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Knowledge and attitudes of elderly persons in the community regarding advance directives

Ogo Ezeokeke
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Ezeokeke, Ogo Comfort, M.S.

San Jose State University, 1994

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**KNOWLEDGE AND ATTITUDES OF ELDERLY PERSONS
IN THE COMMUNITY REGARDING ADVANCE DIRECTIVES**

A Thesis

Presented to

The Faculty of the School of Nursing

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

By

Ogo Ezeokeke

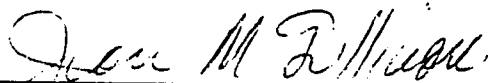
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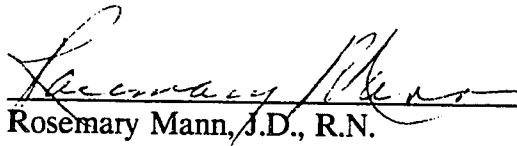
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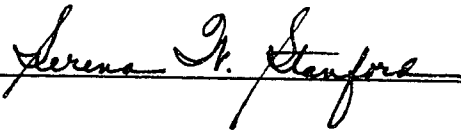


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ABSTRACT

KNOWLEDGE AND ATTITUDES OF ELDERLY PERSONS IN THE COMMUNITY REGARDING ADVANCE DIRECTIVES

By Ogo Ezeokeke

The purpose of this study was to determine the level of knowledge and the attitudes of elderly persons in the community regarding advance directives. A descriptive interviewer-administered survey design was used to explore these variables. A convenience sample of 34 elderly persons, 65 to 95 years old, was recruited from two local senior centers and one senior housing project. A nineteen-item questionnaire was used to guide the interview with the participants.

This study found that knowledge and utilization of advance directives by the elderly population is low; 47% reported they have signed an advance directive. Only 41% could explain or define advance directives.

A majority have a positive attitude about advance directives. Seventy-one percent would like to discuss it with their doctors. This study identified three barriers to knowledge and utilization of advance directives by this group: language, poor education, and limited discussion.

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Chapter 1

INTRODUCTION

Advance directives, which include living wills and durable powers of attorney, are means by which competent persons state in advance their treatment choices or instructions to their care givers in case they become incompetent and unable to participate in health care decision making (Schwarz, 1992). Advance directives can be either instruction directives, which may be written or non-written, or proxy directives, which are the selection of somebody to represent the signer and be the spokesperson in the event of incompetence (Pellegrino, 1992).

In the past, people died naturally at home in the company of family and loved ones. Now, death increasingly occurs in health care institutions in the presence of total strangers (Wold, 1992). This has supported the trend toward protection of patients' rights and increasing autonomy.

Various state legislatures first addressed "Living Will" legislation in the early 1970's. California was the first state to enact a law recognizing the validity of advance directives in 1976 (Wilson, 1988).

All 50 states now recognize and authorize the durable power of attorney for health care (DPAHC). This allows patients to select proxies to make medical decisions for them should the patient become incompetent and unable to make the decisions (Davidson & Moseley, 1986).

In 1990, Congress enacted the Patient Self-Determination Act. The act

became effective in December 1991. The act requires all health care facilities which receive federal funding to provide patients upon admission with information regarding their rights to refuse medical or surgical treatment, to appoint an agent for health care decisions, and to formulate a written advance directive. All patients in these facilities may now receive this information on admission but they are not obligated by law to sign it (Schwarz, 1992).

Despite this act and widespread acknowledgement of the importance of signing one of such documents, very few Americans have done so (La Puma, Orentlicher, & Moss, 1991).

The purpose of this study is to explore what elderly persons in the community know about advance directives and how they view them.

Statement of the Problem

The elderly, 65 years and above, comprise 17 percent of the population of the United States. It is estimated that by the year 2030, the elderly will make up about 21 percent of the population. It is projected that the number of persons living past 100 years will rise from 25,000 in 1986 to 100,000 in the year 2000. This creates a dilemma about quantity versus quality of life (Zweibel & Cassel, 1989). These dilemmas are forcing doctors, patients, and their families to make choices about initiating, withholding, or terminating life-extending medical treatments as provided by mechanical ventilators, cardiopulmonary resuscitation, tube feeding, dialysis, and antibiotic therapy (U. S. Office of Technology

Assessment, 1987).

Advances in medical technology have made it possible to prolong life for people who are terminally ill, comatose, or brain dead (Wilson, 1988). New technologies are continually being developed to perfect the prolongation of life. Modern medicine has become so successful at delaying death that a patient can be kept alive for a long time, even though the underlying disease cannot be cured (Snodgrass & Mozdierz, 1990). An extract from the living will published in 1969 and distributed by the Euthanasia Educational Council stated, "I do not fear death itself as much as the indignities of deterioration, dependence and hopeless pain" (Behnke & Bok, 1975, p. 152).

Regulations presently in practice may lead to medically futile procedures to be done on patients who are clearly not going to benefit from such procedures. These can cause suffering to dying patients or restore them to life for a few more agonizing hours or days.

Health care currently consumes 11% of the gross national product. It is estimated that by the end of the decade, health care will account for more than 15% of the gross national product (Office of National Cost Estimates, 1990; Waldo, Lent, & Lazenby, 1987). A large portion of the health care cost goes to the terminally ill. About 20 to 30 percent of health care expenditure is devoted to this group. A high percentage of this money is used for "heroic" intervention for patients who may die soon after receiving treatment (Lubitz & Prihoda, 1984).

A survey of family and patient preferences for medical intensive care found that 70 percent of patients and their families were willing to undergo intensive care to achieve one month of survival (Danis, Patrick, Southerland, & Green, 1988). Though cost should not be the driving force in deciding who to aggressively treat and who should not be treated, unnecessary waste and disproportional treatment which has brought us to the present "ethico-economic dilemma" may be avoided if people who choose not to be treated aggressively have advance directives (Frankl, Oye, & Bellany, 1989).

About 80% of Americans will spend the last days of their lives in a medical institution. Only about 15 to 20 percent have any form of advance directive (Gallup & Newport, 1991). For the rest of Americans without advance directives, decisions must be made by somebody in the critical days whether to withhold or use life sustaining treatments. Medical professionals are increasingly faced with ethical and moral dilemmas of caring for elderly patients who are incompetent and have no advance directives (High, 1987). Although the need for advance directives appears obvious, they are nevertheless not widely advocated by physicians (Davidson & Moseley, 1986). Most physicians lack knowledge about advance directives (Doukas, Gorenflo, & Coughlin, 1991). Also, most physicians are concerned about patients' reactions to such discussions and legal implications of initiating or following the patients' directives (Fried, Stein, O'Sullivan, Brock, & Novack, 1993; White, Siegler, Singer, & Iserson, 1991). These physicians struggle

to maintain an equilibrium between the role of a physician as specified in their professional oath, personal moral belief, and patient autonomy.

The issue of advance directives is most often addressed in retrospect or when a person is too ill and has neither the strength nor the will to continue to live. Informed consent requires that a patient understand the medical procedure being proposed, that consent be voluntary, and that the patient be competent to give consent (Janofsky, 1991). These conditions are not always present when a person is expected to make treatment decisions; therefore, the burden of responsibility of making important medical decisions is shifted to health professionals and family members who must struggle with guilt and an ethical dilemma. Bioethicists and others suggest that many bedside dilemmas could be avoided if patients were to discuss their wishes regarding life-prolonging treatment and aggressiveness of care well in advance of a crisis situation (President's Commission for the Study of Ethical Problems in Medicine, 1983).

The families of patients without advance directives often suffer tremendous guilt, emotional, and economic consequences in trying to come up with the best decision. The cases of Karen Ann Quinlan and Nancy Cruzan are examples of what can happen when somebody has no clear advance directive.

Karen Ann Quinlan was brain damaged in 1976. She was kept alive by feeding tubes and a ventilator. Her family had to go to court to petition for withdrawal of the life sustaining measures which were clearly not doing anything

but prolonging her suffering and the emotional distress of the family. The New Jersey Supreme Court granted the parents' request, based on testimony by friends that before Karen sustained her injury, she had indicated to them that she would not want to be kept alive artificially (*In re Quinlan*, 1976).

Nancy Cruzan was a 32 year old woman who was involved in an automobile accident in 1983 and suffered severe brain damage after resuscitation. She remained in a vegetative state in the hospital for four years. The family petitioned the Missouri courts to have the life-sustaining measures removed. The courts agreed but the state of Missouri appealed the case to the Missouri Supreme Court in 1988. The Missouri Supreme Court reversed the decision of the lower Missouri court, stating that the wishes of Nancy regarding feeding tubes were not clear (*Cruzan v. Director*, 1990). This case went to the United States Supreme Court in 1990, which returned the case to the Missouri Supreme Court, upholding the right of the state to legislate concerning the health and welfare of its residents. It was only when Nancy's friends provided additional testimony regarding her expressed wishes that the Missouri Supreme Court granted the parents' petition (*Cruzan v. Director*, 1990).

