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AMBULATORY CARE PHYSICIAN BARRIERS CONTRIBUTING TO THE
LOW ADVANCE DIRECTIVE EDUCATION RATE

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
in
Health Services Administration

by
Cindy Lynn Grant

June 2000

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June 2000

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ABSTRACT

OBJECTIVE: To better understand why physicians are reluctant to initiate discussion about advance directives in the ambulatory care setting.

DESIGN: This is a quantitative, non-experimental descriptive study.

SETTING: Four medical groups: one academic and three non-academic ambulatory care settings in San Bernardino County, California.

PARTICIPANTS: A total of 34 physicians were surveyed, 29 of these physicians completed and returned the survey.

MEASUREMENTS: Physician's perception regarding what prominent barrier obstructs advance directive discussions between themselves and their patients. The prominent barriers cited within literature were advance directives 1.) are a risk, 2.) are too upsetting to the patients, 3.) are only for the seriously ill patient, 4.) are the patient's responsibility 5.) take too much time 6.) vary with ethnic/moral background, 7.) are not completed because of a lack of knowledge, and 9.) are not completed because of a physician's comfort level.

RESULTS: Physician's perceive that lack of time is the predominant reason that advance directives are not discussed more frequently in the ambulatory care setting.

CONCLUSION: Medical groups need to develop processes that relieve physicians of as much of the responsibility of the

advance directive process as possible. Utilizing support staff to educate patients on the advance directive process is one alternative to minimizing the physician's time. The physician can then devote the remaining discussion to clinical matters such as the patient's illness and prognosis issues.

Medical Group management should negotiate and increase in contract compensation with managed care healthplans. Additionally, the medical industry should develop a billing code that would reimburse physicians for completing this lengthy process.

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TABLE OF CONTENTS

ABSTRACT	iii
ACKNOWLEDGMENTS.	v
TABLES	viii
CHAPTER ONE - INTRODUCTION	
Problem Statement	1
Problem Background.	4
Statement of Purpose	8
Problem Significance.	9
CHAPTER TWO - REVIEW OF RELEVANT LITERATURE	
Advance Directive Education and Execution	12
Ambulatory Care Setting	16
Physician Barriers.	19
Summary	25
CHAPTER THREE - FRAMEWORK	
Research Question	27
Conceptual Framework.	27
Definitions of Relevant Terms	27
Assumptions	29
CHAPTER FOUR - METHODS AND PROCEDURES	
Research Design	31
Population, Sample and Setting.	31
Measurement	32
Data Collection	36

Data Entry and Calculations	36
Limitations	37
CHAPTER FIVE - FINDINGS	
Research Findings	38
Conclusion.	45
APPENDIX A - Patient Self Determination Act.	48
APPENDIX B - Advance Directive Glossary.	50
APPENDIX C - Physician Perception Questionnaire.	51
APPENDIX D - Questionnaire Instructions.	52
REFERENCES	54

TABLES

Table 1.	Mean Scores for Perceived Barriers	38
Table 2.	Mean and <i>SD</i> Scores for Perceived Barriers. . .	39
Table 3.	Mean Scores for Perceived Barriers by Practice Type	40
Table 4.	Mean and <i>SD</i> Scores for Perceived Barriers by Practice Type.	41
Table 5.	Mean Scores for Perceived Barriers by Medical Group.	42
Table 6.	Mean and <i>SD</i> Scores for Perceived Barriers by Medical Group.	43
Table 7.	Mean Scores for Perceived Barriers by Practice Setting.	44
Table 8.	Mean and <i>SD</i> Scores for Perceived Barriers by Medical Group.	45

CHAPTER ONE

Introduction

Problem Statement

With today's advanced technology, healthcare organizations have the ability to extend a life several years. However, the majority of physicians and patients agree that some interventions are not worth the marginal gains in life expectancy and value that they offer. Many treatment plans focus on the utilization of the latest technology in an effort to extend life, but simply promote suffering and indignity. Dunlap (1997) refers to this phenomena of life quantity versus life quality as the burden-to-benefit ratio.

It is estimated that 90% of all Americans will die in a hospital or skilled nursing facility. Patients over 65 years of age account for 73% of this annual death rate. Of this figure, it is estimated that 30% do not have a spouse, family member, or friend who could speak on their behalf should they become incapacitated. In these cases, the decision-making is subsequently left up to the health care provider.

Today, medical ethics claims that decisions regarding one's healthcare should be those that deliver the best

outcomes for the patient as determined by the patient. Advance directives provide the vehicle for patients to remain in control of their health care throughout their lifetime. This factor is a main reason that advance directive discussion should be approached prospectively within the ambulatory care setting.

Despite an increased awareness by physicians of the importance to preserve patient autonomy, one of the most difficult issues facing them today is assisting patients with the process of executing an advance directive. The physician's role in this process is important, for they can help the patient design an advance directive by offering critical information about their particular health condition. A disease-specific approach is optimal versus the generic preprinted execution of forms (Singer, Robertson, and Roy, 1996).

Although patients have the right to plan their treatment in advance, statistics show that only approximately 15% of the patient population have taken the initiative to execute an advance directive. Many factors involving both the physician and the patient have contributed to this low execution rate.

The low advance directive execution rate is of concern and is a problem that needs to be addressed. Lack of an advance directive can result in invasive care being imposed upon a patient who may have elected to refuse care had they been given the opportunity to do so while competent. Undesired treatment could result in decreased patient satisfaction and medical outcomes, as well as an increase in expenditures and the burden to benefit ratio.

The Patient Self-Determination Act (1991) mandates that each patient be educated on advance directives upon admission into an acute care facility. While this law was a step in the right direction, an increased number of terminally ill patients are being treated in the ambulatory care setting. Higher ambulatory care acuity has increased the probability of patients becoming incompetent prior to an acute admission. This has forced many medical organizations to expand on the Patient Self-Determination Act by examining the value of extending its requirements of education to the ambulatory care setting.

There is literature written and data collected pertaining to advance directives in the ambulatory care setting. Subsequently a review of this information has

identified several physician barriers contributing to the advance directives discussion process.

Arenson, Vovielli, Chambers and Perkel (1996) predict, "Physicians can expect to be faced with increasing pressure from patients, government, insurance companies and hospitals to implement widespread use of advance directives" (p.68). Therefore, research conducted within the ambulatory care setting should be expanded upon.

Problem Background

Autonomy is the bases for a patient's involvement in the directing of their healthcare. This fundamental comes from an ethical principle of respect for people (Dubler, 1991). Autonomy has also been referred to as "self-determination" which is an accepted philosophy and legal view of Western society.

The principle of a patient's autonomy is upheld by two legally accepted United States doctrines. First, the United States Declaration of Independence which states that all individuals have the right to "life, liberty and pursuit of happiness" (Office of the Federal Registrar National Archives and Records Administration, 1997/1998, p.1). Second (1891), the United States Supreme Court stated, "No right is held more sacred or is more carefully

guarded by the common law than the right of every individual to the possession and control of his own person, free from all restraints or interference by others, unless by clear and unquestionable authority" (Raffin, 1991). Therefore, patients who make autonomous decisions about their healthcare, exercise a civil right, the foundation of which was established well over a century ago.

