nursing perspective.

The healthcare delivery system in the United States has limited resources, with an unlimited obligation to the client. Healthcare providers and insurance companies are currently examining a number of avenues for reducing healthcare costs. Rationing of healthcare resources for specific patient groups has been discussed as a method for cutting healthcare costs. Coppa (1996) defines

rationing as "denying a valued resource to a group or groups because of a limited amount of that resource" (p. 20). Kox and Wauer (1996) recommend using a patient scoring system in German intensive care units (ICUs) to determine, as early as possible, those who are terminally ill, and subsequently limit futile allocation of resources. Ross and West (1995) describe a movement in the American healthcare industry toward "prudent rationing" to limit escalating healthcare costs. Proposals have been written to allow the government to limit care by legislative action (Grubb, Walsh, Lambe, Murrells, & Robinson, 1996). Without significant input from the medical community and healthcare clients, legislation regarding the allocation of healthcare resources may not solve the dilemma. Indeed, further government restrictions on healthcare may delay care delivery due to bureaucracy. Coppa (1996) believes rationing of care deemed "futile" may not affect enough patient cases to preserve a significant amount of healthcare resources. Indeed, Emanuel (1996) has found that advance directive usage has resulted in decreased end-of-life costs, but that the amount saved was not significant.

Nationalized health care programs have limited resources and rationing has been suggested by other countries. Kox and Wauer (1996) not only suggested healthcare resource rationing on a recovery probability scale, but also recommended studying post-discharge quality-of-life to better identify what types of patients benefit most from critical care interventions. The information generated from such a study would clearly give credence to healthcare rationing in certain settings. Within American society, the individual's right to self-determination takes precedence over what may be the most beneficial to everyone in society (Sehgal et al, 1996). The right of the individual to govern his or her own fate in light of his or her own personal beliefs is constitutionally

mandated and held paramount to all other guiding principles (Kaplan & Davol, 1996).

According to Ross and West (1995) , due to the increase in average life expectancy, "increasing numbers of elderly patients are kept alive after their decision-making ability is lost" (p.355). Emanuel (1996) examined medical care employed at the end of life and determined that 10-12% of the total health care budget, and 27% percent of the Medicare budget is expended during this period. Coppa (1996) determined sixteen percent of the Medicare budget is spent in the last 60 days of life. Coppa also noted that half of the entire lifetime Medicare benefits are spent in this 60 day time period before death. Decreased use of high-technology interventions, which are often employed in critical care units, could conceptually result in significant cost reduction.

Who should make the decision to reduce or withhold interventions? Which interventions should be withheld in what settings? Ross and West (1995) assert that it is unethical to place the responsibility for these decisions anywhere but in the hands of the healthcare consumer. If the consumer's wishes are expressed in broad statements, it is difficult to interpret the limitations the patient would want. The myriad of technological choices is confusing, and often healthcare professionals give simplified descriptions of treatments. The surrogates are often unable to give truly informed consent, because they do not fully understand the intricacies of the risk and benefit profile. Haisfeld et al (1994) describe "life-sustaining interventions" as "intubation, tube feedings, dialysis, and the administration of antibiotics"(p. 1179). Kolcaba and Fisher (1996) outline "no extraordinary measures" as "dialysis, vasoactive drug therapies, hydration, enteral or parenteral nutrition, and suctioning"(p. 67).

The level of healthcare consumer education must keep pace with the available medical technology. Education should also address the different levels

of care depending on the likely prognosis. Clients may choose to refuse all treatment. Clients may refuse specific treatments, or accept treatments with specific therapeutic goals within a set time period. The quality of life given certain disabilities can only be determined within each client's set of values and beliefs. Individuals desiring any treatment possible to save one's life should have equal access to critical care interventions. Thus, the client's wishes should be clearly documented in a format that promotes easy interpretation by all involved. Haynor (1996) notes that advance directives with instructions such as "no heroics" leave much room for interpretation. The "If I had...I would want" two dimensional grid format is recommended by Haynor (p. 51).

Healthcare ethics and the utilization of finite medical resources have a pivotal relationship. Two opposing ethical viewpoints are considered when making healthcare choices: the utilitarian and the deontological viewpoints. Utilitarian philosophy (Feinberg, 1996) attempts to base decisions on the greater good for all those involved. Rationing of healthcare to permit universal medical access for all is an example of this philosophical viewpoint. Rationing, however, undermines one's right to self-determination. The deontological philosophy (Feinberg, 1996) isolates each ethical decision in a microcosm of that given situation, balancing right and wrong. For example, healthcare consumers must have access to and be maintained on life support without regard to cost, if that is the client's wish. The medical paradox with this philosophy is created due to finite healthcare resources. The young and viable may be denied preventive care, while expensive high technology interventions are utilized on the non-viable client who is avoiding death at any cost. Neither ethical philosophy offers a strong position for the equitable distribution of healthcare resources.

Given the litigious nature of American society, the healthcare community is unwilling to withdraw support from those whose predictable outcomes are clearly

poor. Healthcare providers fear litigation whenever death may be an outcome. An unintended consequence may be prolongation of suffering and the dying process. McCloskey and Grace (1994) state that " ready access to state-of-the-art technology and an extremely litigious environment create circumstances in which aggressive therapy is more the rule than the exception" (p.221). Consequently, in order to improve care delivery, society must become comfortable with the concept that not everyone can be cured. The public must also be advised that medical care provided with the best intentions may have dismal outcomes, and society must become accepting of the concept of planning for death and dying. The process of each person orchestrating their own preferred death experience should be the final ultimate step in freedom and self-determination.

Legal avenues do exist for healthcare consumers to let their wishes be known. Documents which specify one's wishes should one become incapacitated are known as advance directives. The Patient's Self-Determination Act (1991) defines an advance directive as "a client-generated document specifying your desire regarding future medical treatment under certain specified conditions" (p. 2).

At present, there are two recognized standardized formats of advance directives. Ott and Hardie (1997) identifies the first format as the living will and the second format as the durable power of attorney for healthcare (Patient's Self-Determination Act, 1991). A living will is an advance directive by which a person tells caregivers the circumstances in which life sustaining treatment is to be provided or forgone. A durable power of attorney for healthcare exists to allow a patient the right to "appoint a person or persons to make health care decisions for him if he is unable to do so for any reason" (Patient's Self-Determination Act, 1991, p. 2).

Florida Statute 765 (1993) also includes the do-not-resuscitate order as part of the Healthcare Advance Directives. All 50 states have some sort of advance directive statute, but there are differences from state to state (Ott & Hardie, 1995) An advance directive can also be defined as a single document which supplements the living will specifying medical treatments the subject would or would not want depending on a given situation. For the purposes of this study, the "potential healthcare consumer " will be defined as a person participating in the study who may or may not require healthcare in the future.

Advance directives are enacted when a patient becomes legally incompetent to make decisions (Florida Statute 765,1993). Medical treatment can be self-prescribed through the use of living wills and durable power of attorney for health care. Several problems have been identified related to these documents. The living will is not legally binding in many states, and may be instituted only in the setting of "terminal illness" or "vegetative states", which are poorly understood (Florida Statute 765,1993). Outcomes with significant reduction in quality of life outside of these general diagnoses are not addressed. The durable power of attorney allows a designated individual to act in another's behalf, but it is not without weaknesses. People have problems discussing their end-of-life wishes with others, and often state simply that they do not wish to live hooked to machines. With the complexity of critical care interventions currently available, it is often not adequate for a client to complete these documents, because many invasive interventions are not technically machines.

Secondly, the designated individual with durable power of attorney may be faced with an overwhelming number of high-technology interventions during a time of crisis, when someone close to them is critically ill. To intellectually evaluate each intervention in light of the patient's previously stated intentions is

difficult, when the emotional desire exists to give the person every chance at survival.

Permut (1998) actually suggests the three criteria a healthcare proxy should follow for decision-making. The first criterion for decision-making is the patient's instructions. When no instruction was given regarding a specific treatment, the second criterion for decision-making should be consistent with the patient's personal philosophy, religious beliefs, and ethical values. The third criterion the agent must consider is the resiliency of the patient in terms of recovery. Could the patient be able to recover enough to make choices? Permut's research illuminates the complexity of decision-making for a healthcare surrogate.