These cases have focused attention on advance directives. The elderly, who comprise a growing segment of the population, are more likely to be faced with situations when life-sustaining and life-prolonging measures will be used. These conditions identify the elderly as a group who will highly benefit from

drafting advance directives before crisis situations to avoid involvement of the courts. This study will help to create a clear picture about what the elderly people know about advance directives and what they think about them.

Research Questions

This study will attempt to answer the following research questions:

1. What is the level of knowledge about advance directives among elderly persons in the community?
2. What are the attitudes of elderly persons in the community about advance directives?

Purpose and Need

The fear of lingering death, prolonged suffering, dying in the hospital among strangers, and loss of control have driven researchers and patients to search for ways to avoid such situations. The purpose of this study was to describe variables associated with advance directives. This researcher will focus on the following two variables:

- a) Elderly persons' general knowledge about advance directives.
- b) Elderly persons' attitudes towards advance directives.

The study of these variables is important because, according to La Puma, Orentlicher, and Moss (1991), despite widespread acknowledgement of the need for individuals to draft living wills and durable powers of attorney or other advance directives, only a few Americans have done so.

The case of Nancy Cruzan and the enactment of the Patient Self-Determination Act (1990) are two major recent events that have caused increased attention to advance directives. Studies on advance directives have focused mostly on theoretical, legal, and ethical issues. However, the acceptance of advance directives by the very groups who are more vulnerable (the elderly) has not been well researched.

This study will help to provide understanding of elderly persons' knowledge about advance directives and their attitudes towards them. Doctors, nurses, and other health care providers will need a better understanding of these two variables before they can easily assist their patients with advance directives. The use of advance directives by elderly persons will be better understood by identifying how elderly persons view these issues. Results of this study will help to guide doctors, nurses, and other health professionals in exploring ways to increase the use of advance directives.

As this society continues to be diversified in culture, beliefs, and values, our clinical practice and policy must attempt to accommodate these changes. Attitude is a byproduct of values and beliefs. The study of attitudes can help us understand our diversified society. Leininger (cited in Marriner-Tomey, 1989), defined culture as learned, shared and transmitted values, beliefs, norms, and "life way" practices of a particular group that guides thinking, decisions, actions, and patterned ways. Leininger believes that recognition of culture promotes

professional-client relationship.

Definition of Terms

For the purpose of this study, the following definitions were used.

1. Advance directives refer to any advance instructions including living wills and durable powers of attorney, written or non-written, before critical illness or incapacity.
2. Elderly person refers to persons 65 years and older.
3. Life-sustaining or life-prolonging measure is any measure used to maintain life beyond the natural body's ability. These may include: ventilators, feeding tubes, medications, dialysis, and cardiopulmonary resuscitation.
4. Decisional incapacitation happens when a person is unable to take in and comprehend information regarding his or her specific medical situation and deliberate on accessible alternatives and make a reasoned choice (High, 1987).
5. A living will (see Appendix F) is a written declaration which a person makes to instruct the doctors or other health care providers to withhold or withdraw life-sustaining treatments in the event of terminal illness or a permanent unconscious condition in which the person is unable to make decisions for himself or herself (California Natural Death Act of 1976).

The law regarding living will varies from state to state. In California's living will law the declarant must be 18 years or older, and be certified by two doctors as having a terminal illness. Declaration requires two witnesses, one of

whom must not be a person entitled to any portion of the estate of the declarant, a health care provider, or an employee of the health care provider.

6. Durable power of attorney for health care (DPAHC, see Appendix E) is a planning tool for use in addressing health care needs of a person before that person becomes incapacitated. The tool also makes provision for selection of an agent to act on one's behalf in health care decision making (Durable Power of Attorney for Health Care Decision Act 1984).

Summary

An advance directive empowers the patients to participate in future health care decisions before loss of capacity. Biomedical ethics and the law agree that the choices of competent and informed patients regarding their health care should be respected by health care professionals.

Respect for patients' health care choices is not as simple as it may seem. Choices of health care, as faced by patients and the health care professionals, can be viewed as a spectrum, from reasonable to unreasonable, and will vary according to the person who is making the decision. Health care professionals struggle with conflict between the patients' choices and professional ethics, moral beliefs, and legal and societal implications before any appropriate action is taken. Despite these potential conflicts, health care professionals consider patients' preferences as the baseline for any decision.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

Conceptual Framework

In the face of continued medical technology expansion, most people on all fronts are seeking ways to free themselves from becoming slaves to new technologies. Many patients are demanding active participation in the management of their health. In Cassel's The Healer's Art, he said:

If I had to pick the aspect of illness that is most destructive to the sick, I would choose the loss of control. Maintaining control over oneself is so vital to all of us that one might see all the other phenomena of illness as doing harm not only in their own right but doubly so as they reinforce the sick person's perception that he is no longer in control (Cassel, 1976, p. 44).

Failing health and aging bring not only medical problems, but also issues of maintaining independence and control of life, which include identifying responsibility and maintaining independence (Snodgrass & Mozdierz, 1990).

Before the 1970's the relationship between the doctor and the patient was viewed as a father-child relationship. The doctor as the father knew everything and directed the affairs of the child (Veatch, 1991). The issue of maintaining independence and control over one's life when one is sick first gained national attention with the Karen Ann Quinlan case in 1976. This case, followed by the

Patient Self-Determination Act (1990) implemented in 1991, gave patients more power to maintain control of their health care.

The conceptual framework for this study is based on the bioethical theory of basic moral principles as discussed by Beauchamp and Childress (1989) and Veatch (1991). They identify four basic moral principles that guide professional-patient relationships. These four basic moral principles are:

- a) Principle of respect for autonomy
- b) Principle of beneficence
- c) Principle of justice
- d) Principle of nonmaleficence.

Respect for Autonomy

The principle of respect for autonomy states that persons should be allowed to choose and act without any constraint by others, as long as the actions do not jeopardize another person's welfare (Beauchamp & Childress, 1989; Moskowitz & Moskowitz, 1986; Otte & Allen, 1987). Informed consent, the right to autonomous decision making, and advance directives are based on the principle of respect for autonomy (Beauchamp & Childress, 1989). Hall, in her nursing theory of core, care, and cure (cited in Marriner-Tomey, 1989), states that people strive for their own goals, not goals set for them by others. She observes that in the usual medical setting the doctor defines the goals for the patient, but too often these goals do not coincide with the patient's goals for himself. This type of

relationship prevents teaching and learning which are core to patient healing. According to Hall, the core aspect of her theory involves the therapeutic use of self in communicating, teaching, and assisting patients to clarify motives and goals, which will in turn facilitate the process of increasing the patient's self-awareness and autonomy.

Principle of Beneficence

This principle mandates health care professionals to pursue treatments which will contribute to the well-being of the patient, to do good, and use "positive help" to help others. It also requires them to compare the possible good against the possible harm of an action (Davis & Aroskar, 1983). This principle is at the core of the Hippocratic tradition in Western medicine (Schneiderman & Arras, 1985). Health care workers, and physicians especially, face a recurrent dilemma because of conflicts between this Hippocratic tradition and the patient's expressed wishes. In a number of cases, the courts have allowed the withholding or withdrawing of life-sustaining measures even when such decisions meant death of the individual requesting it (Emmanuel, 1988). Because of these confusing situations the American Medical Association has attempted to reexamine the Hippocratic oath and has stated that withholding or withdrawing life-prolonging procedures in cases where those procedures are contributing to prolonging the patient suffering or would have limited value does not constitute unethical behavior. To guide physicians in determining when life-sustaining intervention

may be stopped, the American Medical Association states:

For humane reasons, with informed consent, a physician may do what is medically necessary to alleviate severe pain or cease or omit treatment to permit a terminally ill patient to die when death is imminent. . . . Even if death is not imminent but a patient is beyond doubt permanently unconscious . . . it is not unethical to discontinue all means of life-prolonging medical treatment (Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association, 1989, Sect. 2.20).

The American Nurses Association (ANA) Committee on Ethics encourages nurses to refer to the patients' advance directives to establish certainty about a patient's preferences on withholding or withdrawing medical treatment (ANA, 1988, p. 4). Respecting a patient's decision, and thereby recognizing his or her dignity and personal worth, does not cause harm; therefore, it is in line with the Hippocratic oath to "do good." It is a natural function of the medical and nursing profession to provide humane care consistent with the patient's wishes (Gostin, 1986). Under the principle of beneficence, the physician may use his position to try to prevent a patient from self-destruction, but autonomy takes precedence because physicians and nurses have no right to coerce a patient to follow their own wishes (Schneiderman & Arras, 1985).