Legally, advance directives are provisions for dying patients to refuse medical treatment. However prior to 1970, this behavior was considered unreasonable medical practice. Physician's felt that they were violating their oath to practice medicine, as well as placing themselves at risk should they not perform their medical duty utilizing the most current knowledge and resources.

In 1973, the American Hospital Association introduced the Patient's Bill of Rights, which includes the right to "self determination". Since that time, many healthcare organizations have attempted to establish these rights as a philosophical component of healthcare. Today, conditions for patient rights are commonly written in contracts and posted within healthcare facilities (Flarey, D.L., 1991).

The first of several high profile cases involving legal and ethical considerations of the "right to die"

received overwhelming publicity in 1976. Karen Ann Quinlan was comatose and receiving mechanical ventilation with little chance of recovery from a persistent vegetative state. Her parents fought for the right to remove her from mechanical ventilation. The legal battle was lengthy but eventually the Quinlans won.

Similarly in 1990, Nancy Cruzan's parents went to the Supreme Court to have their incapacitated daughter removed from continuous artificial nutrition and hydration. The Cruzans lost for there was lack of proof that their daughter had authorized the termination of treatment prior to her vegetative state.

In both cases had an advance directive been executed prior to incapacitation, neither situation would have been forced into the legal system for resolution. Although a right of each American, the fact is that advance directives were uncommonly known about until the media coverage of the Cruzan case.

Almost simultaneous to the legal battle of the Cruzan's, a bill known as the Patient Self-Determination Act (PSDA) was introduced into the United States Senate by Senator John Danforth (R-MO). "The bill was a major breakthrough in the attempt to transcribe into law a

patient's rights for self-determination in healthcare" (Flarey, D., 1991, p.20). Approved in 1990 and effective December 1, 1991, the intent of the Bill was to increase an awareness of advance directives through the education process (Appendix A - The Patient Self-Determination Act). Ultimately, it was hoped that increasing education of the subject would improve the advance directive execution rate.

Improved efforts to educate patients regarding their advance directives rights and options has been underway for nearly a decade (Appendix B - Advance Directive Glossary). Unbelievably, this effort has made little impact on the number of patients who have an executed advance directive. Literature says that researchers believe the low execution rate can be attributed to the environment in which the PSDA mandates the education be completed: hospitals, skilled nursing facilities, managed care health plans (HMOs), hospice, and home health agencies. While the PSDA requires education intervention during an acute health care event, literature suggests that patients may actually be more receptive to these important discussions if presented to them at a regular scheduled physician appointment (Mezey, Bottrell, & Ramsey, 1996).

While the PSDA does not directly require ambulatory care settings to comply with the education requirement, the Health Care Financing Association (HCFA) requires managed care health plans to assess whether the status of a patient's advance directive has been addressed during routine office appointments.

Recently, HCFA has gone one step further delineating additional beneficiary patient right requirements within the Balance Budget Act. As of January 1, 2000 it is required that advance directive documentation be a condition within all ambulatory care managed care (senior) contracts. Specifically, the Balanced Budget Act says that all medical groups will incorporate into their processes the education of all physicians regarding the requirement to document advance directive patient education information in a prominent place in their medical record. This documentation is to occur whether a patient has executed an advance directive or not (Balance Budget Act, 1999).

Statement of Purpose

This study has provided additional information for management and administrators of medical groups. Collecting data regarding a physician's perception of advance directive barriers was relevant based on legal,

ethical and monetary reasons. Organizations should utilize such data to restructure their current processes to improve their patient education rates. Ultimately, increasing education rates will promote patient autonomy, satisfaction and medical outcomes as well as preventing undesired care which may result in additional cost.

Problem Significance

First and foremost, advance directives are of ethical significance. As the advance directive is the preferred mechanism for assisting physicians with end-of-life decisions, the low advance directive rate is a significant issue. Although the concept is not perfect, it is the only way to preserve a patient's self determination. Without a signed advance directive, there is less chance that a patient's pre-determined wishes will be followed. Additionally, advance directives provide assistance to a family member who would be left to make difficult decisions on behalf of a loved one.

Ross and West (1995) say that the decision to terminate life-sustaining treatments should be made by the patient or their family for humanitarian reasons and not for monetary reasons. This decision is made without consideration of benefit of state, the hospital or the

patient's insurance company (Sprung, 1990). This is why ethical reasons of significance supercede any other reason to execute an advance directive.

In addition to ethical reasons, another matter of significance is the impact of unwanted health care on the national budget. Some alarming statistics are revealed by Singer and Lowry (1992): in the Medicare population, 27.9% of the annual spending is attributed to the 5.9% of Medicare covered patients who died in that year. Thus, approximately \$184 billion was spent in 1990 on patients who died. With 15% of Americans having completed an advance directive, this translates into \$156 billion for terminal care of patients without an advance directive.

When patients are asked to imagine themselves incompetent, lying in bed incapacitated and with a poor prognosis, approximately 70% decline life-sustaining treatments. Patients chose quality of life not quantity. Therefore, it could be surmised that over half of the \$156 billion spent in 1990 could have been reduced or simply avoided had advance directives been implemented.

Researchers in the Dana-Farber Cancer Institute and Harvard Medical School estimate that reducing life-sustaining care for the terminally ill would have reduced

health care costs by over \$30 billion in 1993. A savings of \$30 billion would have gone a long way to cover the nation's 39 million people who did not have medical insurance at that time (Winslow, 1993).

It is maintenance of this ethical-monetary balance that becomes of utmost priority, and is the impetus of the continued collection of advance directive data by the medical industry. Barriers that disturb this delicate, combined relationship are deserving of analysis.

CHAPTER TWO

Review of Relevant Literature

A literature review was conducted and organized into main topics that support the problem statement: 1.) advanced directive education and execution rate, 2.) ambulatory care setting, and 3.) physician barriers. Most literature reviewed was conceptual in nature, as limited research was found that had been conducted on advance directive education in the ambulatory care setting. The literature review included both primary and secondary sources.

Advance Directive Education and Execution

Current rate issues. Many reasons can be attributed to the low execution rate of advance directives, both avoidable and unavoidable. However, reports and studies show that although advance directives are a patient right, patients are not taking advantage of this right. Much speculation has taken place as to why this is occurring, and what can be done about the problem.

Studies have found that certain types of institutions provide less education on advance directives than others. One such environment is an academic or teaching hospital setting (Emanuel, 1993). This information does not come as a surprise, for academic centers generally have the latest

technology available and seemingly their attitude is to use it, at any cost.

What has been done. Several years ago, a study was conducted at a community hospital which showed that a mere 12% of elderly patients discharged with an advance directive education brochure and verbal nursing education executed an advance directive (Reilly, Wagner, Ross, Magnussen, Papa, and Ash, 1995). Likewise, when HMO patients over 65 years were sent information on advance directives, 18% chose to execute an advance directive (Rubin, Strull, Fialkow, Weiss & Lo, 1994).