Emanuel (1995) describes the reluctance of healthcare proxies to carry out a loved one's wishes to withdraw life support. She states " The burden on healthcare proxies is high, and conflicting interests may interfere with their ability to accurately represent the patient's wishes" (p.36). Critical care interventions often result in the patient being unable to communicate due to endotracheal intubation, or a lack of cognitive clarity due to heavy sedation. The healthcare proxy may err on the side of doing too much, partly because of a lack of understanding regarding the interventions available, and also because of a lack of communication in times of crisis between health care providers, clients, and their families. It is legally mandated to perform interventions required to save a person's life, if the existence of an advance directive is unknown or the patient's wishes are not clear(Anonymous, 1996).

Johnson (1996) discovered that patients' preferences for end-of-life care are most influenced by their expected outcomes. The author notes that the poorer the prognosis, the fewer interventions were desired. Alpert, Hoijtink, Fischer and Emanuel (1996) questioned outpatients regarding their preferences

for care, given certain scenarios. Treatment desirabilities of clients in this study were related to invasiveness of the procedure. The client's future level of functioning, and the suffering involved in recovery were also important factors in the healthcare decision-making process.

The purpose of this study is to film a videotaped teaching tool with the intention of educating potential healthcare clients about critical care interventions when they are not experiencing an acute health crisis. Each intervention can be examined objectively on a risk and benefit basis. This direction of thought will encourage individuals to examine their beliefs and values in relation to illness, recovery, and the death experience.

An intervention-specific outcome-based sample advance directive is used to determine the impact of the videotaped teaching tool on the desirability of interventions in various outcome settings. The study directly relates procedures with outcomes, for enhanced realism and applicability. A videotaped teaching tool allows the potential healthcare consumer to examine the risks and benefits of invasive critical care procedures prior to the onset of an acute illness. This permits a more educated and rational level of decision-making. An advance directive that specifies treatments desired considering their interrelationship with overall prognosis would leave very little speculation about the patient's intentions.

The teaching tool combined with intervention-specific outcome-based sample advance directive may provide an opportunity for empowerment of the healthcare consumer as a central figure in examining the desirability of critical care procedures. This could result in more personalized and realistic healthcare goals and the advance planning of a dignified and self-directed death experience.

A new standard for physician-client interaction could be created through education, encouraging open dialogue about death prior to any illness. Realism and the eventuality of death must be the core of these discussions. The

limitation of suffering must be discussed and openly evaluated in light of the probability of success of any treatment. Successful treatment itself must be defined in the client's context, not by the healthcare provider. Discussions between healthcare providers and consumers involving difficult subjects such as end-of-life care could be facilitated through a non-threatening educational tool outside of the healthcare setting. Healthcare providers should encourage the client to be the deciding element when curative and completely restorative options are not available.

Chapter 2

Review of the Literature

The review of the literature begins with a focus on the legal precedents regarding end-of-life healthcare choices. Literature outlining the withdrawal of life-support is then considered. The financial impact of end-of-life care is reviewed, followed by relevant literature on advance directives and patient empowerment.

End-of-life Healthcare Choices

Two million people die in American hospitals every year. It has been estimated seventy percent of individuals die after a decision is made to forego life-sustaining treatment (State of Nevada, Office of the Attorney General, 1996). The decision can be made by the individual, or in light of incapacitation, the physician and family. A recent article in Circulation (Krumholz et al, 1998) reveals that the physician's perception of the patient's desire to be resuscitated was incorrect in one quarter of those studied. This study also revealed that in eleven patients who stated they did not wish to be resuscitated, the course of treatment was independently chosen by their physicians. More than half of these patients experienced a full resuscitation attempt, although only one survived until hospital discharge. In a study by Haisfeld et al (1994) some physicians admitted feeling ambivalent towards advance directives because they felt it would legally restrict their practice. When patients refuse treatment, physicians may stop treating them altogether. This could be a frightening thought if one was very ill or in pain.

Technological advances spawned the right to die movement as permanently unconscious patients were kept alive via life support. The New Jersey Supreme Court set the tone for right to die cases in its monumental ruling in 1976, allowing Karen Ann Quinlan's family to remove the life-supporting

ventilator (Quinlan, 1975). The Court cited her constitutional right to privacy as the basis for withdrawing life support. In 1990, in the Nancy Cruzan case, the court denied the family's initial wishes to withdraw a life-supporting feeding tube. Nancy Cruzan was in a car accident in 1983 from which she never regained consciousness. She laid in a vegetative state, sustained by tube feedings. In 1989, her parents petitioned the court to terminate artificial nutrition and hydration procedures. The court denied the request because Ms. Cruzan had never placed her wishes in writing (Cruzan V. Director, Mo. Dept. of Health, 1990).

In 1991, a federal law called the Patient Self-Determination Act was enacted. This law states that all health care providers are required to inform patients of their right to refuse treatment through the use of advance directives if they become incapacitated (White & Fletcher, 1991). The Florida Statute 765 (1993) defines advance directives as :

... a witnessed written document or oral statement in which instructions are given by a principal or in which the principal's desires are expressed concerning any aspect of the principal's healthcare , and includes, but is not limited to, the designation of a health care surrogate, a living will, or a do-not-resuscitate order.
(Florida Statute 765, 1993, p.1432)

The living will is a preprinted advance directive by which a person tells caregivers the circumstances in which life sustaining treatment is to be provided or forgone. A durable medical power of attorney is a witnessed preprinted document designating another person to make health care decisions for the client in the event of incapacitation. A more specific document, also termed an advance directive, can be written usually with the help of legal council, giving guidelines for treatment consent or refusal given various conditions. This type of free form advance directive, according to Campbell (1995), is usually more

specific than the Living Will in outlining the treatment desired in particular settings. Campbell states advance directives are to "provide accurate reflections of a patient's preferences, and are best understood as advisory statements" (p. 228).

The wording of living wills varies from document to document and is often ambiguous. Johns (1996) notes that these documents exist in a variety of forms. It is often left to the discretion of the physician and the family to ascertain if and when a living will applies. When patients become incapacitated and do not have a designated person to make decisions for them, decisions regarding length of treatment become the responsibility of the healthcare provider. Currently, if the patient's wishes are unknown, physicians often employ all manner of treatment to save the patient's life, assuming the patient's desire to live. Campbell (1995) writes "knowledge and interpretation of the patients' wishes are not always available or understood at the time of crisis. A delay in initiating therapy can result in the patient's death" (p. 227). Most clients envision the Living Will as permission to withdraw mechanical ventilation, or "pull the plug". The current level of technology employed in Intensive Care Units (ICU) requires monitoring and treatment by numerous machines, and it is difficult for patients or families to know which types of machines to withdraw. Kolcaba & Fisher (1996, p. 67) recommend "a definition or framework for care that would be helpful to guide nurses... as they work with patients and families through the decision-making process". Campbell (1995) acknowledges that "no intubation" is often "too vague" to represent a "goal-directed treatment plan"(p. 227).

Living wills are written simply, and usually state medical treatment will be withheld if the client is terminally ill or in a permanently vegetative state. Should a living will ensure A Do Not Resuscitate(DNR) status for the client? Most available living wills do not address such issues as Cardiopulmonary

Resuscitation (CPR), medicated intravenous (IV) drips to maintain blood pressure, palliative surgery, blood or blood products, antibiotics, dialysis, and invasive lines such as arterial and pulmonary catheters (Haynor, 1996). If a patient becomes incapacitated, the burden for interpreting the patient's wishes may fall on a family member. The subsequent guilt and anxiety about making the right decisions may be overwhelming, particularly if there is conflict between the family members (Emanuel, 1995).

Withdrawal of Life Support

Once life-sustaining treatment has been instituted, it is often not rapidly withdrawn, even in consideration of a poor prognosis. Faber-Langendoen (1996) reviewed the charts of 274 clients in the acute care setting, and examined the timing of decisions to forego treatment and the sequence of decisions made. His findings suggest that resuscitation and intubation were generally the first measures withheld. Once a client was mechanically ventilated, withdrawing ventilatory support was a difficult, and frequently postponed decision. The author also found that treatment was withdrawn by removing one intervention at a time, taking several days, thus prolonging the client's suffering. Identification of any clinical reasoning or ethical foundation could not be found for this practice.

Asch and Christakis (1996) surveyed four hundred and fifty university affiliated internists on their preference for withdrawal of eight forms of life support outlined by a panel of critical care physicians. In general, the physicians studied preferred to withdraw forms of life support that are "scarce, expensive, invasive, artificial, unnatural, emotionally taxing, high technology, and rapidly fatal when withdrawn. They preferred not to withdraw forms of therapy that require continuous rather than intermittent administration, and forms of therapy that cause pain when withdrawn"(1996, p. 109).