Principle of Justice

This principle means equal treatment and giving each person what he or she is due. The key issue is whether the pattern of distribution of goods is morally important in addition to the amount of good that action generates (Veatch, 1991). Sometimes, there is a conflict between the principle of beneficence and the principle of justice. The nurse, as patient's advocate, should ensure that equal treatment is given to each patient. The nurse should also use moral judgment to resolve this kind of conflict while maintaining protection for the patient. The ANA Committee on Ethics advises nurses and other health care providers to use both moral and clinical judgment to resolve conflicts between the principle of beneficence and the principle of justice (ANA, 1988).

In health care, patients tend to be treated uniformly, ignoring individual, cultural, and religious differences. Leininger, another nursing theorist (cited in Marriner-Tomey, 1989), defined nursing as:

A learned humanistic art and science that focuses upon personalized (individual and group) care behaviors, function, and processes directed towards promoting and maintaining health behavior or recovery from illness which have physical, psychocultural, and social significance or meaning for those being assisted generally by a professional nurse or one with similar role competencies (p. 148).

Leininger stated that care behaviors, goals, and functions vary transculturally

because of the social structure, world view, and cultural values of people from different cultures. She also stated that patients are sensitive to interactions when their cultures are not respected or accommodated and this increases the interpersonal distance between the nurse and the patient and decreases the patient's satisfaction.

Principle of Nonmaleficence

This principle forbids one person to do harm to another (Beauchamp & Childress, 1989). Nurses and doctors follow standards of care as stipulated in their professional oaths to prevent causing harm to their patients. In medical situations there are sometimes conflicts between beneficence and nonmaleficence. Beneficence involves positive acts, preventing harm, removing harm, and promoting good. Nonmaleficence involves no infliction of harm (Beauchamp & Childress, 1989). It is difficult sometimes to categorize particular actions under beneficence or nonmaleficence. Allowing a patient to die because of previously expressed wishes may be characterized as doing good, by respecting the patient's wish, or as inflicting harm by allowing death to occur. In such conflicting situations, the principle of autonomy should take precedence. The nurse as the patient advocate should protect this basic moral principle.

Literature Review

Bioethicists, physicians, and patients acknowledge the need to draft advance directives, but very few persons have done so in the United States

(La Puma, Orentlicher, & Moss, 1991; President's Commission, 1983).

Approximately 4% (Cassel & Zweibel, 1987) to 17.5% (High, 1988) of adults in the United States have completed any form of advance directive. In a study conducted by Sachs, Stocking, and Miles (1990) in a geriatric clinic at the University of Chicago Hospital, they found that despite "empowering" interventions of teaching and frequent discussion of advance directives, only 5% of their patients had advance directives. In a public opinion survey conducted by the American Medical Association (1985), 56% of adults reported that they had discussed their treatment preferences with family members, but only 15% of the adults in the same survey had completed a living will. In another study conducted in a nursing home, 90% had heard of a living will, but only 18% had signed one (High, 1988). Thirty percent claimed to have heard about durable powers of attorney, but only 15% of this group had appointed a spokesperson (High, 1988). Cassel and Zweibel (1987) reported that 10% of older outpatients who participated in their study had given family members advance instructions regarding future medical care. Thirty-seven percent of the subjects in the same study had had a general discussion on life-saving measures but nothing specific was written.

People tend to wait until a crisis situation before having any discussion of advance directives. Each person struggles through life to maintain personal autonomy, but illness threatens this freedom of choice and action (Levenson, List, & Zaw-Win, 1987). Some researchers found little interest in health care

decision-making among patients (Strull, Lo, & Charles, 1984).

Ende, Kaziz, Ash, and Moskowitz (1989) found that the desire to make decisions declines for most of the patients when they are faced with chronic illness. However, in another study conducted by Lo, McLeod, and Saika (1986), 56% of their younger and older outpatient respondents with chronic illness reported having discussed their wishes and preferences with relatives.

The timing of discussion of advance directives has been the subject of debate in medical circles. Advocates of early discussion believe that it improves the quality of the patient-physician relationship, makes clear the patient's values, and helps to identify areas where the physician and the patient disagree (Edinger, Douglas, & Smucker, 1992). Older citizens wish to discuss their wishes with the physician during routine visits and not when seriously ill (Lo et al., 1986). Gleeson & Wise (1990) noted that "Do not resuscitate" discussions are frequently postponed until the patients are so ill that they cannot participate in the discussion. Bedell, Pelle, Maher, and Cleary (1986) found that discussion about patients' health care involve family members 86% of the time and patients themselves only 22% of the time.

Physicians have been blamed in much of the literature for the late discussion of advance directives. Although the need for advance directives appears obvious, they are not widely advocated by physicians (Davidson & Moseley, 1986). Many physicians are reluctant to raise the subject of advance

directives with their patients (Edinger, Douglas, & Smucker, 1992). About 13% of hospitalized patients discuss their "Do not resuscitate" (DNR) preferences before the order is written (U. S. Office of Technology Assessment, 1987). A survey of Arkansas physicians found strong support for use of advance directives among the physicians, but only 28 percent of these physicians had discussed advance directives with more than 25 patients (Davidson, Hackler, Caradine, & McCord, 1989). Responsibility for the initiation of the discussion on advance directives has been shifted back and forth between the patients and the physicians. Physicians view advance directives as the responsibility of the patients and expect them to initiate discussion of the matter. The patients, on the other hand, believe that initiation should come from the doctor (Kohn & Menon, 1988; Lo et al., 1986).

Part of the physician's reluctance in discussing end of life issues has been attributed to unpredicted patient reaction to such a discussion (Finucane, Shumway, Powers, & D'Alessandri, 1988). Rodriguez (1990) warned that indiscriminate implementation of advance directives discussion may trigger suspicion on the part of the patient. Patients might interpret this discussion to mean that their illness is getting more serious or that the doctor knows something different. None of these fears has been supported by research. In a study of homebound, frail elderly patients, Kellog, Crain, Corwin, and Brickner (1992) found no emotional trauma as a consequence of discussing life-sustaining issues.

They also found that the depression rating decreased for the entire group because of satisfaction of being in control. Eighty-seven percent of outpatients surveyed by Broadwell, Boisaubin, Dunn, and Engelhardt (1993) stated they would not be offended if, on admission to the hospital, they were asked whether they have completed a living will. Patients who have completed advance directives report a sense of being in control (Kellog et al., 1992). One study in a retirement community with terminally ill residents who had living wills showed that specific advance planning decreased anxiety about death (Henderson, 1990). In another study, nursing home residents' support of living wills was found to be directly related to feelings of internal control (Slavenas, Karuza, & Katz, 1990). Ouslander, Tymchuk, and Krynski (1993) found that discussion about enteral feeding tubes as a means of life-prolonging measure with elderly persons in a senior adult center was not anxiety promoting. Lo et al. (1986) found that although only 6% of patients have discussed advance directives with their physicians, 68% wanted such a discussion.

When patients do not make decisions of health care before a crisis situation, the burden of making such decisions often falls on health care professionals and family members. One study found that during crisis situations, most patients preferred that decisions be made principally by their doctors (Ende et al., 1989). This claim has been disproved by other studies. In another study, 65% of the patients chose their closest relatives to make health care decisions for

them (High, 1988). Some patients seem to hold the implied assumption that since they have lived with their family all these years and their family knows them well, the family will be able to make acceptable health care decisions for them when the time is right. However, very few of these patients have discussed their preferences with their selected proxies (High, 1988; Gamble, McDonald, & Lichstein, 1991). There are inconsistencies in the literature about how well the proxies represented the patients. Ouslander, Tymchuk, and Rahbar (1989); and Zweibel and Cassel (1988) found that decisions made by selected proxies deviated from patient preferences. In contrast, Hare, Pratt, and Nelson (1992) found that patients and their proxies agreed on treatment decisions 70% of the time. The reason for this inconsistency in the literature has not been established.

Summary

All these contradictions and inconsistencies in the literature indicate the need for continued investigation of this issue. By virtue of their age, elderly persons are more likely to be chronically ill and also in need of life-support measures. In a study by Gamble et al. (1991), only 52% of the respondents were familiar with living wills. This number is low, considering the need for this group to draft advance directives. This study will attempt to determine what elderly persons know about advance directives and their attitudes toward them. This will help policy workers and health care professionals in developing new strategies to increase the use of advance directives by older persons.

Chapter 3

METHODOLOGY

The aim of this study was to determine what elderly persons in the community know about advance directives and their attitudes towards them. In the process of this study, the researcher hoped to increase awareness about advance directives among the population recruited for the study.