A recent report issued from a Crawford Long Hospital Atlanta, Georgia, demonstrates that more than 1000 patients received information about advance directives, but that less than 10% ask for additional material or information regarding the subject (Haynor, 1998).

The Institute for Health Promotion and Disease Prevention at the University of Southern California School of Medicine and the American Association of Critical Care Nurses have researched this topic and found that specific education materials would be helpful. Therefore, the institutes collaboratively developed a planning guide that assists patients with knowledge of their options. This

encourages patients to ask specific questions and partake in advance directive discussion with their health care provider (Haynor, 1998).

A randomized, controlled trial research study was recently conducted in an outpatient general medicine practice. The objective was to determine what effect a computerized-generated reminder to physicians had on the frequency of advance directive discussion with their patients. The findings showed there was an increased rate of discussion of advance directives and completion of advance directive forms in elderly outpatients with serious illnesses (Dexter, Wolinsky, Gramelspacher, Zhou, Eckert, Waisburd & Teirney, 1998). As advanced directives have not become part of the routine annual physical, a reminder card served its purpose by increasing the amount of advance directive discussion documented within the patient's medical record.

Lynn and Teno discuss (1993) the array of efforts that have been used in order to increase the advance directive education and execution rate. These include value history forms, simplified formal advance directive forms, consumer education material, videos, interactive videodiscs, and skilled legal counseling. Despite the development of these

tools and the availability of professional counseling, the education rate remains low.

Benefits to increasing rate. Literature focuses on several benefits to increasing the advance directive education and execution rate. The two most prominent reasons pertain to promoting patient rights and cost containment.

Ethically the degree to which the physician provides education and encourages the execution of an advanced directive, determines the degree to which the role of the patient advocate is fulfilled (Lynn and Teno, 1993). When a patient does exercise their right to self-determination making a directive in advance of incompetence, it takes away the inherent ambiguities and compromises that sometimes result in its absence. Additionally, Mezey and Latimer say that application of advance directive ethical principles has proven to improve patient satisfaction and quality of care (1993).

A survey of Americans supports the notion that autonomy is important to patients while discussing their treatment plans with their physicians. A 1987 Harris poll showed that only 22% would want their doctors to make a terminal care decision without their input (Taylor, 1990).

Cost savings as it relates to advance directive execution has also been studied. One such study showed that the Mean hospital charge for 324 patients having no discussion about advance directives was more than three times that of the 132 patients having such discussion (\$95,305 versus \$30,478). This information is presented after application of control for severity of illness (Schneiderman & Pearlman, 1992).

Ambulatory Care Setting

Current advance directive setting. The Patient Self-Determination Act requires that the advance directive process be initiated at the time of patient admission. Most organizations comply with this law. Legislative requirement has much to be desired in defining the "how" and "who" of accomplishing this task. A variety of approaches have been established to meet the intent of the law. However, this has had little impact on the targeted outcome of increasing advance directive execution. Most organizations are complying with minimal requirements of the law, with disregard to the desired goal of increasing the advance directive education and execution rate.

Ambulatory care setting support. Extensive research has been completed on advance directive education and

execution processes within the acute care setting. While conducting these studies, researchers frequently note that the predominant setting in which advance directive education is taking place is not conducive to attaining the best results. It is suggested that although it has not been a requirement to initiate such discussion in the ambulatory care setting, that ideally patients are more apt in that setting to understand and follow through with execution when not faced with an acute illness.

Physicians have been surveyed, as well, on their opinions of when the advance directive discussion should begin. Several years ago, 100 physicians were surveyed; 73% said it should occur in the outpatient setting (Walker, 1995).

Eileen Dimond, Clinical Nurse Specialist at the National Institutes of Health in Bethesda, MD writes that the advance directive process should be completed prospectively, prior to forced decision-making on life-sustaining treatment. She says that statistics show that 80%-90% of cancer patients receive their therapy in the ambulatory care setting. These figures confirm the importance of implementing processes to discuss, educate

and execute an advance directive in the ambulatory care setting.

In 1994 Haisfield, McGuire, Krumm, Shore, Zabora and Rubin conducted a study to gain a better understanding of a physicians' preference as to when, how, and by whom advance directive information should be provided. Results showed that advance directive information should be given prior to a hospital admission and provided in a variety of formats. It also supported nurses and other health care professionals assisting with the process, but that physicians play the major role in providing objective, expert advice regarding the potential benefits and burdens of the proposed therapy in each individual case.

Studies have shown that patients do desire to discuss life-sustaining versus forgoing treatment prior to hospitalization. Specifically, one study documented 68% of 152 patients indicated a desire to discuss advance directives. Of this number, more than half preferred to have their physician initiate the conversation. When physicians did discuss advance directives, patients reported that they felt cared for and important (Lo, McLeod, Saika, 1986).

Furthermore, physicians agree that patients' involvement in end-of-life decision-making is inadequate. Although they acknowledge the concept that patients theoretically have the right to decide, this has not yet caught up with their ambulatory care physician practice (Dunlap, 1997). Physicians admit that their own conscience has in many cases directed the care of the patient, which in fact has been attributed to the physician preparedness on the subject (Soliman, 1993).

Some professionals argue that the ambulatory care setting is too early to start discussing end of life decisions. However, Danis (1994) showed that 85% of elderly out-patients who had decided to forgo life-sustaining treatments did not change their mind when followed longitudinally. This number is significant and reinforces the appropriateness of initiation of the advance directive process in the ambulatory care setting.

Physician Barriers

Barriers identified. It has been noted that physician discussion of advance directives with patients can have an impact on the education and execution rate. However, various barriers prevent these discussions, including ethical, cultural, societal, legal and institutional

factors (Leowy, 1998). Many believe that the physicians resistant to the subject do not wish to admit personal failure of treatment and losing the patient to death. They would rather save lives than to risk personal defeat, regardless of cost (Hoeftler, 1994). This opinion intertwines with the physician's belief that they are at risk legally if they do not exhaust all avenues of treatment.

LaPuma, Orentlicher and Moss say that many physicians are uneasy about discussing withholding treatment due to the questionable legal status of these documents (1991). However, the Hastings Center's *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* specifically addresses this issue by saying that there has been no successful criminal prosecution for the withdrawal of life-sustaining treatment in the presence of accurate medical diagnosis and clear advance directive.

This feeling that advance directives propose a risk to the physician, goes hand and hand with the thought that advance directives could potentially interfere with clinical judgement and the optimal recommended treatment plan. Ultimately, physician's fear that advance directives will provide them with the ability to rationalize

substandard clinical judgement in the wake of the nation's concerns regarding reduction of healthcare costs (Silverman, Vinicky, and Gasner, 1992).