Once the decision has been made to institute treatment, who makes the decision that the obligation for treatment no longer exists? There is a legitimate role for the families and durable medical power of attorney designees, however there may be a lack of understanding or agreement about withdrawal of treatment. Some families may feel that withdrawing supportive measures may imply no treatment at all, including pain control (Neumann, 1994). Families may derive some emotional solace out of not withdrawing treatments already instituted and letting nature take its course. This passive stance may be preferable to the possibility of withdrawing supportive treatments too soon.

Financial Impact of End-of-Life Care

Emanuel (1996) suggests that the combined use of hospice services and advance directives can save between twenty five and forty percent of health care costs over the last month of life. Considering that advance directives do not significantly increase the cost of end-of-life care, promoting their use would conserve medical resources.

Fakhry, Kercher, and Rutledge (1996) completed a study evaluating long-term outcome, quality of life, and charges in surgical clients requiring prolonged ICU stays (> fourteen days). The authors used a random sample of eighty three intensive care patients, although only one intensive care unit site is listed. Only sixty two percent survived to hospital discharge. Seventy percent of the survivors reported less than fifty percent return of functional capacity eighteen months after discharge. The average ICU charge was \$51,512 per client, and the average hospital charge was \$164,019 per client. Schuster, Wilts, Ritschel, and Schuster (1996) found that patients requiring prolonged (not defined) intensive care unit stays had significant residual neurological dysfunction. The use of advance directives clarifying client's wishes would seemingly result in significant cost-reduction. Alternatively, in a study conducted by Danis et al (1996) at a large

university affiliated hospital, there was no significant association between the patients that desired or refused to receive care and the life-sustaining procedures used or the hospital cost. Danis et al used a stratified random sample by selecting from a population of terminally ill patients over fifty years of age and currently hospitalized. The decision-making on advance directives may have been biased by the knowledge one was terminally ill and hospitalized.

Current Usage of Advance Directives

Fifty states and the District of Columbia have laws which permit the use of advance directives (John, 1996). The concept of advance directives is widely accepted by lay persons. Heffner, Fahy, and Barbieri (1996) disclose that 90% of the patients in their study wished to discuss end-of-life with their physicians. Only 10% of subjects in the study had completed advance directives. In an emergency, healthcare providers treat life-threatening conditions immediately. Discussion clarifying the patient's end-of-life wishes are often postponed during physiologic stabilization. Even when the patient appears severely physically and mentally debilitated, healthcare providers will perform life-saving procedures unless they have legal authorization not to resuscitate (Anonymous, 1996).

Standardization of notification of medical intervention desires could be created, similar to the Medic Alert bracelet system. Dunn et al (1996) suggest a standardized coversheet to document client preferences with a set of appropriate physicians orders to relieve the health care providers from decision-making at the time of crisis. The research design utilized 87 providers of long-term care and emergency medical personnel in rural and urban areas. Dunn, et al state:

Comparing responses to hypothetical scenarios without the medical coversheet to those with the medical coversheet, 37 % of treatment decisions changed for acute care and 29% changed for long term care providers. Changes were attributable

overwhelmingly to withholding treatments consistent with patient preference. (p. 790)

Multiple studies have addressed the issue of using advance directives usage within multiple types of health care settings. Despite attempts at a system for advance directive education, the availability of comprehensive consumer education and information remains fragmented. In-house patient representatives were shown to be important liaisons in promoting the recognition of advance directives when clients were transferred from ambulatory care to acute care settings (Meier, et al,1996). Davitt and Kaye (1996) surveyed home health agencies and discovered that only 67% had any mechanism for honoring advance directives. Although the majority of clients responded that they were informed of patient rights, most of them had not heard of advance directives. Heffner, Fahy, and Barbieri (1996) reports that when a questionnaire survey was distributed to 346 pulmonary rehabilitation programs, only 33% of the programs questioned clients regarding advance directives, and only 17% provided them to clients who had not instituted one.

Patient Empowerment

Littrell, Diwan, and Bryant (1996) recommend approaching the advance directive in the context of patient empowerment. The pinnacle of patient empowerment is the advance directive document, which preserves self-determination after mental capacity is lost. Littrell, et al (1996) state advance directives should be approached as a separate entity, not "embedded in other paperwork", as is often the case in hospital admission packets (p. 52). The conclusion could be reached that this process is best accomplished in some forum other than the healthcare setting, perhaps in a lawyer's office or as part of estate planning. Burg, McCarty, Allen and Denslow (1995) state "Advance directives, living wills and designated healthcare surrogates have been

championed as a means of empowering patients to exert control over the types of medical interventions they receive if they become incapacitated for medical decision-making" (p. 812).

Rein et al (1996) identified four phases of advance directive decision making. After advance directive education, people began to evaluate their level of illness. This led to establishment of priorities, and consideration of the implications of having advance directives. Eventually, the directives will be accepted or rejected. Rein et al demonstrated in their study that the sample of clients interviewed had limited understanding of advance directives and their implications. This highlighted the issue of true informed consent if one does not fully understand the choices. Miles, Koepf, and Weber (1996) defined "advance planning" as "the process of reflection, discussion, and communication of treatment preferences for end-of-life care that precedes and may lead to an advance directive"(p. 1063). This process is best begun prior to any acute illness being diagnosed, such as during the making of a will.

Family members of the terminally ill have been determined to feel relieved after discussions pertaining to the patient's and family's final wishes. Wharton, Levine, Buka, and Emanuel (1996) found 100% of parents with terminally ill children desired guidelines for critical care interventions. They recommend the initiation of end-of-life planning early after the onset or discovery of a terminal illness. This allows for a more philosophical viewpoint than during times of physiologic crisis or terminal illness. This also permits life support measures to be withheld, rather than withdrawn resulting in feelings of guilt. Family members are more comfortable withholding interventions than withdrawing them which could lead to additional suffering.

Theoretical frameworks identified in the literature that are relevant to this study are Maslow's Hierarchy of Needs (Maslow, 1954) and the American

Association of Critical Care Nurses' Synergy Model of Nursing (Curley, 1998). Maslow provides a societal construct regarding the motivation of behavior, and the Synergy Nursing Model looks at patient characteristics and Nurse competencies providing better outcomes.

Maslow (1954) described the construct of motivational behavior in human beings. He stated no single desire is isolated. The desire within a context of environment and cultural determination actualizes the self in any given setting. Given an attainable goal, man will be motivated to progress through a series of clearly defined needs.

The overall framework illustrates the person's inability to advance toward one's unique potential unless other, more basic needs, are first satisfied. Maslow himself labeled his framework the "holistic-dynamic theory". The most basic needs to be fulfilled by man are physiologic, such as eating. These needs must be satisfied before motivation will occur to move to the next level. Safety needs must then be met, including safety, security and freedom from fear. Love needs create a place to belong in the universe. Esteem needs create the desire for strength and mastery. Finally self-actualization allows a person to become what they can become. A person can finally be true to his own nature without constraint.

Babcock and Miller (1998) refer to Maslow as the father of humanistic psychology. Babcock and Miller cite three characteristics of humanistic education. First, humanistic education should allow learners to direct their own education. Secondly, humanistic education focuses on affective learning as much as cognitive education. Finally, humanistic education should be valued for education's sake, and should not be goal-driven. This reinforces the need to approach the general public with education within the home setting, with a videotape which can be reviewed. The potential healthcare consumers would

thus be provided an opportunity for healthcare decision-making, and be proactive by expressing their feelings about life-supportive measures. Clarifying end-of-life wishes prior to the onset of illness would advance them toward Maslow's concept of self-actualization.

The American Association of Critical Care Nurses' Synergy Model of Nursing has application to this study (Curley, 1998). This model describes the synergistic effects when client characteristics blend with nurse competencies. The interplay between the two promotes optimal outcomes for the client, the nurse, and the system. The Synergy Model identifies seven patient characteristics: stability, complexity, resiliency, resourcefulness, vulnerability, predictability, and the ability to participate in decision-making and care. Eight nursing competencies are also identified: clinical judgment, advocacy and moral agency, clinical inquiry, caring practices, collaboration, systems thinking, facilitation of learning and response to diversity. The model states when patient characteristics match nursing competencies well, the outcomes are enhanced.

The framework demonstrates the dynamic interaction between patient and nurse within any care giving setting. The relevance of this model to the proposed study is threefold. First, the patient's characteristics of decision-making and participation in care, in conjunction with the nurse competency of agency and moral advocacy, would be emphasized in the proposed study. Secondly, the educational videotape demonstrates critical care nursings' ongoing commitment to facilitation of learning outside of a crisis setting. Finally, this model acknowledges death as a potential outcome in the system. This facilitates patient driven decision-making by placing the patient's wishes at the forefront of the healthcare experience.