Research Design

This study used a descriptive interview survey design. A questionnaire was used to guide the questioning during the interviews which included open ended and forced choice answers. The interview method was used because of the population being studied. Some elderly persons have poor sight and would, therefore, find it too difficult and time consuming to read the questions. The interview method was also chosen so that the researcher could explain the often confusing terms: living wills, durable power of attorney for health care, and advance directives. The questionnaire helped the researcher to conduct an organized interview and collect valuable qualitative responses in the shortest amount of time. The centers requested that each interview not exceed 30 minutes.

Sample and Setting

A sample of 36 elderly persons was recruited from three different community agencies. Two participants withdrew in the middle of the study,

leaving a total of 34 subjects. The three agencies were:

1. A senior services center in a local town. The center provides a social atmosphere, nutrition, and classes on several topics of interest to the seniors. The participants in the center are multicultural but predominantly white.

2. A local housing organization which provides retirement housing for elderly persons. The residents are multiracial.

3. A nutrition center in another local town which provides daily nutrition classes and social activities for the elderly. The group at this center is also multicultural.

The researcher was allowed a 20-minute segment during activity sessions in each of the centers to present the study. At the end of the presentations, questions were answered. The researcher also emphasized that participation was voluntary. Sign-up sheets were passed around and the first twelve persons were recruited from each center.

Instrument

The instrument used for this study was a nineteen-item questionnaire originally developed by Gamble, McDonald, and Lichstein (1991) at East Carolina University School of Medicine. They used the questionnaire to study the knowledge, attitudes, and behavior of elderly persons regarding living wills. Permission to use this questionnaire and modify it for this sample was obtained from Dr. Gamble (see Appendix A). A change was made in question 1, which

originally stated, "Are you familiar with the North Carolina Right to Natural Death Act?" This was changed to read, "Are you familiar with living wills?" Also, the first part of the questionnaire, which contains demographic questions on level of education and income, was added to present a better picture of the characteristics of the sample (see Appendix D). Questions 1 through 8 were used to determine knowledge about advance directives, and questions 9 through 19 were used to determine attitudes towards advance directives.

Data Collection and Method

Approval to conduct this study was granted by the Human Subjects Institutional Review Board of San Jose State University (see Appendix B). Informed consent was reviewed and signed before each interview was started (see Appendix C). The researcher reminded all subjects of their right to refuse to answer any question or withdraw from participating if they felt uncomfortable.

Each subject was interviewed in a private area provided by the centers. Each subject was asked all questions on the questionnaire. Because the focus of this study is advance directives, not living wills, the researcher, during the interview, substituted advance directive whenever the question read living will (see Definition of Terms, Chapter 1). On the question on income, the subjects were asked to rate their income as high, medium, or low by their own definition.

Data collected did not bear names of the subjects. The documents with signatures and initials of the subjects and the consent forms were separated from

the data. The researcher conducted all the interviews and handled all data and informed consents. The data were sent to the statistician in aggregate form. All data and informed consents, when not in use, were kept in a locked cabinet in the home of the researcher. Only the researcher had access to the cabinet.

Analysis

Descriptive statistics, including percentages and nominal measures, were used to analyze the responses to the questions. Questions 1 through 8 were used to answer the first research question, which is: What is the level of knowledge about advance directives among elderly persons in the community? Questions 9 through 19 were used to answer the second research question, which is: What are the attitudes of elderly persons in the community about advance directives? For ease of analysis, some similar responses to the same questions were presented in aggregate. Percentages were rounded to the nearest whole number.

Demographic data were used to identify group characteristics of the subjects.

Limitations

This study was limited in several aspects: sample, instrument, design and data collection.

A convenience sample of local elderly persons who volunteered for the study was recruited. The result may have been influenced by this recruiting method. The subjects may have had similar interests or attitudes about advance directives that led them to volunteer. The sample size was small. This would

make it difficult to freely generalize the results. Because of the sample size, some responses to some items were too small to allow for a meaningful comparison.

This instrument was originally developed and used by Gamble et al. (1991) for the study of "knowledge, attitudes, and behavior of elderly persons regarding living wills." The focus of this study is advance directives, not living wills. During the interviews, "advance directives" was substituted for "living wills." The subjects may have been confused by different types of advance directives, especially living will, which was confused with will of property. Because of the confusion, the number that reported they have signed advance directives is not reliable, because some of them may be will of property, not living will. The revised questionnaire used for this study was not pilot tested prior to data collection; therefore, this confusion was not detected or anticipated before the study.

The descriptive design does not allow determination of relationships between variables, which could have helped to explain some of the variations in responses by the subjects. This method also does not permit manipulation of variables, thereby preventing determination of cause and effect.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

Introduction

This study was conducted to determine what elderly persons in the community know about advance directives and their attitudes about advance directives. A total of 36 elderly persons were originally recruited from three community centers, but two withdrew in the middle of the study. The number of participants who completed the study was 34. The data collection instrument was a 19-item questionnaire which contained demographic questions, open-ended questions, and yes or no questions.

Demographics

The sample of 34 elderly persons was made up of 76% females and 24% males (see Table 1). Their ages ranged from 65 to 95, with a higher concentration in the 65-to-75 range (47%). The sample consisted of 33 whites (97%) and one Indian. Forty-one percent of the subjects were Protestants, 26% were Catholic, 21% Jewish and 12% reported no religion. The majority (94%) reported they were in good or fair health. A majority of the participants considered themselves in the middle or low income group (97%). Thirty-eight percent reported higher than high school education, 41% had a high school education, and 21% had a lower than high school education. More than half of the sample (53%) lived alone; 30% lived with spouse or other family members.

Table 1

Sample Characteristics (N = 34)

	<u>n</u>	<u>%</u>
<u>Gender</u>		
Female	26	76
Male	8	24
<u>Age</u>		
65-75	16	47
76-85	12	35
86-95	6	18
Older	0	0
<u>Race</u>		
Caucasian	33	97
Black	0	0
Others	1	3
<u>Religion</u>		
Protestant	14	41
Catholic	9	26
Jewish	7	21
No religion	4	12
<u>Health</u>		
Good	16	47
Fair	16	47
Poor	2	6

Table 1 (cont.)

	<u>n</u>	<u>%</u>
<u>Income</u>		
High	0	0
Medium	20	59
Low	13	38
Decline to answer	1	3
<u>Education</u>		
Less than high school	7	21
High School	14	41
Higher than high school	13	38
<u>Housing</u>		
Lives alone	18	53
Lives with spouse	7	21
Lives with other family member	3	9
Communal style	0	0
Nursing facility	0	0
Retirement facility	6	18

Note: Percentages add to more than 100% due to rounding.

Knowledge

The first research question in this study is: What is the level of knowledge among elderly persons in the community regarding advance directives? Items 1 through 8 as tabulated in Table 2 are used to answer this question. Sixty-eight percent said they were familiar with advance directives, 26% stated they were unfamiliar, and 6% were not sure. Fourteen persons (41%) were able to explain what an advance directive means. A majority of the subjects knew that signing an advance directive may authorize a doctor to discontinue or withdraw extraordinary means in the event of a terminal or incurable illness. However, only 8 (24%) were able to explain or define "terminal" and "incurable."

Close to half of the subjects (47%) reported they had signed an advance directive. Twenty-nine percent had discussed advance directives or issues of death with their doctors. The subjects gave several reasons why they had signed or not signed an advance directive (see Appendix D, Item 8). A majority stated they signed to relieve the family of the burden of making decisions for them when they are incapacitated. The second most common reason was to maintain autonomy and make sure their wishes were carried out. The most frequent reasons given for not signing were lack of knowledge and procrastination.

Attitudes

Questions 9 through 19 (Table 3) were used to answer the second research question: What are the attitudes of elderly persons regarding advance directives?

Table 2

Knowledge of Advance Directives (N = 34)

Item	Yes (%)	No (%)	Uncertain (%)
Familiar with advance directives	23 (68%)	9 (26%)	2 (6%)
Able to define or explain advance directives	14 (41%)	20 (59%)	0
Knew that an advance directive may authorize a doctor to withhold or discontinue extraordinary means	24 (71%)	10 (29%)	0
Able to define or explain terminal and incurable	8 (24%)	26 (76%)	0
Have signed advance directive	16 (47%)	18 (53%)	0
Discussed advance directive with doctor	10 (29%)	24 (71%)	0
Discussed issues of death with doctor	10 (29%)	24 (71%)	0

The responses on attitudes are tabulated in Table 3. All subjects who stated they had discussed advance directives or issues of terminal care also said that they felt satisfied with the discussion. Ninety percent of the time the discussion was initiated by the subjects. Ten persons (29%) thought that their doctor was aware of their wishes, and 29% had discussed their wishes with their doctor. A majority (71%) stated they would like to discuss advance directives or end of life care with their doctors.

In response to the timing of the discussion of an advance directive and end of life issues, 85% believed that the discussion should be done when the person is well, during a routine visit to the doctor. Nine percent believed discussions should start when a person is seriously ill. Six percent would prefer not to discuss the issues at all.