Presently, the advance directive process is not owned by any one particular group of health care providers. According to an organization's needs it may be delegated to medical staff, nursing, admitting, or medical records departments. In fact many physicians believe that initiation of the advance directive discussion is the responsibility of the patient. This is contrary to the reasons cited that advance directives should be a physician's responsibility: one from an ethical perspective, as the patient advocate, and the other monetarily, as a business-owner.

Emanuel, Barry and Stoeckle conducted a study of 405 outpatients and 102 healthy subjects. The results were that 93% of the outpatients and 89% of the healthy subjects wanted an advance directive but that only 7% actually had one. Barriers to patient execution of an advance directive were cited as lack of physician initiation of discussion, and physician beliefs that the advance directive was for the seriously ill. On the other hand, the least cited

barriers were sensitivity of the subject and opposition to discussing advance directives (1991).

Physician's comfort level with the topic was seen as an issue, for they lack the skills and experience needed. Many medical schools are now incorporating this topic into their curriculum to provide the graduate medical student with the tools to overcome this discomfort (Saultz, 1990).

Physicians who come from ethnic groups that avoid the discussion of death, or who believe that end of life decisions should be made by the family may also propose barriers to the advance directive execution rate. These physicians must set aside their personal beliefs and focus on being an advocate for the patient. Additionally, physicians who are caring for patients of these ethnic groups must also make accommodations by seeking other means of communication about these issues with them.

Morrison, Morrison, and Glickman (1994) discuss two physician barriers: general lack of knowledge about completing advance directives and perception of a lack of necessity for young, healthy patients. One study conducted identified that two-thirds of physicians who were aware of a patient's end-of-life desires did not look at their advance directive status. Reportedly, other problems that

were identified in this study were the tendency of physicians to shy away from bad news, patient suffering at the end of their lives, and the devastation of families resulting from the cost of dying (Idemoto, 1993).

Little information was found regarding the time it takes to conduct such communication. Annas (1992) contends that any physician who refuses to deal with issues regarding advance directives should not be entitled for compensation for services. On the other hand, those physicians who do take the time to address advance directives should be compensated. White (1991) says that without some form of compensation for time consuming advance directive discussions and cognitive care, many physicians who are already overburdened day to day will continue to believe that the price of discussion is too high and will not engage in these crucial dialogues. Advance directive process implementation is perceived as an up front cost with no immediate return for service. However, in these instances physicians fail to recognize the potential cost savings of avoiding unnecessary care.

In an ambulatory care setting, the physician's focus is on the event or issue that lead up to that appointment: annual wellness exam, acute common illness or follow-up

appointment for ongoing issues. From an ethical perspective, patient advocacy should be a priority or focus. Implementation of advance directives has not been mandated and therefore has not been widely instituted in the patient routine appointment. It was suggested that a reversal of priorities in ambulatory care is indicated with focusing on recognition of the ethical value of the advance directive process. Berrio and Levesque (1996) cite these barriers that they have identified.

Barrier analysis importance. Many authors have described the importance and advantages of the advance directive process. For example Davidson, Hackler, Caradine and McCord discussed advance directives as a means of improving communication and trust between the patient and physician (1989).

An analysis of the barriers cited has supplied additional information about why advance directive education and execution rates are low. It has provided information that can be utilized in the wake of the Balance Budget Act to formulate processes that will attain the most benefit for the effort expended.

Summary

Advance directive education and execution is a proactive process which improves patient outcomes by respecting their wishes and imparting the care they desire. They are a relief to families who sometimes struggle with decision-making in a time of crisis.

Teno (1997) rightfully notes that advance directives cannot be expected to function well unless they arise from effective communication between the physician and the patient. Physicians must be well informed on all aspects that may attribute to the low advance directive rate.

The literature suggests that physicians have a lack of knowledge regarding advance directives. They should be educated on erroneous perceptions and beliefs associated with the advance directive process, including associated increase in legal risk, impairment of clinical judgement, responsibility for initiation of discussions, these discussions are only for the seriously ill and are upsetting to patients. They should also be mindful of the avoidance of transference of their cultural beliefs onto the patient.

It is recommended that physicians have the knowledge about advance directives, including statistics regarding

life-sustaining procedures and treatment, and take the time to communicate the information regarding the burden to benefit ratio to their patients. Ideally, by being fully informed, the physician's comfort level with advance directive discussions should improve. Overall knowledge of this subject should include what forms are needed and knowledge of the steps to be taken to complete the education and execution process.

This study surveyed physicians on their perceptions of the prominent barriers cited above. This was conducted for the purpose of utilizing the physician's perspective on barriers to enhance a medical group's advance directive process.

CHAPTER THREE

Framework

Research Question

What barrier is perceived by ambulatory care physicians to have the most impact on obstructing advance directive discussions between themselves and their patients?

Conceptual Framework

The research variables identified are the barriers cited within the literature as main contributors to the low advance directive education and execution rate. These barriers were the focus of this study. Specifically, this study listed the barriers on a survey and asked the physician participants to rank them according to how they perceived the degree of contribution to the problem. Ranking was done on a scale of 1-5, with 1 being the least contributing factor and 5 being the most contributing factor.

Definitions of Relevant Terms

1. Adult - Patient that is 18 years and older.

2. Advance directive execution rate - Rate in which all patients complete an advance directive within the ambulatory care setting.
3. Advance directive discussion/education rate - Rate in which a physician discusses the advance directive process with their patients.
4. Perceptions - Physician's belief.
5. Ambulatory care setting - Outpatient clinics or physician offices where patients are seen for routine and acute care.
6. Self determination - A patient's ability to determine their course of health care throughout their lifetime.
7. Autonomy - The ability to think and act on one's own behalf.
8. Burden to benefit ratio - The ratio that a physician needs to consider when assessing a patient's healthcare needs. What value will be attained from a treatment versus the burden it will cause.
9. Advance directive - Living Will and Durable Power of Attorney for Healthcare.
10. End of life - When a patient is terminally ill or incapacitated to the degree that they cannot make decisions or speak for themselves.

11. Ethical - The right thing to do.
12. Monetary - Cost.
13. Impact of obstructing - Level that a barrier contributes to the lack of discussion on advance directives in the ambulatory care setting.
14. Balanced Budget Act - HCFA initiated law that went into effect 1-1-00 that states ambulatory contracts must contain language regarding a physicians education on and documentation of advance directives for each patient.
15. Patient Self Determination Act - A Law that went into effect in 1991 that requires acute care facilities to educate patents and document the education process of advance directives. Additionally, it requires organizations to develop policies and procedures to delineate what their process is in attaining compliance.
16. Questionnaire - Survey.

Assumptions

There are several assumptions that must be delineated:

1. Physicians know what an advance directive is because they are presently or have been participants of the quality management process. The Quality Management

Department is the overseer of the advance directive compliance rate within medical groups.

2. Physicians will answer what they really perceive versus what they think the surveyor wants to hear.
3. Differences in physician ethnic background will not have an impact on this study.