This study potentially contributes to the currently available literature by educating the healthcare consumer regarding the treatment options that may be

offered to them should they require critical care. A videotaped teaching tool, focused on critical care interventions was viewed in their own homes, at their leisure, and reviewed if questions or misunderstanding occurred. The potential healthcare consumer was encouraged to consider the desirability of living with certain types of disability. Their desires were compared to a control group who were not provided with the benefit of the explanations provided on the videotape. This determined the impact of learning about the risks and benefits of high technology care often required to maintain the client in the final days of life.

Summary

The review of the literature suggests a lack of standardization of format or availability of advance directives to prevent the institution of life-sustaining interventions in congruence with client wishes. Once treatment has been instituted, studies show physicians often allow only partial withdrawal of life-sustaining measures, or withdraw each measure individually. This promotes the concept of the family's role in patient advocacy.

Cost containment issues are at the center of the health policy debate. Significant cost savings was noted with the use of hospice and advance directives. Hospice care occurs in the non-institutional setting, and may be the greater contributor to cost reduction.

Multiple studies have been cited on the factors facilitating the use of advance directives. Patient representatives were useful in assuring the continuity of the directive between ambulatory and acute care settings. The majority of home health agencies are not encouraging the use of advance directives by providing forms or education. Pulmonary rehabilitation programs are rarely offering teaching for advance directives. Primary care physician counseling enhances the participation and return rate on advance directives.

It is well documented that advance planning should optimally occur prior to the onset of illness. The advance directive should be issued individually, not as part of admission paperwork, and should be approached as an opportunity for client empowerment.

A question not adequately addressed by previous investigators is related to the level of understanding regarding commonly used critical care interventions by the general public. Further clarification of education about specific medical interventions and their risks and benefits could increase the adherence to patient's final wishes if the healthcare providers were confident the patient was fully informed.

Chapter 3

Methodology

The research hypothesis of this study is that the healthcare consumer will choose to reduce the number of medical interventions on an advance directive form when poor outcomes are predicted. The methodology chapter covers the sample, instrument development, data collection procedure, and the data analysis.

Sample

The target population for this research was individuals over the age of eighteen residing in the St. Petersburg/Tampa Bay area. The sampling frame was composed of eight hundred and eleven potential health care consumers. Responses from individuals under the age of eighteen were excluded. Four hundred and eleven experimental and four hundred control packets were distributed. The control group received a packet which contained a trifold (see appendix A) featuring a cover letter of explanation, informed consent, a demographics questionnaire, and an intervention-specific outcome-based sample advance directive also known as "the medical directive" (Emanuel, 1991). Krames' instructional booklet entitled "Advance Medical Directives"(Appendix B) was also enclosed, along with a self-addressed, stamped envelope. The medical directive was patterned after one developed by Emanuel (1991) and was used as a prototype for a later revision by Gillick (1997). Permission for its use had been obtained (see appendix C). Psychometric analysis of this document has already established construct validity, external validity, and reliability (Alpert, et al, 1996). The experimental group was provided with the videotaped teaching tool in addition to the control group's packet. The completed medical directive, demographic data, and informed consent were returned for comparative analysis.

The research population was individuals residing in the St. Petersburg/Tampa Bay area who are 18 years of age and older. There were no other exclusion criteria. All subjects completing the sample medical directive and informed consent were included. The sample was a nonrandomized convenience sample. Basic demographic data was collected including age, sex, marital status, and highest level of education. Closed ended questions were asked as to whether the respondents were under medical care themselves, if a family member had been critically ill in the last three years, and had they been satisfied with the family member's care.

One estimate of survey size was determined by using the central limit theorem (Triola, 1995). This allows the investigator to be 95% confident that the sample proportion will be within 0.05 of the true proportion of the general population if 385 surveys are returned. Sample size was also calculated by using a proportion comparison using the z-test. These tests were run on Sigma Stat Computer Software (Version 6). Power analysis was also completed on the 22 pilot study subjects to determine the appropriate sample size for this study. Required sample sizes determined by power analysis varied with each recovery scenario. In recovery scenario one, the person is ill for one year, but returns to a normal state of health. In recovery scenario two, the person would be ill for a short time, have a small degree of physical or mental disability, but could still reside alone. In recovery scenario three, the person would be ill for a short time, have moderate mental or physical disability, have to reside in an assisted living facility, but could still perform the activities of daily living. In recovery scenario four, the person would be ill for a short time, and have a severe mental or physical disability requiring continuous assistance. In recovery scenario one, a sample size of 517 was determined to be minimally acceptable. For recovery scenario two, sample size was determined to be 154. In recovery scenario three,

sample size was determined to be 133. In recovery scenario four, sample size was determined to be 336. This would achieve a power of 0.80, with a 95 % confidence when $\alpha = 0.05$.

Instrument Development

A videotaped teaching tool regarding the risks and benefits of commonly used invasive procedures was written and produced by the researcher. The video script was carefully written including more positive statements about interventions than negative. The educational videotaped teaching tool was screened for content validity. An independent counsel was recruited to review the materials and provide guidance. This panel consisted of an estate lawyer and a theologian. Approval of the independent counsel has been obtained (see Appendix E). Approval for stock footage used as filler for the videotape was also obtained (see Appendix E).

The Krames' booklet has full and concise definitions of living wills, and medical directives in a soothing format that focuses on self-determination written at a fifth grade reading level. It was purchased and distributed without formal permission.

A pre- test / post-test study was conducted with a convenience sample of eleven experimental and eleven control subjects. Informed consent was obtained from the pilot study subjects prior to the initiation of the study. The medical directive chosen was evaluated for clarity of directions and questions. Reliability was established with a test-retest analysis. A Mann-Whitney U test with arcsine conversion of percentages revealed statistical significance in all four recovery scenarios (p values were .0063 in scenario one, .0002 in scenario two, .0001 in scenario three, and .001 in scenario four). Pre- test / post-test subjects were questioned about their impressions of the study to help identify

weaknesses. The most common complaint was the print was too small. Due to financial constraints, this could not be addressed in the study.

Procedure

A quantitative experimental study in the format of a difference between two sample proportions was performed. Each question on the advance directive was answered either yes or no given each outcome in a grid format. The research hypothesis of this study is that the healthcare consumer, when provided education outlining critical care interventions and their purposes, will choose to reduce medical interventions in situations where poor outcomes are predicted. There was no attempt to control other variables. The proposed research addresses several other issues included in the literature including education on critical care interventions in relation to the medical directive, education provided by videotape in the home setting, and education created with a nursing perspective.

The research proposal was submitted and approved by the Institutional Review Board at the University of Tampa, Tampa, Florida. The study was also submitted to All Children's Hospital IRB, but was not considered under the purview of the committee. The forms for IRB approval were completed (see appendix D). Informed consent was included on the trifold, and implied if the subject returned the sample medical directive.

The test packets were distributed door to door without interviewer contact. This yielded a non randomized convenience sample. Informed consent was included in the trifold obtained via return mail.

Data was collected by return mail in a self-addressed prepaid postage envelope which was included in the packet. The medical directive was scored in nominal measurement. The nonparametric test for equality of proportions was then

performed for comparison. The tests have a ninety five percent level of confidence and a .05 margin of error.

Data Analysis

The data was analyzed using nonparametric tests for nominal data. Demographics were summarized using percentages. Medical directive data were compared for significant differences between control and experimental groups between all four recovery scenarios. All medical directive answers were converted into percentages, and those percents were then compared using a test for equality of proportions. This yields a z value which reflects the statistical significance with a ninety five percent confidence interval and a .05 margin for error.

Summary

The sample population for this study was eight hundred and eleven individuals over the age of eighteen residing in the Tampa Bay/St. Petersburg area. Control and experimental packets were designed and delivered door to door in a non randomized convenience sample. The experimental group also received the educational videotape.

Instrument development involved writing and producing a videotaped teaching tool. This was screened and accepted by an independent panel. The medical directive was patterned after a tool which has successfully undergone psychometric analysis.

The procedure involved a nonparametric test for equality of two proportions to determine if the null hypothesis were true. The study was approved by the Institutional Review Board at the University of Tampa. Informed consent was obtained for this study.