A high percentage of the subjects (94%) would prefer basic or comfort care when faced with a disease or illness that, regardless of medical treatment, would probably end in death. When asked about whom they would prefer to make decisions for them if they were not able to make decisions themselves, 91% preferred family members or a spouse to make decisions for them. Nine percent would prefer the doctor. Eighty-one percent of those who would prefer family members or a spouse to make decisions for them have discussed their wishes with those family members or their spouse, and only one person out of the three who preferred the doctor had discussed her wishes with the doctor.

Table 3

Attitudes towards Advance Directives (N = 34)

Item	Yes (%)	No (%)	Uncertain (%)
Preferred basic or comfort care only	32 (94%)	2 (6%)	0
Discussed preferences of medical treatment with doctor	10 (29%)	24 (71%)	0
Felt satisfied with the discussion	10 (100%)	0	0
Discussion of terminal care initiated by patient	9 (90%)	1 (10%)	0
Think that doctor is aware of wishes	10 (29%)	24 (71%)	0
Would like to discuss advance directives with doctor	24 (71%)	9 (26%)	1 (3%)
Would like to discuss end of life care with doctor	24 (71%)	9 (26%)	1 (3%)
Prefer discussion when well or at routine visit	29 (85%)	3 (9%)	2 (6%)
Would like family/spouse to make decisions or serve as proxy	31 (91%)	0	0
Would like doctors to make decisions	3 (9%)	0	0
Have discussed wishes with spouse or designated family member	25 (81%)	6 (19%)	0
Have discussed wishes with doctor	1 (33%)	2 (67%)	0

On Item 16 (see Appendix D) subjects were asked their reasons for wanting or not wanting to discuss advance directives or end of life care. The most frequent reason given for wanting to discuss advance directives and end of life care with the doctor was to make sure the doctor was aware of their wishes, and the most frequent reason for not discussing these issues was the lack of trust in the doctors.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

This study used a descriptive interview survey design to explore what elderly persons in the community knew about advance directives and what their attitudes were towards advance directives. The sample consisted of 34 elderly persons whose ages ranged from 65 years to 91 years. The participants were recruited from two senior centers and one retirement home. The instrument used was a 19-item questionnaire which was used to determine what the elderly persons knew about advance directives and their attitudes towards advance directives. Questions to gather demographic information were also part of the questionnaire.

The participants were ambulatory and active. A majority of them reported they were in fair or good health. Most of the participants had high school or higher education. Only 20% did not finish high school. They answered the questions with no problem or hesitation. The sample was predominantly white. The sample was a convenience sample recruited from three centers where the participants had social activities. Most participants reported medium or low income by their own definition.

Knowledge

It is surprising to find that only 41% were able to explain or define an advance directive, though 67% claimed that they were familiar with advance

directives. There was confusion among this group about living wills and wills for property. Some of the participants stated that a living will was a legal document where you stated how you want your assets divided when you die. Others simply called it "Deed of Trust." Seventy-five percent said they knew that signing an advance directive may authorize a doctor to withhold or discontinue "extraordinary means" when faced with a condition which is "terminal and incurable." Only 17% were able to explain the meaning of "terminal and incurable." Most of the participants thought that being on life support meant "terminal and incurable." People who have this understanding may have problems understanding an advance directive form or clearly expressing their wishes. This is an example of how language can be a barrier for elderly persons in understanding or using advance directives. Elderly persons who are not familiar with advance directives or who are confused by the legal and medical language would be less likely to sign one.

Education can play a tremendous role in clearing this confusion which could affect elderly persons' use of advance directives. This group might benefit greatly from a structured educational program because of their interest in this subject, their educational background, and their cognitive level.

This study found that doctors were not adequately promoting advance directives. Only 29% of the participants reported that their doctors had discussed advance directives or issues of life and death with them. The doctors for the

participants were not surveyed to find out the possible reasons for this low percentage. However, several reasons have been reported in the literature as to why doctors are reluctant to discuss living wills or issues of life and death with their patients. One reason, the fear of prematurely initiating discussion and triggering off an emotional trauma, has not been supported by the literature. In a study of home-bound frail elderly patients, Kellog et al. (1992) found no emotional distress as a result of discussing life sustaining issues. Eighty-seven percent of outpatients surveyed by Broadwell et al. (1993) stated they would not be offended if, on admission to the hospital, they were asked whether they had completed a living will. This researcher found the participants in this study very willing and freely discussed what they knew about advance directives and their attitudes towards them. There was no sign of any emotional distress. Some of them thanked the researcher for studying such an "important issue."

Despite the inadequate education of this group on advance directives, 47% claimed that they had signed an advance directive. This number may be misleading because of the confusion that existed among this group between a living will and a will of property. It is not clear how many of the 47% actually signed a living will or actually signed a durable power of attorney. Lack of knowledge and procrastination ranked high among the reasons given by the participants for not signing an advance directive. For those members of the group who had signed an advance directive, family concern was their main reason. They

were worried about overburdening their family members with the task of making such an emotional and difficult decision for them. Another frequently given reason for signing an advance directive was the fear of being held hostage by technology when there was no hope of survival or survival with very poor quality of life. It is the belief of this researcher that this group has not been adequately exposed to the issue of advance directives. The Patient Self-Determination Act (1990), which was enacted in 1991, mandated health care institutions and agencies to present information about advance directives to their patients before admission. There is no existing plan for education on advanced directives in the community by the government or the agencies.

Attitudes

A high number of the participants (94%) would prefer basic or comfort care only in case of a terminal illness. This is similar to the finding of Gamble et al. (1991). Despite the overwhelming preference for basic or comfort care by the participants, 71% had not discussed these preferences with their doctors. This gap in communications could be associated with the doctors not introducing the subject. Nine out of ten participants who said they had discussed their preferences with their doctors also said that the discussions were initiated by the participants themselves. If 71% of this population stated they would like to discuss advance directives or end of life care with their doctors, why then have very few (29%) discussed advance directives with their doctors? The most likely

explanation, as indicated by the results of this study, is lack of education and communication by the doctors who are privileged by their position to initiate the discussions.

Eighty-five percent of the sample thought the best time to initiate these discussions was when the subject was well, during a routine visit. This was similar to the finding of Lo et al. (1986) whose population overwhelmingly supported discussion of their wishes about medical care during routine visits. These findings are contrary to the current practice of doctors and nurses who wait until a patient is seriously ill or until a patient initiates discussion before advance directives or health care preferences are discussed. Gleeson and Wise (1990) noted that "Do not resuscitate" discussions were frequently postponed until the patients were too ill to participate in the discussion. Hall (1992), in her study of nurses' perception of their roles in discussing end of life issues with patients, found that 85% of the nurses discussed end of life issues when patients initiated "dialogue."

The reasons given by most participants in this study for not discussing advance directives or end of life issues with their doctors were lack of trust in the doctors and non-continuity of care. Some complained about having several doctors, therefore not knowing which one would be present during a crisis situation. Others who gave lack of trust as their reason added that they felt the doctors did not care enough to carry out their wishes. Frankl et al. (1989) found that patients with personal doctors have more life-support discussions than those

without a personal doctor.

A majority of the participants in this study (91%) would prefer a spouse or other family members to make decisions for them in case of incapacitation.

Eighty percent of those who would choose a spouse or family member as proxy have discussed their wishes with those family members. These participants have lived with their spouses and family members for a long time and have, therefore, developed a strong trust, and hence more communication with spouses and family members. These discussions were not of a legal or official nature with respect to advance directives.

Recommendations

Based on the findings of this study, the following recommendations are made.

1. Results of this study showed that, although less than 50% of the sample had signed an advance directive, 71% would like to discuss advance directives or end of life care with their doctors. This result showed interest in this group in wanting to share planning for terminal illness with their doctors, but they have not received adequate support or education, as indicated by the number who stated that they have not discussed advance directives or issues of life and death with their doctors. Community, health care agencies, nurses, and doctors should take a more active role in educating the elderly population about advance directives. The present practice as mandated by the Patient Self Determination Act (1990),

which requires patients to be informed about advance directives at the time of admission to an acute care hospital, is only reaching a small portion of the population.

2. Communication was one of the barriers to advance directives identified by this study. Further studies are needed to determine how to encourage and motivate elderly persons to discuss end of life care. A comparative study of well and hospitalized elderly persons on utilization of advance directives would also be helpful in evaluating the success of the Patient Self Determination Act (1990).

3. This study was limited by lack of ethnic and cultural diversity. Another study is needed which would have an adequate representation of different ethnic backgrounds. Such a study would throw more light on the differences in attitudes among the ethnic groups, which would be helpful in developing personalized education and communication strategies.