CHAPTER FOUR

Methods and Procedures

Research Design

This study is a quantitative, non-experimental descriptive design. The research was performed merely to gain more information about barrier characteristics, specifically which barriers physicians perceive contributes to the problem. The main objective was to discover which of the nine elements identified in the literature review had the most impact on advance directive education and discussion as perceived by the physician's who were surveyed.

Population, Sample and Setting

The population sampled was physicians from four medical groups within the Inland Empire. Physician participants were from a variety of ethnic backgrounds, practicing specialties and gender.

The environment was the medical group setting. The surveys were either sent to the physician's office with the instructional information attached or administered as part of the Quality Management/Utilization Management Committee.

Physician participants were comprised of both primary care physicians as well as specialty care physicians. This

mixture provided a random sample of physician specialties in order to exclude bias that could be linked to any particular specialty type. The medical groups were both academic and non-academic settings.

The medical groups who participated were: Beaver Medical Group, Loma Linda University Health Care, Desert Medical Group and San Bernardino Medical Group.

Measurement

Operational Definitions.

The operational definitions were the nine survey barriers:

1. Knowledge
 - a. Law knowledge - The physician's knowledge of federal laws regarding advance directives such as the Patient Self-Determination Act and the Balanced Budget Act as well as any applicable state laws.
 - b. Form Knowledge - The physician's knowledge of legal documents that constitute a Living Will or a Durable Power of Attorney for Health Care.
2. Cultural Differences - The physician's ability to recognize cultural differences when addressing end of life decision-making alternatives.

3. Comfort level - The physician's feeling of comfort in discussing end-of-life alternatives with patients.
4. Time demand - The time it takes to complete the advance directive education on who, why and how an advance directive is executed.
5. Cost too much - The lack of compensation for taking the time to discuss a patient's advance directive rights.
6. Risk
 - a. Withholding care - The belief that physicians are legally at risk for a lawsuit if they follow a patient's wishes and withhold care that could sustain life.
 - b. Clinical judgement impaired - Physicians believe that some practitioner's clinical judgement is impaired and is an excuse to withhold care for monetary reasons.
7. Should be initiated by the patient - The belief that advance directive discussion is a patient right and therefore should be initiated by the patient.
8. Only for the seriously ill - The belief that only patients who are seriously ill and who are facing end of life decisions should be the only patients

with whom physicians should discuss advance directives.

9. Discussions upset the patient - The belief that physician discussion of advance directives does affect a patient's will to live which subsequently impacts a patient's hope.

Tool. The measurement tool was a questionnaire which utilized a 5 point rating scale (Appendix C - Physician Perception Questionnaire). The questionnaire was developed utilizing the issues listed as physician barriers in the literature reviewed. Additional information requested was the type of each participant's specialty. A series of steps were taken to develop the tool.

Utilizing the literature barrier concepts, questions were developed. Each item contained only one idea or potential rated barrier variable. The reading level for the tool was not a factor as participants were physicians who knew what an advance directive was and who could read and write English.

The tool was reviewed by several physicians for accuracy, appropriateness and relevance. Recommendations

made by these reviewers were considered and changes made to the tool.

The tool then went through a preliminary trial by two physician representatives. Special attention was paid to the representative's reactions during testing: noting pauses, answer changes and confusion. After this testing, there was a debriefing. The participants were asked to offer recommendations or suggestions for improving the tool. Improvements were completed according to physician recommendations.

Scoring. The physicians ranked their perception on a scale of 1 - 5: 1 contributing the least to the low advance directive discussion rate and 5 contributing the most to the low advance directive discussion rate. The data collected from the survey was ordinal in nature with the intervals between the ranking not being equal due to subjectivity. Each question was analyzed independently by calculating the Mean total to determine where the question or barrier falls within the scheme of central tendency. This analysis determined which item was perceived to contribute the most to the low advance directive discussion rate, thus answering the research question.

Data Collection

Data collection was conducted by utilizing a Questionnaire Instruction sheet (Appendix D - Questionnaire Instruction) which explained how to complete the survey questionnaire. Those surveys that were sent out had an instruction sheet attached. However, the instruction sheet was reviewed personally for those physician participants whose surveys were administered in a Quality Management or Utilization Management Committee.

Data Entry and Calculations

All surveys were given identifiers: medical group initials, and random numbers. This was completed as to provide identification should a need arise to re-review specific data from one particular survey. A spread sheet was developed utilizing one-word descriptions of each question. Surveys were entered on to the spread sheet specifying the medical group, specialty type, and physician rankings for each question.

Once the data was entered, a Mean analysis was calculated on all of the questions to determine which of the barriers had the highest average, indicating the greatest contributor. The Standard Deviation was also calculated to determine how much on the average the values

deviated from the Mean. The smaller the standard deviation the higher the indication that the Mean or average was a overall reflection of the physician perception.

Limitations

A limitation to this study was the control of the environment. Several medical groups expressed concern about taking up valuable committee time to complete a survey. Therefore, control of the environment was limited due to the survey being sent out to the physician participants in three of the medical groups.

The sample size depended on the number of physicians who completed and returned the survey. Several physicians who were sent the survey did not complete and return them as requested. There were 34 surveys handed out and 29 returned equaling a 78.3% return rate.

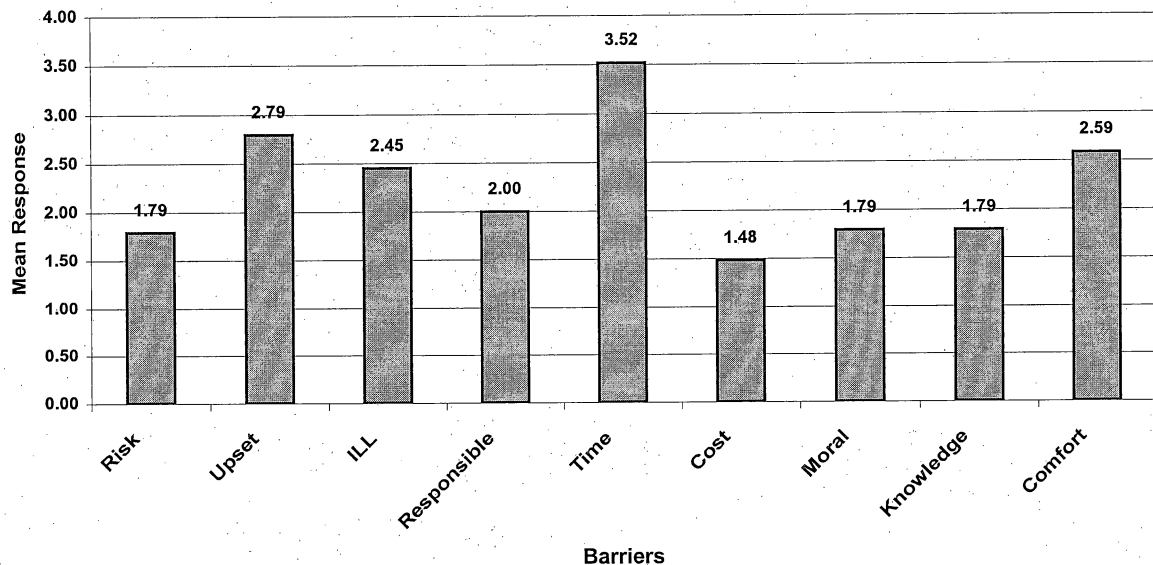
CHAPTER FIVE

Findings

Research Findings

The highest Mean score was time (Table 1 - Mean Scores for Perceived Barriers). Physicians perceive they do not have enough time to complete the advance directive process. It was the only barrier that received a score between 3.0 and 5.0.