Chapter 4

Results

The collected data was analyzed and interpreted using both descriptive and inferential statistics. The null hypothesis states there will be no difference in the experimental and control group choices on the medical directive. The research hypothesis states that there will be an increase in negative choices on the medical directive for critical care intervention in the experimental group as recovery outcomes deteriorate. These data support the primary research hypothesis that states that there will be an increase in negative choices on a positively worded questionnaire for critical care interventions in the experimental group. The specific hypothesis tested was:

H1. The number of negatively answered responses will be higher in the experimental group in comparison to the control group when poorer outcomes are predicted.

General Sample Characteristics

A total of eight hundred and eleven packets were delivered door to door in the St. Petersburg/Tampa area. A total of one hundred and sixty five medical directives were returned, ninety three experimental and seventy two control. The twenty two medical directives utilized for the pre- test post-test study are not included in this analysis. The overall response rate was twenty percent.

Descriptive Data

The demographic descriptive statistics are represented in Figures 1 through 4. The control respondents were primarily female (66%), married (55%), had graduated college (30%), and had an age range of 21 to 75, with the mean age of 46.3 years old. The experimental respondents were primarily female (64%), married (60%), had some college after high school (39%), and were

between the ages of 23 and 82 years old. The mean age for the experimental group was 54.1 years old. Refer to Figures 1 through 4.

Figure 1. Gender of Study Participants

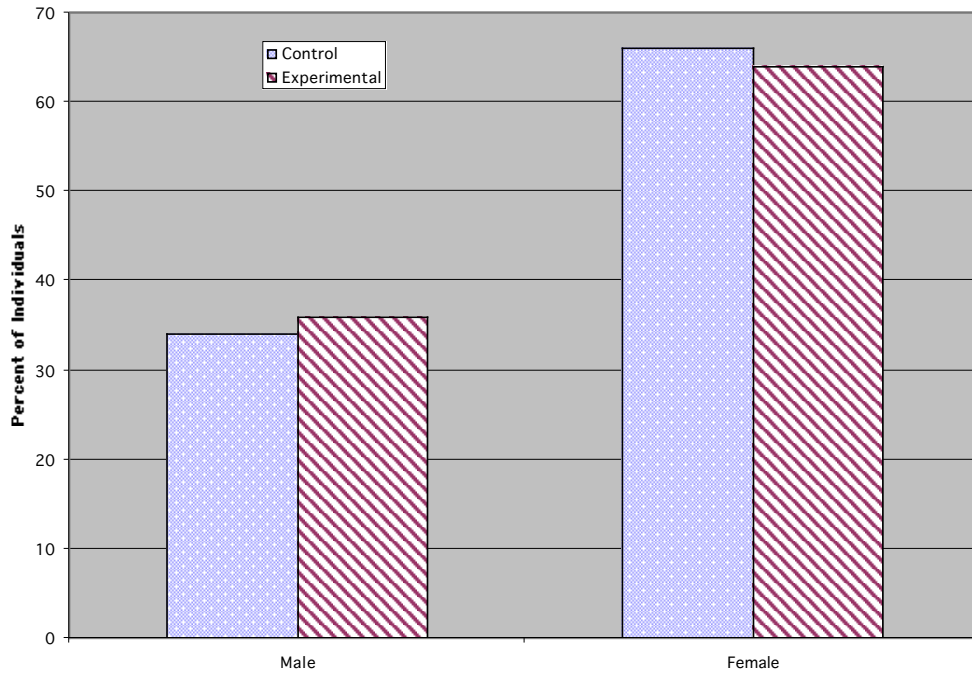


Figure 2. Marital Status of Study Participants

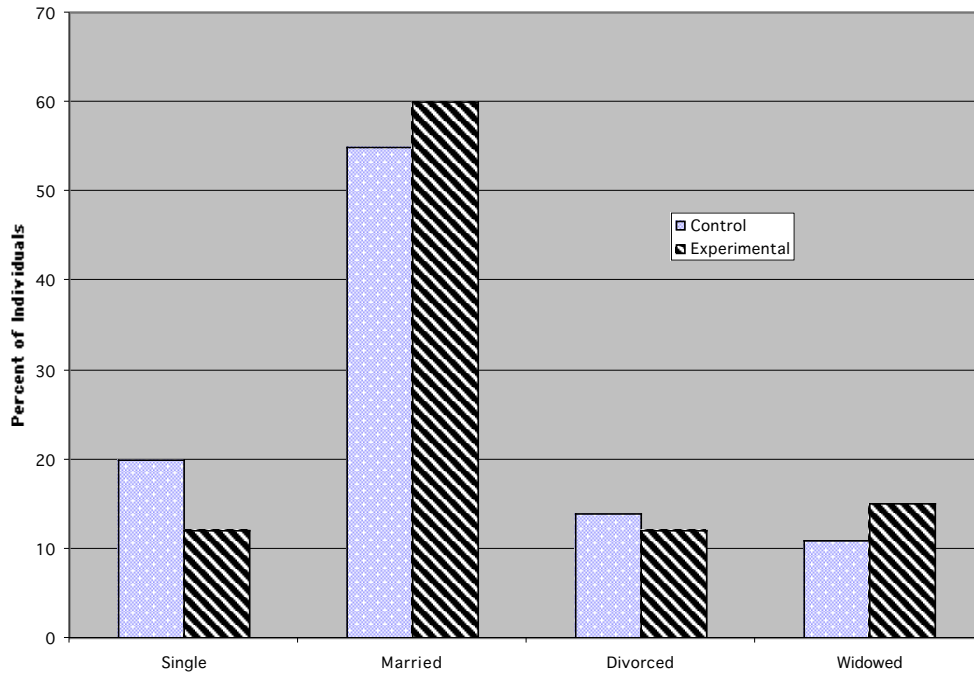


Figure 3. Highest Level of Education

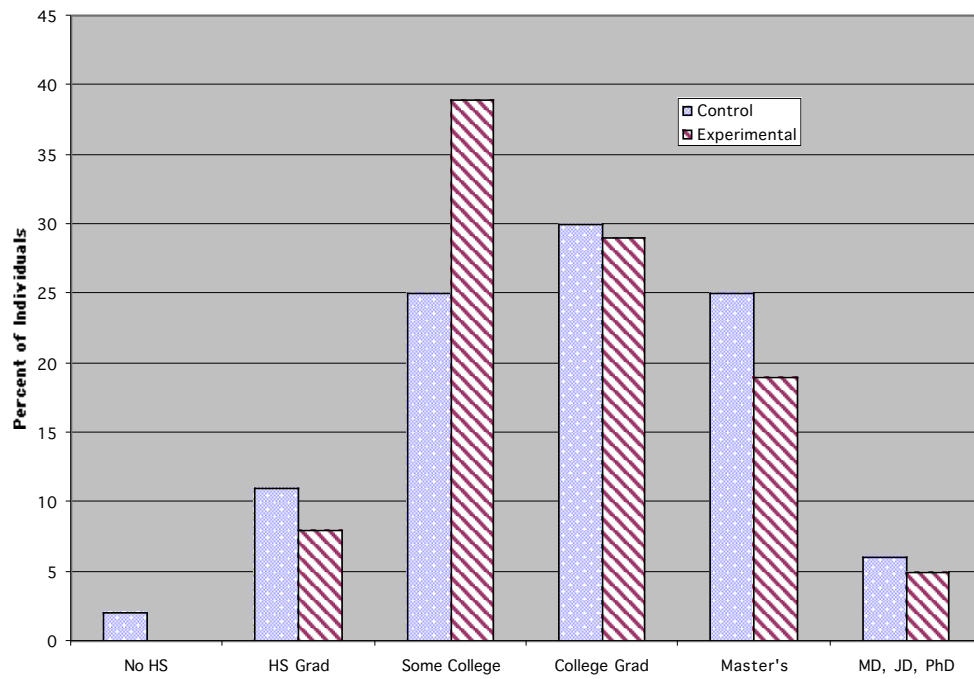
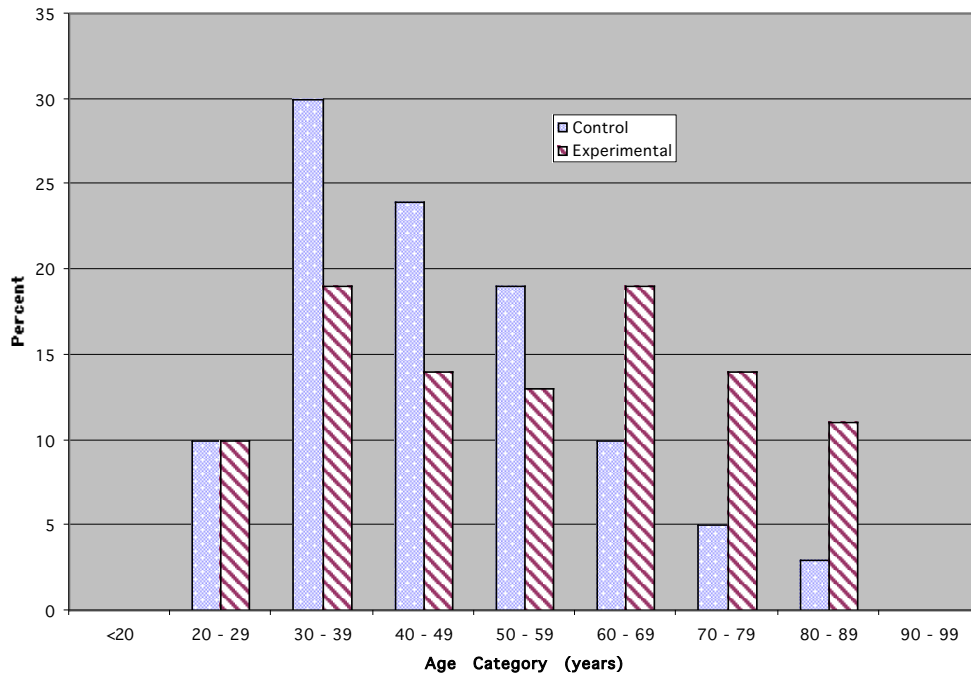