4. The sample used in this study is too small to allow for generalization of the result. The study should be replicated using a larger sample or elderly persons from other geographical areas so results could be compared.

Summary

Advance directives, living wills, and durable powers of attorney for health care provide a sense of security for the patient about maintaining autonomy at the end of life. They protect the moral and legal right of an individual, reduce ambiguity about patient preferences, and reduce anxiety of family members and

health care workers about making life and death decisions.

Geriatric nursing as a specialty has become very important in recent years because of the growing number of elderly persons. The need to protect the moral and legal right of the elderly, which includes life prolongation, self-determination, and autonomy, is also growing. The nurses as patient advocates should play an active role in ensuring protection of these rights for the elderly patient.

This study, with other studies, will help to provide insight into the utilization of advance directives by the elderly population. Despite the renewed interest and increased discussion about advance directives, caution should be exercised to avoid their use for rationing of health care or to fulfill family members' and health care workers' self interest or ulterior motives.

Advance directives should not be viewed as a warning for severe illness or death. Rather, they should be viewed as a partnership contract between the health care provider and the patient who must work together for the protection of each other's rights. The world is full of uncertainties, including the uncertainty of where and how the life of anybody will end. One of the ways to have control about the medical care one would receive is to create and sign an advance directive.

References

- Alexander, E. J., Beagle, C. J., Butler, P. Dougherty, D. A., Andrew-Robards, K. D., & Velotta, C. (1989). Madeleine Leininger cultural care theory. In A. Marriner-Tomey (Ed.), Nursing theorists and their work (2nd ed., pp. 146-163). St Louis: Mosby.
- American Medical Association. (1985). Physicians and public attitudes on health care issues. Chicago: Author.
- American Nurses' Association, Committee on Ethics. (1988). Guidelines on withdrawing or withholding food and fluid. Kansas City: Author.
- Beauchamp, T., & Childress, J. (1989). Principles of biomedical ethics (3rd ed.). New York: Oxford University Press.
- Bedell, S. E., Pelle, D., Maher, P. L., & Cleary, P. D. (1986). Do-not-resuscitate orders for critically ill patients in the hospital: How are they used and what is their impact? Journal of American Medical Association, 255, 233-237.
- Behnke, J., & Bok, S. (1975). The dilemmas of euthanasia. Garden City, NY: Doubleday.
- Broadwell, A. W., Boisubin, E. V., Dunn, J. K., & Engelhardt, H. T. (1993). Advance directives on hospital admission: Survey of patients' attitudes. Southern Medical Journal, 86, 165-168.
- California Natural Death Act. (1976). California Health & Safety Code, Sect. 7186-7195.

- Cassel, E. J. (1976). The healers act. Philadelphia: Lippincott.
- Cassel, C. K., & Zweibel, N. R. (1987). Attitudes regarding life-extending medical care among the elderly and their children. (Special issue). Gerontologist, 27, 229A.
- Cruzan v. Director, Missouri Department of Health, 110 S. Ct. 2841. (1990).
- Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association. (1989). Chicago: American Medical Association.
- Danis, M., Patrick, D. L., Southerland, L. I., & Green, M. L. (1988). Patients and families preferences for medical intensive care. Journal of American Medical Association, 260, 797-805.
- Davidson, K. W, Hackler, C., Caradine, C. R., & McCord, R. S. (1989). Physicians' attitudes on advance directives. Journal of American Medical Association, 262, 2415-2419.
- Davidson, K. W., & Moseley, R. (1986). Advance directives in family practice. Journal of Family Practice, 22, 439-442.
- Davis, A. J., & Aroskar, M. A. (1983). Ethical dilemmas and nursing practice (2nd ed.). Norwalk, CT: Appleton-Century Crofts.
- Doukas, D., Gorenflo, D., & Coughlin, S. (1991). The living will: A national survey. Family Medicine, 23, 352-356.
- Durable Power of Attorney for Health Care Decision Act. (1984). California Civil Code, Sec. 2410-2430.
-

- Edinger, W., Douglas, R., & Smucker, D. R. (1992). Outpatients' attitudes regarding advance directives. Journal of Family Practice, 35, 650-653.
- Emmanuel, E. J. (1988). A review of the ethical and legal aspects of terminating medical care. American Journal of Medicine, 84, 291-301.
- Ende, J., Kaziz, L., Ash, A., & Moskowitz, M. (1989). Measuring patients' desire for autonomy: Decision-making and information seeking preferences among medical patients. Journal of General Internal Medicine, 4, 23-26.
- Finucane, T. E., Shumway, J. M., Powers, R. L., & D'Alessandri, R. M. (1988). Planning with elderly outpatients for contingencies of severe illness: A survey and clinical trial. Journal of General Internal Medicine, 3, 322-325.
- Frankl, D., Oye, R. K., & Bellany, P. E. (1989). Attitudes of hospitalized patients towards life support: A survey of 200 medical inpatients. The American Journal of Medicine, 86, 645-648.
- Freid, T. R., Stein, M. D., O'Sullivan, P. S., Brock, D. W., & Novack, D. H. (1993). Limits of patient autonomy: Physicians attitudes and practices regarding life-sustaining treatments and euthanasia. Archives of Internal Medicine, 153, 722-728.
- Gallup, G., & Newport, F. (1991). Mirror of America: Fear of dying. Gallup Poll News Services, 55, 1-6.

- Gamble, E. R., McDonald, P. J., & Lichstein, P. R. (1991). Knowledge, attitudes and behavior of elderly persons regarding living wills. Archives of Internal Medicine, 151, 277-280.
- Gleeson, K., & Wise, S. (1990). The "do-not-resuscitate" order – still too little too late. Archives of Internal Medicine, 150, 1057-1060.
- Gostin, L. (1986). A right to choose death: The judicial trilogy of 8. Law, Medicine and Health Care, 14, 198-205.
- Hall, P. (1992). Nurses' perception of their role in discussing end of life issues with patients. Unpublished Master's Thesis, San Jose State University, San Jose, CA.
- Hare, J., Pratt, C., & Nelson, C. (1992). Agreement between patients and their self-selected surrogate on difficult medical decisions. Archives of Internal Medicine, 152, 1049-1054.
- Henderson, M. (1990). Beyond the living will. Gerontologist, 30, 480-485.
- High, D. M. (1987). Planning for decisional incapacity: A neglected area in ethics and aging. Journal of American Geriatric Society, 35(8), 814-820.
- High, D. M. (1988). Extended autonomy and expectations in surrogate health care decision making. Gerontologist, 28, 46-52.
- In re Quinlan, 70 N. J. 10, 355 A. 2d 647. (1976).
- Janofsky, J. S. (1991). Assessing competency in the elderly. Geriatrics, 45, 45-48.

- Kellog, F. R., Crain, M., Corwin J., & Brickner, P. W. (1992). Life-sustaining interventions in frail elderly persons: Talking about choices. Archives of Internal Medicine, 152, 2317-2320.
- Kohn, M., & Menon, G. (1988). Life prolongation: Views of elderly outpatients and health care professionals. Journal of American Geriatric Society, 36, 840-844.
- La Puma, J., Orentlicher, D., & Moss, R. (1991). Advance directives on admission: Clinical implications and analysis of the Patient Self Determination Act of 1990. Journal of American Medical Association, 266, 403-405.
- Levenson, S. A., List, N. D., & Zaw-Win, B. (1987). Ethical considerations in critical and terminal illness in the elderly. Journal of American Geriatric Society, 29, 563-567.
- Lo, B., McLeod, G. A., & Saika, G. (1986). Patients' attitudes to discussing life-sustaining treatment. Archives of Internal Medicine, 146, 1613-1615.
- Lubitz, J., & Prihoda, R. (1984). The use and cost of Medicare services in the last two years of life. Health Care Financing Review, 5, 117-131.
- Marriner-Tomey, A., Peskoe, K. T., & Gumm, S. B. (1989). Lydia E. Hall: Core, care and cure model. In A. Marriner-Tomey (Ed.), Nursing theorists and their work (2nd ed., pp. 109-132). St. Louis: Mosby.
- Moskowitz, L. D., & Moskowitz, S. (1986). Autonomy and the critically ill patient: The legal issues. Heart and Lung, 15, 520-524.
-

- Office of National Cost Estimates. (1990). National health expenditures, 1988. Health Care Financing Review, 11, 1-54.
- Otte, C. M., & Allen, K. S. (1987). Ethical principles in the nursing care of the terminally ill adult. Oncology Nursing Focus, 14, 87-89.
- Ouslander, J. A., Tymchuk, A. J., & Krynski, M. D. (1993). Decisions about enteral tube feeding among the elderly. Journal of American Geriatric Society, 41, 70-77.
- Ouslander, J. A., Tymchuk, A. J., Rahbar, B. (1989). Health care decisions among elderly long-term care residents and their potential proxies. Archives of Internal Medicine, 149, 1367-1372.
- Patient Self-Determination Act: Omnibus Budget Reconciliation Act of 1990, 4206, 4751. Pub. L101-508.
- Pellegrino, E. D. (1992). Ethics. Journal of American Medical Association, 268, 354-355.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). Deciding to forego life-sustaining treatment. Washington, D. C.: U.S. Government Printing Office.
- Rodriguez, G. S. (1990). Discussions of advance health care directives: Are we ready? An opposing view. Journal of Family Practice, 31, 656-659.
-