Table 1 - Mean Scores for Perceived Barriers



The other eight barriers are divided evenly between two groups: Mean scores 1.0 - 1.9 and 2.0 - 2.9. First, those barriers between 1.0 - 1.9 were 1.) risk, 2.) cost, 3.) moral, and 4.) knowledge. These four barriers were perceived to contribute the least to the problem. Last,

those barriers between 2.0 -2.9 were 1.) upset, 2.) ill, 3.) responsible, and 4.) comfort. This group received a higher average perception rating toward contributing more to the problem. Both groups, however, had a greater central tendency toward "contributes the least" to the problem scoring below 3.0 (Table 2 - Mean and *SD* Scores for Perceived Barriers).

Table 2 - Mean and *SD* Scores for Perceived Barriers

	Risk	Upset	ILL	Responsible	Time	Cost	Moral	Knowledge	Comfort
Mean	1.79	2.79	2.45	2.00	3.52	1.48	1.79	1.79	2.59
S.D.	1.17	1.23	1.29	1.30	1.42	0.94	1.20	1.26	1.61
N	29	29	29	29	29	29	29	29	29

Upon reviewing the standard deviation (*SD*) of each Mean score, it is noted that time was the second highest variation in perception at *SD*=1.42. As time had a higher average score, it also had a higher variation among the physician perception than all of the other barriers except comfort.

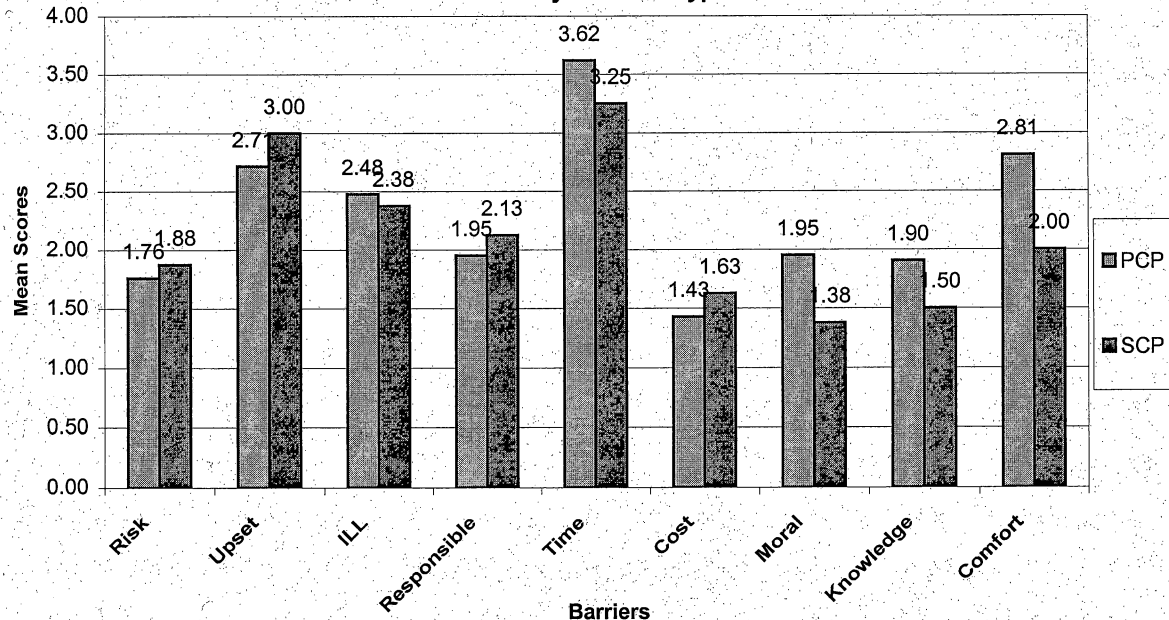
The remaining barrier *SDs* can be divided into two groups: above and below 1.35. Many of the barriers that received a low Mean score also received the least amount of variation. Cost, risk, moral, upset, knowledge, ill and responsible scored *SDs* below 1.35. This indicates that the variation of physician perception was the less among these

seven barriers. Considered in conjunction with the Mean scores of less than 3.0, these seven barriers were perceived to “contributes the least” to the advance directive education process problem.

The *SD* for comfort had the highest number. Comfort also had the third highest Mean which indicates even though there was a greater central tendency toward thinking that comfort contributed more, this barrier received the highest variation among physician perceptions.

As this preceding data took into account an aggregate summary of all medical groups, the data was subsequently

Table 3 - Mean Scores for Perceived Barriers by Practice Type



divided into two groups, primary care physicians and

specialty care physicians. This was done to determine whether time would still be perceived as the main contributor to the problem. (Table 3 – Mean Scores for Perceived Barriers by Practice Type). Upon reviewing the two types of practices, the data shows that time has the highest average.

The *SD* for time in both practice types, received the highest variation (Table 4 – Mean Scores and *SD* for Perceived Barriers by Practice Type). This information indicates that although time was the highest average, physician's perceptions varied more with time than any other barrier. This information is consistent with what is