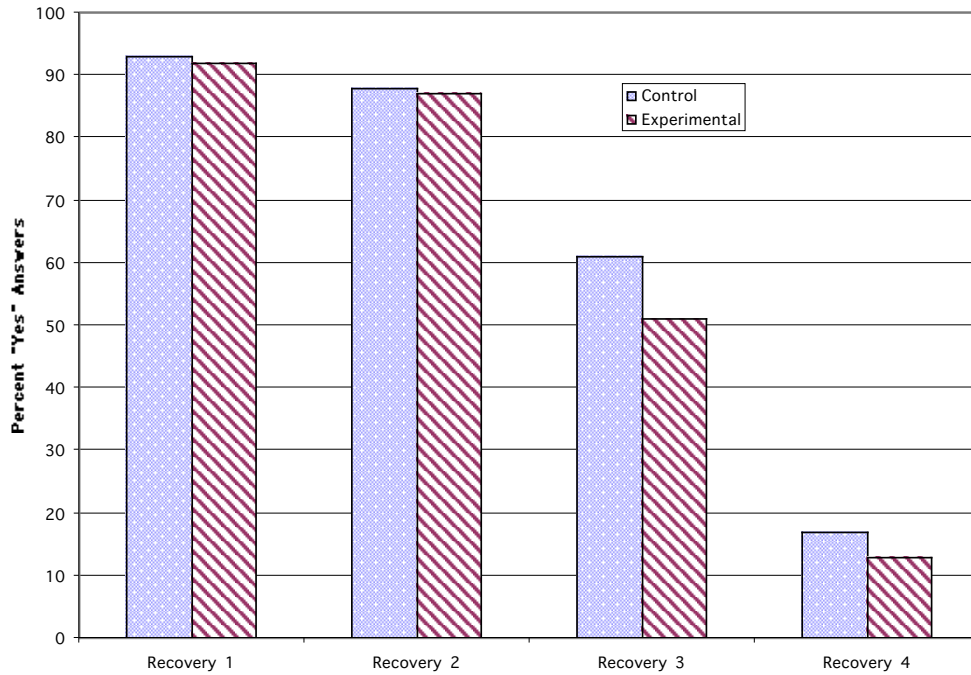
Figure 4. Age Distribution of Test Participants



Hypothesis Testing

All yes and no responses on the medical directives were converted to percentages, adjusting for any missing data (Figure 5).

Figure 5. Percent "Yes" Answers to Interventions



The percentages of affirmative answers are listed and confirm the primary hypothesis that there are more negatively answered responses in the experimental over the control group. The overall differences in yes and no answers when compared by the test of equality of proportions revealed no statistical significance in recovery scenario 1 & 2 ($p = 0.738$ and $p = 0.408$ respectively). The differences between control and experimental groups regarding yes and no answers were statistically significant in recovery scenarios 3 & 4 ($p = < 0.001$ and $p = 0.001$ respectively). Refer to Table 1 for summary data.

Table 1. Test For Equality of Two Proportions

	Recovery Scenario #1	Recovery Scenario #2	Recovery Scenario #3	Recovery Scenario #4
Number	Control n= 713 Exp. n = 911	Control n= 708 Exp. n = 918	Control n= 709 Exp. n = 900	Control n= 710 Exp. n = 930
%	Control P= 0.930 Exp. P= 0.924	Control P= 0.884 Exp. P= 0.869	Control P= 0.607 Exp. P= 0.509	Control P= 0.177 Exp. P= 0.114
z value	z= 0.334	z= 0.827	z= 3.858	z= 3.584
Probability	p= 0.738	p= 0.408	p= <0.001	p= <0.001
Power*	0.0512	0.127	0.972	0.944

* Power denotes performance at 95% confidence interval for difference with alpha 0.05

In summary, the research hypothesis was not supported in recovery scenario one and two, and was supported in recovery scenario three and four. This places the differences in responses in direct relationship to the potential patient outcomes.

Secondary Analysis of Results

The respondents in this study indicated the most desired intervention was antibiotics, and the least desired intervention was an endotracheal tube, which was consistent in all four recovery scenarios both control and experimental groups. It was also noted that cardiopulmonary resuscitation (CPR) was consistently more frequently desired in the control group than the experimental group. This could be related to the unrealistic societal expectations of full recovery after CPR. Miller, Jahnigen, et al (1992) found that lay persons consistently overestimated the survival to actual hospital discharge of patients who had undergone an episode of CPR by nearly 300%. Thurber (1996) studied

the misconceptions of treatment included in CPR by lay persons who had successfully completed a CPR certification class. CPR certified individuals often included weighing the patient and applying TED hose as part of an in hospital resuscitation process. Further societal education regarding the efficacy and procedure of in house resuscitation should be implemented.

Another aspect of these data that was interesting surrounded those individuals who chose to answer all yes and all no to the entire sample advance directive. Only one individual answered all questions negatively. He was an 84 year old widowed male with a high school education who had recently lost his wife, and was satisfied with her care. He was not currently under medical care. There did not appear to be any significant demographic differences in the individuals who chose all yes answers in either control or experimental groups. It may have been interesting to include the presence of young children in the household to determine if married females were choosing all yes because they had small children. Figure 6 shows the percentages of individuals who were under medical care. This was one variable considered in the study. It was determined that only 20 to 25 % of the sample population were currently receiving medical care.