- Sach, G., Stocking, C. B., & Miles, S. H. (1990). Failure of an intervention to promote discussion of advance directives. Journal of American Geriatric Society, 38(8), 3. Abstract.
- Schneiderman, L. J., & Arras, J. D. (1985). Counseling patients to counsel physicians on future care in the event of patient incompetency. Annals of Internal Medicine, 102, 693-698.
- Schwarz, J. K. (1992). Living wills and health care proxies: Nursing practice implications. Nursing and Health Care, 13, 15-19.
- Slavenas, J. P., Karuza, J., & Katz, P. R. (1990). Ethical perspectives and attitudes towards advance directives by nursing home residents and their families. Journal of American Geriatric Society, 38(8), 12. Abstract.
- Snodgrass, R. W., & Mozdierz, G. J. (1990 August). Dying with dignity. Paralegal News, pp. 33-35.
- Strull, W. B., Lo, B., & Charles, A. (1984). Do patients want to participate in medical decision-making? Journal of American Medical Association, 252, 2990-2994.
- U. S. Office of Technology Assessment. (1987). Life-sustaining treatments and the elderly (OTA-BA 306). Washington, DC: U. S. Government Printing Office.
- Veatch, R. (1991). Death, dying, and the biological revolution. New Haven: Yale University Press.
-

- Waldo, D., Lent, K., & Lazenby, H. (1987). National health expenditures. Health Care Financing Review, 8, 1-22.
- White, B. D., Siegler, M., Singer, P. A., & Iserson, K. V. (1991). What does Cruzan mean to the practicing physician? Archives of Internal Medicine, 151, 925-928.
- Wilson, J. W. (1988). Living will: The right to self determination. Executive Health Report, 24, 12-16.
- Wold, J. L. (1992). The living will: Legal and ethical perspectives. Journal of Neuroscience Nursing, 24, 50-53.
- Zweibel, N. R., & Cassel, C. K. (1989). Treatment choices at the end of life: A comparison of decisions by patients and their physician selected proxies. Gerontologist, 29, 615-621.

APPENDIX A
Letters of Permission

DEPARTMENT OF MEDICINE
 SCHOOL OF MEDICINE
 EAST CAROLINA UNIVERSITY
 Greenville, North Carolina 27858-4354

MEMORANDUM

TO: Ogo Ezeokeke . DATE: 1/26/93

FROM: Elizabeth Gamble pt

- | | |
|--|---|
| <input type="checkbox"/> Appropriate Action | <input type="checkbox"/> Per your request |
| <input type="checkbox"/> Information & Files | <input type="checkbox"/> Your comment |
| <input type="checkbox"/> Other | |

Sorry for the mix-up. We have many questionnaires floating around and, by mistake sent you the wrong one. Dr. Gamble no longer is employed with the University, but has issued you permission to use this questionnaire.

Peter Lichstein MD / for
 Elizabeth R. Gamble, MD

CITY OF CAMPBELL
RECREATION & COMMUNITY SERVICES

53



February 10, 1993

Ogo Ezeokeke
3462 Rio Bravo Drive
San Jose CA 95148

Dear Ms. Ezeokeke:

The staff of the City of Campbell Senior Center grants permission for you to interview prospective senior citizen participants as part of your Master of Science research proposal for San Jose State University. As agreed, your study will focus on "Knowledge, Attitudes and Behavior of Elderly Persons Regarding Advance Directives."

Please note the Agreement Form (Attachment A) which must be completed prior to initiating your research. We look forward to working with you as the information from the research will allow us to better serve our participants through programs and services.

Thank you.

Sincerely,

Kathy Whitcomb

Kathy Whitcomb
Senior Services Supervisor

Attach.



Chai House Incorporated

Jewish-sponsored living arrangements for the elderly

814 ST. ELIZABETH DRIVE
SAN JOSE, CALIFORNIA 95126
TELEPHONE (408) 947-1818

54

March 15, 1993

Ogo Ezeokeke
3462 Rio Bravo Drive
San Jose, CA 95148

Dear Ms. Ezeokeke,

You have my permission to recruit residents of Chai House, Inc. for your study of elderly persons regarding Advance Directives. Of course residents have the option to withdraw from the study without any consequences and all information will be kept confidential.

If further assistance is needed please do not hesitate to contact us.

Sincerely,

A handwritten signature in cursive script, appearing to read "Roberta Swenson". The ink is dark and the signature is written in a fluid, connected style.

Roberta Swenson
Resident Manager

cc: Health Center



March 23, 19

O90-

Permission has been granted to proceed with the study of elderly clients here at the Nutrition Center regarding advance directives. Of course with the consent of individual clients and as long as the interview does not become too tedious ($\frac{1}{2}$ hour would be maximum time), the Board of Directors also feels that questions concerning religious preference be deleted if possible.

Thank You

Sincerely

Cleo B. B. B.


Director - Site No.

APPENDIX B

Human Subjects' Approval

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San Jose, California 95192-0025 • 408/924-2480

To: Ogo Ezeokeke
3462 Rio Bravo Dr.
San Jose, CA 95148

From: Serena W. Stanford 
AAVP, Graduate Studies and Research

Date: October 20, 1993

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"Knowledge and attitudes of elderly persons in the community regarding advance directives"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at anytime. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted. If you have questions, please contact me at 408-924-2480.

APPENDIX C
Informed Consent

School of Applied Arts and Sciences • Department of Nursing • Graduate Program
One Washington Square • San Jose, California 95192-0057 • 408/924-3134

Agreement to Participate in Research
San Jose State University

Responsible Investigator: Ogo Ezeokeke

Title of Protocol: Knowledge, attitudes and behavior of
community-based elderly persons regarding advance directives.

I have been asked to participate in this study, to find out
what elderly persons in the community know about advance
directives, their attitudes and behavior towards it.

I will be interviewed by the researchers in a private room.
The interview will last approximately 30 minutes. In addition to
my feelings about advance directives, I will be asked to provide
some personal information.

There are no foreseeable risks or discomfort to me for
participating in this study.

I understand that by participating in this study, I am
contributing to knowledge and more insight into this very
important subject.

Results of this study will be reported in aggregate form
only. The identity of participants will be kept in strictest
confidence. Collected data will be kept in a locked cabinet,
which only the researcher has access to. Names of participants
will not be needed for the research.

I will not be financially compensated for participating in
this study.

Questions about the research may be addressed to the
principal investigator at (408) 270-8770. Complaints about the
research may be presented to Jean Sullivan RN, Ed.D. at
(408) 924-3151. Questions or complaints about research-subjects'
rights or research related inquiries may be presented to Serena
Stanford, Ph.D., Associate Academic Vice President for Graduate
Studies and Research, at (408) 924-2480.

No service of any kind will be lost if I refuse to
participate in this study.

Subject's Initials

School of Applied Arts and Sciences • Department of Nursing • Graduate Program
One Washington Square • San Jose, California 95192-0057 • 408/924-3134

I am willingly giving this consent. If at any point during the study, I decide not to participate any more, I may withdraw without any consequences or denial of services. Also, I may refuse to answer any of the questions during the interview.

I have read, understood and received a signed and dated copy of this consent.

- The signature of a subject on this document indicates agreement to participate in the study.
- The signature of the researcher on this document indicates agreement to include the Subject in the research, and attestation that the Subject has been fully informed of his or her rights.

Subject's Signature

Date

Investigator's Signature

Date

APPENDIX D

Questionnaire

Questionnaire on Knowledge, Attitudes
and Behaviors Regarding Living Wills

Age _____

Sex

Male _____ Female _____

Race _____

Religious preference _____

Personal assessment of present state of health

Good Fair Poor

A) What is your level of education?

B) What is your average annual income?