Table 4 – Mean and *SD* Scores for Perceived Barriers by Practice Type

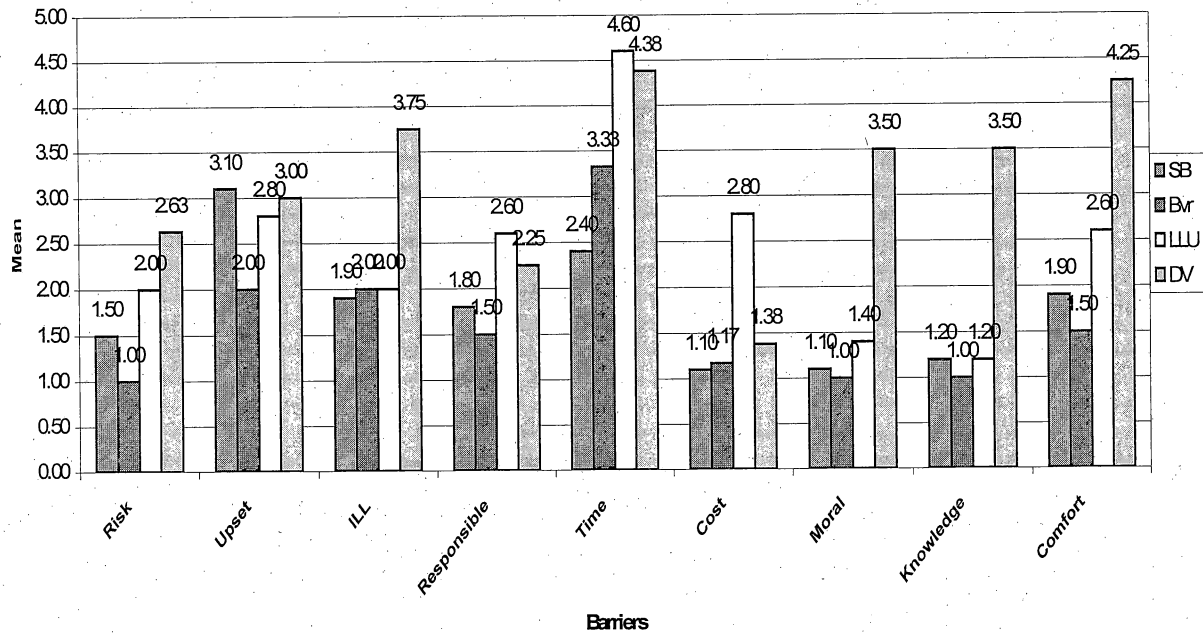
MD Type		Risk	Upset	ILL	Responsible	Time	Cost	Moral	Knowledge	Comfort
Primary	Mean	1.76	2.71	2.48	1.95	3.62	1.43	1.95	1.90	2.81
	S.D.	1.10	1.17	1.26	1.27	1.56	1.15	0.64	0.87	1.17
	N	29	29	29	29	29	29	29	29	29
Specialist	Mean	1.88	3.00	2.38	2.13	3.25	1.63	1.38	1.50	2.00
	S.D.	0.46	1.09	0.85	0.48	1.45	0.19	0.92	0.72	1.15
	N	29	29	29	29	29	29	29	29	29

seen with the aggregated medical group data.

Upon noting the similarities between the aggregate summary data and practice type summary data, the information was divided into two other types of groupings: medical group specific and practice setting, academic

versus non-academic settings. First, each medical group's aggregate data was reviewed to determine whether there were

Table 5 - Mean Scores for Perceived Barriers by Medical Group



similarities in physician perceptions (Table 5 - Mean Scores for Perceived Barriers by Medical Group). Time received the highest perception except in SB medical Group. SB medical group physician's felt that upset was the barrier that contributed the most to the advance directive problem.

When taking the *SD* into account, LLU and DV medical group physicians rated time as the highest contributor,

4.60 and 4.38 respectively. However, very little variation is seen in these two medical groups, $SD=.55$ for LLU and $SD=.92$ for DV. This indicates that physicians in these two medical groups not only averaged time as the highest barrier but that their perceptions were consistently higher toward "contributes the most". BVR medical group, on the

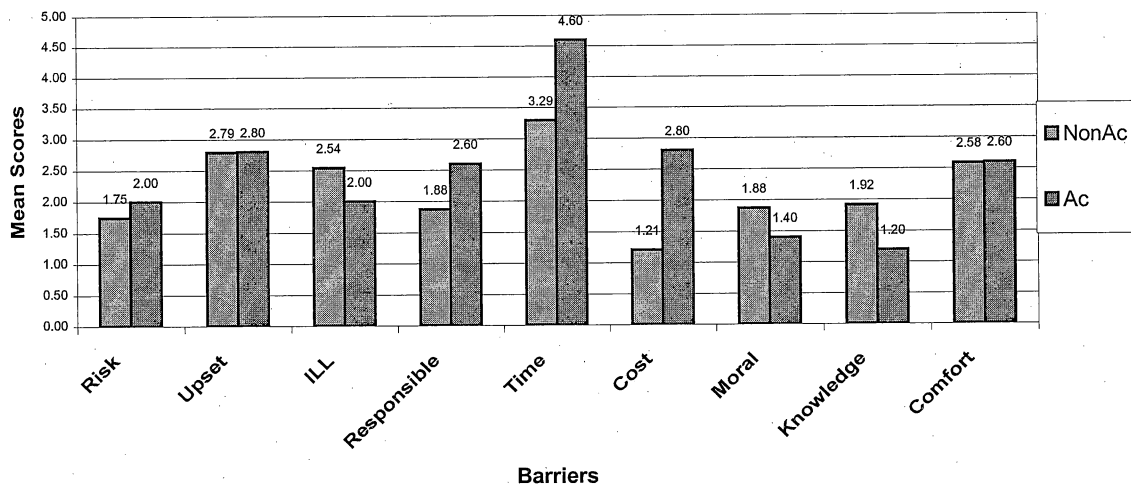
Table 6 – Mean and SD Scores for Perceived Barriers by Medical Group

Group		Risk	Upset	ILL	Responsible	Time	Cost	Moral	Knowledge	Comfort
SB	Mean	1.50	3.10	1.90	1.80	2.40	1.10	1.10	1.20	1.90
	S.D.	1.27	1.45	0.99	1.14	1.17	0.32	0.32	0.63	1.37
	N	29	29	29	29	29	29	29	29	29
Bvr	Mean	1.00	2.00	2.00	1.50	3.33	1.17	1.00	1.00	1.50
	S.D.	0.00	1.10	1.10	0.84	1.63	0.41	0.00	0.00	0.55
	N	29	29	29	29	29	29	29	29	29
LLU	Mean	2.00	2.80	2.00	2.60	4.60	2.80	1.40	1.29	2.60
	S.D.	1.22	1.30	1.00	1.82	0.55	1.48	0.89	0.45	1.34
	N	29	29	29	29	29	29	29	29	29
DV	Mean	2.63	3.00	3.75	2.25	4.38	1.38	3.50	3.50	4.25
	S.D.	1.06	0.93	1.16	1.49	0.92	0.74	0.76	1.07	1.39
	N	29	29	29	29	29	29	29	29	29

other hand, was more consistent with the overall medical group aggregate data, high mean and higher variation (Table 6 – Mean and SD Scores for Perceived Barriers by Medical Group). SB medical group having rated upset as a higher contributor, had a higher variation in physician perception with the $SD=1.45$.

Last, the medical groups were divided into two group settings: academic and non-academic (Table 7 - Mean Scores for Perceived Barriers by Practice Setting). Time rated the highest perception for both settings. However the difference between average ranking is significant. The academic setting average ranking was 4.60 while the

Table 7 - Mean Scores for Perceived Barriers by Practice Setting



non-academic setting scored more consistent with the overall medical group aggregate data scoring 3.29.

Comparing *SDs* of both practice settings shows that the academic setting (LLU) has low variation among practitioners, however non-academic settings (Bvr, SB, and DV) remain consistent with the overall medical group aggregate ratings (Table 8 - Mean and *SD* Scores for Perceived Barriers by Medical Group).