Figure 6. Participants Currently Under Medical Care

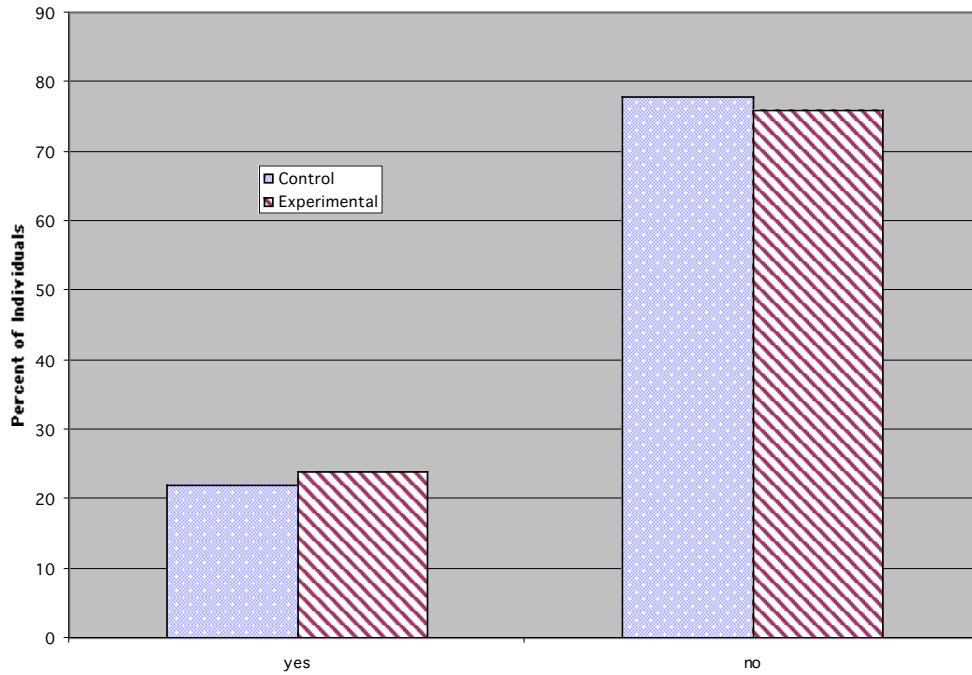
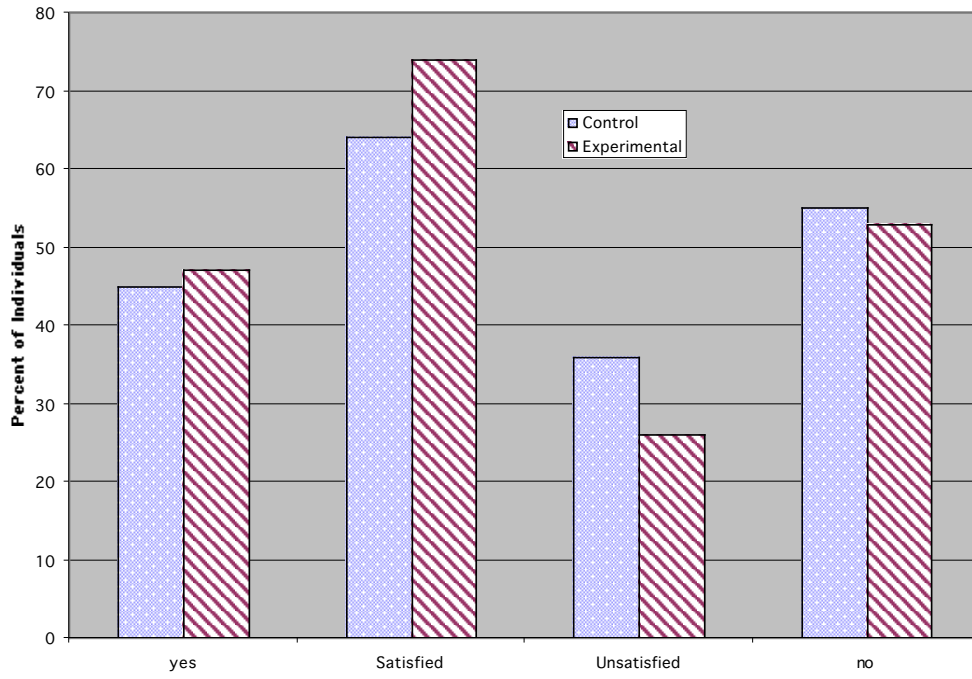


Figure 7 shows responses to the question if any family member had been critically ill within the last three years, and if so, was the individual satisfied with the care received. Nearly half answered that a family member had been in critical care, and two thirds were satisfied with the care received.

Figure 7. Participants with Recent Illness in Family



Chapter 5

Discussion

The research hypothesis of this study is that the healthcare consumer, when provided education outlining critical care interventions and their purposes, will choose to reduce medical interventions in situations where poor outcomes are predicted. This hypothesis was supported. This chapter compares these findings to existing literature. Study limitations and implications for further study are also discussed. Finally, implications for practice are considered.

Summary of Results

The majority of respondents were married females. The experimental group was older than the control group, which may have introduced age-related bias.. The majority of respondents were college educated. Approximately one fourth of the individuals in both control and experimental groups surveyed stated they were currently receiving medical care. Half of the individuals had a family member in critical care in the last 3 years, and one third of them were dissatisfied, which remained consistent between experimental and control groups. Individuals in both the experimental and control groups chose fewer interventions when given poorer outcomes. The highest degree of variability in answers was seen with recovery scenario three. The response in total were fairly heterogeneous in variance, which may reflect some response set bias. This supports Gillick and Mendes study (1996) that respondents would choose fewer aggressive treatment interventions as outcome scenarios progressed from robust to frail and dying.

Explanation of Findings

These data cautiously suggest that American healthcare consumers value autonomy and self-care. It may be an important component of American life to live on one's own, in a non-institutional setting. Most of the respondents were

committed to remaining alive even with some disability, if they could continue to live on their own.

The variability of recovery scenario three suggests a situational dilemma. Residing with a family member or in an assisted care facility would be an additional financial burden on family members. However, advances in medical technology could enhance life with disability. The higher percentages of negative responses after viewing the videotape may be related to the visual image of the intervention, and fear of physical pain.

Integration of Findings with Past Literature

This study supports Kolcaba and Fisher's article (1996) calling for a framework for patient decision-making. One purpose of the advance directive document clarified by this study would be defining common interventions instituted during critical illness, as outlined by Haynor (1996). Emanuel's (1991) advance "medical directive" is an acceptable and understandable format for the general public. Gillick's (1996) grid format is also easily understood. The tool used for this study was patterned after Gillick's tool, which was conceptualized from Emanuel's instrument (see letter in Appendix C).

In relation to patient empowerment, the topic of advance directives was raised outside of the healthcare setting. This supports Littrell, Diwan and Bryant's (1996) research which recommends approaching patients about advance directives separate from hospital admitting forms. The utilization of the home setting for advance directive learning allows individuals to progress at different rates through the four phases of advance directive decision-making as described by Rein et al (1996). This also supports the concept of advance death planning before the onset of illness as recommended by Wharton, Levine, Buka and Emanuel (1996).

Limitations

The most obvious limitation of this study was the use of a non randomized convenience sample. On analysis of the data, the heterogeneous distribution results in overall weaker inferential findings. Another limitation was lack of contact with the sample population. The respondents may have been mentally incompetent or confused. A larger sample size may have given a homogenous distribution. The research was also conducted in a single setting, the respondent's home. Varied settings could have influenced the findings. There was also limited control over data collection. Finally, multiple variables were not controlled, included health status, age, gender, marital status and comfort level with the healthcare system.

Implications for Practice and Suggestions for Further Research

A random, age-stratified sample population could identify trends among certain age groups. It would also be interesting to compare data between differing geographical or cultural areas. Ersek, Kagawa-Singer, et al (1998) identify several groups where sociocultural values may conflict with the premise on which advance directive documents are based, i.e. the need for self-determination.

The implications for acute care nursing are clear. Advance directives should not be part of an admissions packet. This topic should be discussed with a healthcare professional prior to admission. However, if this is not possible, a trained nursing professional should be available to counsel patients after admission, consistent with the spirit of the Patient Self-Determination Act. American Heart Association could incorporate survival statistics for CPR, both in the community and in the hospital, available during certification training to allow for more informed decision-making by the general public.

The impetus for clear patient understanding must come from the community health care providers. Critical care nurses must enter into community

service through professional organizations, and teach about critical care interventions. Nurse practitioners must spend the time during an office visit to discuss the purpose of acute care, and when it may not be beneficial given certain treatment goals. The bedside nurse must take cues from what inpatients say regarding their treatment goals and facilitate discussion with their families.

Summary

The majority of the respondents were married females. The experimental group was older than the control group. Individuals in both experimental and control chose fewer interventions when given poorer outcomes. There was the highest degree of variability in recovery scenario three. These findings support the existing literature on this topic. The study is limited by use of a nonrandomized convenience sample, a small sample size, a single setting and limited control of the data. Implications for nursing practice include education, counseling and assistance with completion of advance directive documents.

Appendix A

Appendix B

Appendix C

Appendix D

Appendix E

References

- Alpert, H.R., Hoijtink, H., Fischer, G.S., & Emanuel, L. (1996). Psychometric analysis of an advance directive. Medical Care, 34(10), 1057-1065.
- American Dietetic Society: issues in feeding the terminally ill adult. (1992). Journal of the American Dietetic Association, 92. 996-1005.
- Anonymous. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). Journal of the American Medical Association, 274(20), 1591-1598.
- Asch, D.A., & Christakis, N. (1996). Why do physicians prefer to withdraw some forms of life support over others? Intrinsic attributes of life-sustaining treatment are associated with physician preferences. Medical Care, 34(2), 103-111.
- Babcock, D., & Miller, M. (1994). Client Education: Theory and Practice. St. Louis: Mosby.
- Burg, M., McCarty, C., Allen, W., & Denslow, D. (1995). Advance directives. Population prevalence and demand in Florida. Journal of the Florida Medical Association, 82(12), 811-814.
- Campbell, M. (1995). Interpretation of an ambiguous advance directive. Dimensions of Critical Care Nursing, 14(5), 226-232.
- Coppa, S. (1996). Futile care: confronting the high cost of dying. Journal of Nursing Administration, 26(12), 18-23.
- Cruzan v. Mo. Dept. of Health. 110 S. Ct. 2841, 111 L. Ed. 2d224 (1990).
- Curley, M. (1998). Patient-Nurse Synergy: Optimizing Patient Outcomes. The American Journal of Critical Care, 7(1), 64-72.