Table 8 - Mean Scores for Perceived Barriers by Practice Setting

Practice Setting		Risk	Upset	ILL	Responsible	Time	Cost	Moral	Knowledge	Comfort
Non-Academic	Mean	1.75	2.79	2.54	1.88	3.29	1.21	1.88	1.92	2.58
	S.D.	1.19	1.25	1.35	1.19	1.46	0.51	1.26	1.35	1.69
Academic	Mean	2.00	2.80	2.00	2.60	4.60	2.80	1.40	1.20	2.60
	S.D.	1.10	1.17	0.89	1.62	0.49	1.33	0.80	0.40	1.20

Conclusion

Overall, time was the consistent factor that physicians perceived to have the greatest impact on obstruction of advance directive discussions and education with their patients. The survey data was divided and analyzed four ways: overall data, practice type (pcp/scp), individual medical group, and by practice setting (academic/non-academic).

The overall data summary indicates that physicians perceive time to be the average main contributor but there is a high variation in among physician perception. The practice type summary was consistent with this indication.

The most significant differences were seen when analyzing the data of the individual medical groups. Two of the medical groups, LLU and DV, ranked high for time averages and received low variation scores. These medical group physicians, as a whole, agreed that time was the most significant issue. One medical group, Bvr, was consistent

with the overall perception; and the remaining medical group, SB, identified the most significant barrier to be that the advance directive process upsets their patients.

Last, the academic and non-academic settings were evaluated. The non-academic setting was consistent with the overall perception of physicians. However, the academic setting scores that highest average that time was the main contributor with the lowest variability in perception. This could be due to the academic setting ambulatory patient higher acuity.

Having assessed that time is perceived to be the major barrier to completing the advance directive process, medical group administration should develop processes that consider the physician's time. Much of the education and interaction with the patient on form selection and completion could be assigned to support staff. Documenting in the medical record that advance directive education has taken place also could be the responsibility of the support staff.

Whether or not physicians perceive there is enough time to complete the process, they still have an ethical and legal duty to make sure the process is completed.

Therefore, limiting the physician's involvement in the process to clinical discussion is recommended.

Last, the medical industry should take into account the cost of the advance directive education process and re-evaluate the need for compensation for the literature provided and lengthy discussions undertaken. Knowledge that advance directives reduce costs, should be considered as a special point during the negotiation of ambulatory care health care contracts. Another reimbursement tactic should be the assigning of a billing code to be utilized by those physicians who comply. As time was indicated to be the major concern amongst physicians, reducing and reimbursing them for their time should be an incentive that could improve the advance directive education rate in the ambulatory care setting.

Appendix A

Patient Self-Determination Act

(Provided by the Office of Senator John Danforth).

Purpose: It is the purpose of this Act to ensure that a patient's right to self-determination in health care decisions be communicated and protected.

Findings: 1) Common law and medical practice have traditionally recognized the right of a competent adult to accept or reject medical or surgical treatment affecting one's own person. 2) Recent advances in medical science and technology have made it possible to prolong dying through the use of artificial, extraordinary, extreme, or radical medical or surgical procedures. 3) The use of such medical or surgical procedures increasingly involves patients who are unconscious or otherwise incompetent to accept or reject medical or surgical treatment affecting their persons. 4) The traditional right to accept or reject medical or surgical treatment should be available to an adult while competent, so that in the event that such adult becomes unconscious or otherwise incompetent to make decisions, such adult would more easily continue to control decisions affecting their health care. 5) Estimates identify that 9 percent of the adult population have signed a living will, much less than 9 percent have designated a durable power of attorney for health care. 6) While providers of services should respect the wishes of patients, even in the absence of advanced directives, increased knowledge and use of advance directives as a vehicle of patient decision-making would enhance patient participation in health care decisions. **Medicare and Medicaid Provider Agreements Assuring the Implementation of a Patient's Right To Participate in and Directing Health Care Decisions Affecting Such Patients:**

1. Inform any such patient of such patient's right to make decisions concerning such patient's medical care, including the right to accept or refuse medical or surgical treatment, the right to appoint an agent or surrogate through a written power of attorney to make health care decisions on behalf of such individual, and the right of such patient to provide to such provider written instructions concerning the patient's health care, including instructions for the disposition of patient's organs.

2. Inquire whether or not such patient may have prepared a living will or written power of attorney while under no circumstances denying a patient admission based on presence or absence of such documents.
3. Document the treatment wishes of such patient, and periodically review such wishes with the patient.
4. Ensure that legally valid advance directives (living wills and written durable powers of attorney recognized as legally valid in the state where executed) shall be implemented to the maximum extent permissible under the law.
5. Arrange for the prompt and orderly transfer of a patient to the care of others when as a matter of conscience the provider cannot implement the wishes of such patient.
6. Implement an institutional ethics committee which would initiate educational programs for staff, patients, residents and the community on ethical issues in health care, advise on particular cases, and serve as a forum on such issues."

APPENDIX B

Advance Directives Glossary

Living Will (instructional directive) - Allows a competent adult to give directions for future care in the event that they become incapacitated due to terminal illness or impending death. Limited to instructions given in a document.

Medical Power of Attorney (health care proxy) - names a trusted person to act as an agent or proxy in making health care decisions in the event of incapacity. Broader implications for decision making; proxy can clarify living will or make decisions independently according to patient's values.

APPENDIX C

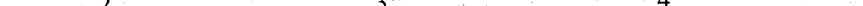
Physician Perception Questionnaire

Medical Group Name: _____

Physician Specialty: _____

According to your perception, please rank the following statements contribution to the low advance directive discussion rate in the ambulatory care setting. The rating scale is as follows:

Contributes Least Contributes Most

1 2 3 4 5 

Advance directive discussion:

1. places you legally at risk? _____
2. upsets your patients? _____
3. is only for your seriously ill patients? _____
4. should be initiated by your patients? _____
5. takes you too much time? _____
6. costs your medical group too much? _____
7. is effected by your ethnic/moral background? _____
8. is not done because of your lack of knowledge? _____
9. is not done because of your lack of comfort level? _____

APPENDIX D

Questionnaire Instructions

A literature review has been conducted to gather information on the advance directive discussion rate in the ambulatory care setting. Although much of the research conducted on advance directives is done so in the acute care setting, information available on ambulatory care demonstrates that the physician advance directive discussion rate is low.

Therefore, you are being asked to participate in a research study involving physicians' perceptions of barriers that are perceived to have the most impact on obstructing advance directive discussion in the ambulatory care setting. Participants of this study will be selected from 4 medical groups located in the Inland Empire. The participants will be those physicians who are or who have been involved with the Quality Management Committee or Department of the medical group. The purpose of this study is to identify what physicians feel is/are the main obstacle to conducting advance directive discussion in the ambulatory care setting.

When filling out the questionnaire, please include the name of your medical group and your practicing specialty. There are 9 questions with 5 possible rating measures per question. Please indicate the number in which you perceive best reflects the statement's contribution to the low advance directive discussion rate. For example a #1 would indicate that you feel the statement contributes the **least** to the low advance directive discussion rate and #5 would

indicate the statement contributes the **most** to the low
advance directive discussion rate.

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