Danis, M., Mutran, E., Garrett, J.M., Stearns, S.C., Slifkin, R.T., Hanson, L., Williams, J.F., & Churchill, L.R. (1996). A prospective study of the impact of patient preferences on life-sustaining treatment and hospital costs. Critical Care Medicine, 24(11), 1811-1817.

Davitt, J.K., & Kaye, L.W. (1996). Supporting patient autonomy: Decision making in home care. Social Work, 41(1), 41-50.

DesRosiers, M. & Navin, P. (1997). Implementing effective staff education about advance directives. Journal of Nursing Staff Development, 13(3), 126-130.

Dunn, P.M., Schmidt, T.A., Carley, M.M., Donius, M., Weinstein, M.A., & Dull, V.T. (1996). A method to communicate patient preferences about medically indicated life sustaining treatment in the out-of-hospital setting. Journal of the American Geriatric Society, 44(7), 785-791.

Emanuel, E.J. (1996). Cost savings at the end of life. What do the data show? Journal of the American Medical Association, 275(24), 1907-1914.

Emanuel, L.L., Barry, M., Stoeckle, J., Ettelson, L., & E. J. Emanuel. (1991). Advance directives for medical care—a case for greater use. New England Journal of Medicine 324(13), 889-95.

Emanuel, L.L. (1995). Advance directives: do they work? Journal of the American College of Cardiology, 25(1), 35-38.

Emergency medical services need not resuscitate. (1996). Nursing Management, 27(1), 50-52.

Ersek, M., Kagawa-Singer, M., Barnes, D., Blackhall, L. & Koenig, B.A. (1998). Multicultural considerations in the use of advance directives. Oncology Nurse Forum 25(10), 1683-90.

Faber-Langendoen, K. (1996). A multi-institutional study of care given to patients dying in hospitals. Ethical and practice implications. Archives of Internal Medicine, 156(18), 2130-2136.

Fakhry, S.M., Kercher, K.W., & Rutledge, R. (1996). Survival, quality of life, and charges in critically ill surgical patients requiring prolonged ICU stays. Journal of Trauma, 41(6), 999-1007.

Feinberg, J. (Ed). (1996). Reason and Responsibility. (9th Ed.) . Belmont: Wadsworth Publishing Company.

Florida Statute, Health Care Advance Directives, Volume 765 (1993).

Gillick, M.R. (1995). A broader role for advance medical planning. Annals of Internal Medicine, 123(8), 621-624.

Gillick, M.R. & Mendes, M.L. (1996). Medical care in old age: What do nurses in long term care consider appropriate? Journal of the American Geriatric Society, 44(11), 1322-1325.

Grubb, A., Walsh, P., Lambe, P., Murrells, T., & Robinson, S. (1996). Survey of British clinicians' views on management of patients in persistent vegetative state. Lancet, 348(9019), 35-40.

Haisfeld, M., McGuire, D., Krumm, S., Shore, A., Zabora, J., & Rubin, H. (1994). Patients' and healthcare providers' opinions regarding advance directives. Oncology Nursing Forum, 21(7), 1179-1187.

Haynor, P. (1996). The Patient Self-Determination Act. A chief nurse executive's perspective. Journal of Nursing Administration, 26(10), 47-55.

Heffner, J., Fahy, B., & Barbieri, C. (1996). Advance directive education during pulmonary rehabilitation. Chest, 109(2), 373-379.

Johns, J. (1996). Advance directives and opportunities for nurses. Image: Journal of Nursing Scholarship, 28(2) 149-153.

Johnson, S.C. (1996). Advance directives: from the perspective of the patient and the physician. Journal of Social Medicine, 89(10) 568-570.

Kaplan, K. & Davol, S. (1996). Exploring the issue of physician-assisted suicide. Choices: The Newsletter of Choice in Dying, 5(3), 1-2.

Kolcaba, K. & Fisher, E. (1996). A holistic perspective on comfort care as an advance directive. Critical Care Nursing Quarterly, 18(4), 66-76.

Kox, W.J., & Wauer, H. (1996). The limits of intensive care medicine. Zentralbl Chir, 121(7) 515-520.

Krumholz, H., Phillips, R., Hamel, M.B., Teno, J., Bellamy, P., Broste, S., Califf, R., Vidaillet, H., Davis, R., Muhlbaier, L., Connors, A., Lynn, J., & Goldman, L. (1998). Resuscitation preferences among patients with severe congestive heart failure. Circulation, 98. 648-655.

Levine, A. (1977). Understanding Psychology. New York: Random House.

Littrell, J., Diwan, S., & Bryant, C.J. (1996). Negotiating advance directives for people with AIDS. Social Work and Health Care, 23(2), 43-65.

Maslow, A. (1954). Motivation and Personality. New York: Harper & Row Publishers.

McCloskey, J. & Grace, H. (Eds.). (1994). Current Issues in Nursing. (4th Ed.) St. Louis: Mosby.

Meier, D.E., Fuss, B.R., O'Rourke, D., Baskin, S.A., Lewis, M., & Morrison, R.S. (1996). Marked improvement in recognition and completion of health care proxies. A randomized controlled trial of counseling by hospital patient representatives. Archives of Internal Medicine 156(11), 1227-1232.

Miles, S.H., Koepf, R., & Weber, E.P. (1996). Advance end-of-life treatment planning. A research review. Archives of Internal Medicine, 156(10), 1062-1068.

Miller, D.L., Jahnigen, D.W., Gorbien, M.J., & Simbartl, L. (1992). Cardiopulmonary resuscitation: How useful? Archives of Internal Medicine 152 (3), 578-82.

Molloy, D.W., Silberfield, M., Darzins, P., Guyatt, G.H., Singer, P.A., Rush, B., Bedard, M., & Strang, D. (1996). Measuring capacity to complete an advance directive. Journal of the American Geriatric Society, 44(6), 660-664.

Neumann, D. (1994). Providing information about advance directives to patients in ambulatory care and their families. Oncology Nursing Forum, 21(4), 771-775.

Ott, B., & Hardie, T. (1995). Readability of Advance Directive documents. Image: Journal of Nursing Scholarship, 29(1), 53-57.

Patient Self-Determination Act, USC§1395cc (1991).

Permut, S.R. (1998). Advance directives: Physician's rights and responsibilities. Hospital Medicine 34(3), 21-30.

Polit, D., & Hungler, B. (1993). Essentials of Nursing Research. Philadelphia: J.B. Lippincott Company.

Quinlan, 137 N.J. Super. 227, 348 A. 2d 801 Ch. Div. 1975.

Rein, A.J., Harshman, D.L., Frick, T., Phillips, J.M., Lewis, S., & Nolan, M.T. (1996). Advance directive decision making among medical inpatients. Journal of Professional Nursing, 12(1), 39-46.

Ross, P. & West, D. (1995). Advance directives: the price of life. Nursing Economics, 13(6), 355-361.

Schuster, H.P., Wilts, S., Ritschel, P., & Schuster, F.P. (1996). Predictive value of score parameters of the Simplified Acute Physiology Score(SAPS)-II for the duration of treatment of ICU patients. Wien Klin Wochenschr 108(15), 462-466.

Sehgal, A., Weisheit, C., Miura, Y., Butzlaff, M., Kielstein, R., & Taguchi, Y. (1996). Advance directives and the withdrawal of dialysis in the US, Germany, and Japan. Journal of the American Medical Association, 276(20), 1652-1556.

Triola, M. (1995). Elementary Statistics. Reading: Addison-Wesley Publishing Company.

Thurber, C. (1996). Public awareness of the nature of CPR: A case for values-centered advance directives. The Journal of Clinical Ethics 7(1), 55-59.

Wharton, R.H., Levine, K.R., Buka, S., & Emanuel, L. (1996). Advance care planning for children with special health care needs: a survey of parental attitudes. Pediatrics, 97(5), 682-687.

White, M., & Fletcher, J. (1991). The Patient Self-Determination Act. Journal of the American Medical Association 266, 410-412.