Type of housing

Alone _____ Spouse _____ Family _____ Communal Style _____
Nursing facility _____ Retirement facility _____

1. Are you familiar with living will?
Yes No

2. What does living will mean?

3. Did you know that you could sign a legal document that states
". . . being of sound mind, desire that my life not be
prolonged by extraordinary means if my condition is
determined to be terminal and incurable. I am aware and
understand that this writing authorizes a physician to
withhold or discontinue extraordinary means"?
Yes No

4. What are your definitions of "terminal and incurable" and
"extraordinary means"?

5. Do you have a formal living will? Yes No

6. Has your doctor ever discussed a living will with you?
Yes No

7. Has your doctor ever discussed issues of your death with you?
Yes No

8. Why did you sign (or not sign) a living will?

9. In the event that you should be diagnosed as having a disease or illness that, regardless of medical treatment, will probably end in death, of the following choices below concerning medical treatment, which would you most likely choose? (In other words, this disease is considered terminal and incurable.)
- All possible means of medical treatment, which might include cardiopulmonary resuscitation, life support such as respirators or breathing machines
 - Basic medical care such as antibiotics and intravenous fluids
 - Comfort care only that would be for keeping physical pain and suffering to a minimum
 - Other _____
10. Have you discussed with your doctor your preferences in the type of medical treatment that you would want if you were ever to be diagnosed as having a terminal and incurable illness?
Yes No
11. Do you feel satisfied with the outcome of the discussion?
Yes No
12. Was the discussion self- or physician initiated?
Self _____ Physician _____
13. Do you feel that your doctor is
- Aware of your feelings and would abide by them under the circumstances described earlier in question 9?
 - Aware of your feelings but would follow his or her own feelings (even if in conflict with your own) under the circumstances described earlier in question 9?
 - Unaware of your feelings about this matter?
 - I am uncertain or do not know if my doctor is aware of my feelings.
14. Would you like your doctor at some time in the future to discuss a living will with you?
Yes _____ No _____
15. Would you like your doctor at some time in the future to discuss with you your feelings about the type of medical treatment you would prefer if you were ever to become ill with a terminal and incurable disease?
Yes _____ No _____
16. If you answered no to either question, what would be your reason(s) for not wanting to discuss this?
- If you answered yes to either question, what would be your reason(s) for wanting to discuss this?

17. When do you think is the best time for a doctor to discuss these issues with a patient?
- _____ You are well and at a routine visit.
 - _____ You are seriously ill.
 - _____ You reach a certain age. Specify age _____
 - _____ Other. Please specify.
18. In the event that you were unable to make decisions about your medical care, who would you prefer to make these decisions on your behalf?
- Spouse _____ Family member _____ Friend _____ Doctor _____ Other _____
(please specify) (please specify)
19. Have you discussed your feelings with the person that you would prefer to make these decisions for you?
- Yes No

APPENDIX E

Durable Power of Attorney for Health Care

DURABLE POWER OF ATTORNEY
FOR HEALTH CARE DECISIONS

(California Civil Code Sections 2410-2443)

WARNING TO PERSON EXECUTING THIS DOCUMENT*

THIS IS AN IMPORTANT LEGAL DOCUMENT. IT CREATES A DURABLE POWER OF ATTORNEY FOR HEALTH CARE. BEFORE EXECUTING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:

1. THIS DOCUMENT GIVES THE PERSON YOU DESIGNATE AS YOUR ATTORNEY-IN-FACT THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU. THIS POWER IS SUBJECT TO ANY LIMITATIONS OR STATEMENT OF YOUR DESIRES THAT YOU INCLUDE IN THIS DOCUMENT. THE POWER TO MAKE HEALTH CARE DECISIONS FOR YOU MAY INCLUDE CONSENT, REFUSAL OF CONSENT, OR WITHDRAWAL OF CONSENT TO ANY CARE, TREATMENT, SERVICE, OR PROCEDURE TO MAINTAIN, DIAGNOSE, OR TREAT A PHYSICAL OR MENTAL CONDITION. YOU MAY STATE IN THIS DOCUMENT ANY TYPES OF TREATMENT OR PLACEMENTS THAT YOU DO NOT DESIRE.
2. THE PERSON YOU DESIGNATE IN THIS DOCUMENT HAS A DUTY TO ACT CONSISTENT WITH YOUR DESIRES AS STATED IN THIS DOCUMENT OR OTHERWISE MADE KNOWN OR, IF YOUR DESIRES ARE UNKNOWN, TO ACT IN YOUR BEST INTERESTS.
3. EXCEPT AS YOU OTHERWISE SPECIFY IN THIS DOCUMENT, THE POWER OF THE PERSON YOU DESIGNATE TO MAKE HEALTH CARE DECISIONS FOR YOU MAY INCLUDE THE POWER TO CONSENT TO YOUR DOCTOR NOT GIVING TREATMENT OR STOPPING TREATMENT WHICH WOULD KEEP YOU ALIVE.
4. UNLESS YOU SPECIFY A SHORTER PERIOD IN THIS DOCUMENT, THIS POWER WILL EXIST FOR SEVEN YEARS FROM THE DATE YOU EXECUTE THIS DOCUMENT AND, IF YOU ARE UNABLE TO MAKE HEALTH CARE DECISIONS FOR YOURSELF AT THE TIME WHEN THIS SEVEN-YEAR PERIOD ENDS, THIS POWER WILL CONTINUE TO EXIST UNTIL THE TIME WHEN YOU BECOME ABLE TO MAKE HEALTH CARE DECISIONS FOR YOURSELF.

* Note: This warning (including paragraphs 1-10) must be in at least 10 point bold type in printed forms or all capital letters in typed forms.

5. NOTWITHSTANDING THIS DOCUMENT, YOU HAVE THE RIGHT TO MAKE MEDICAL AND OTHER HEALTH CARE DECISIONS FOR YOURSELF SO LONG AS YOU CAN GIVE INFORMED CONSENT WITH RESPECT TO THE PARTICULAR DECISION. IN ADDITION, NO TREATMENT MAY BE GIVEN TO YOU OVER YOUR OBJECTION, AND HEALTH CARE NECESSARY TO KEEP YOU ALIVE MAY NOT BE STOPPED IF YOU OBJECT.
6. YOU HAVE THE RIGHT TO REVOKE THE APPOINTMENT OF THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU BY NOTIFYING THAT PERSON OF THE REVOCATION ORALLY OR IN WRITING.
7. YOU HAVE THE RIGHT TO REVOKE THE AUTHORITY GRANTED TO THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU BY NOTIFYING THE TREATING PHYSICIAN, HOSPITAL, OR OTHER HEALTH CARE PROVIDER ORALLY OR IN WRITING.
8. THE PERSON DESIGNATED IN THIS DOCUMENT TO MAKE HEALTH CARE DECISIONS FOR YOU HAS THE RIGHT TO EXAMINE YOUR MEDICAL RECORDS AND TO CONSENT TO THEIR DISCLOSURE UNLESS YOU LIMIT THIS RIGHT IN THIS DOCUMENT.
9. THIS DOCUMENT REVOKES ANY PRIOR DURABLE POWER OF ATTORNEY FOR HEALTH CARE.
10. IF THERE IS ANYTHING IN THIS DOCUMENT THAT YOU DO NOT UNDERSTAND, YOU SHOULD ASK A LAWYER TO EXPLAIN IT TO YOU.

1. DESIGNATION OF HEALTH CARE AGENT. I, _____

(Insert your name)

do hereby designate and appoint: Name: _____

Address: _____

Telephone Number: _____

as my attorney-in-fact to make health care decisions for me as authorized in this document.

(Insert the name and address of the person you wish to designate as your attorney-in-fact to make health care decisions for you. None of the following may be designated as your attorney-in-fact: (1) your treating health care provider, (2) an employee of your treating health care provider, (3) an operator of a community care facility, or (4) an employee of an operator of a community care facility.)

2. CREATION OF DURABLE POWER OF ATTORNEY FOR HEALTH CARE.

By this document I intend to create a durable power of attorney by appointing the person designated above to make health care decisions for me as allowed by Sections 2410 to 2440, inclusive, of the California Civil Code. This power of attorney shall not be affected by my subsequent incapacity.

3. GENERAL STATEMENT OF AUTHORITY GRANTED.

In the event that I am incapable of giving informed consent with respect to health care decisions, I hereby grant to the attorney-in-fact named above full power and authority to make health care decisions for me before, or after my death, including: consent, refusal of consent, or withdrawal of consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition, subject only to the limitations and special provisions, if any, set forth in Paragraph 4 or 6.

4. SPECIAL PROVISIONS AND LIMITATIONS.

(By law, your attorney-in-fact is not permitted to consent to any of the following: commitment to or placement in a mental health treatment facility, convulsive treatment, psycho-surgery, sterilization, or abortion. If there are any other types of treatment or placement that you do not want your attorney-in-fact to have authority to give consent for or other restriction you wish to place on his or her attorney-in-fact's authority, you should list them in the space below. If you do not write in any limitations, your attorney-in-fact will have the broad powers to make health care decisions on your behalf which are set forth in Paragraph 3, except to the extent that there are limits provided by law.)

In exercising the authority under this durable power of attorney for health care, the authority of my attorney-in-fact is subject to the following special provisions and limitations:

5. DURATION.

I understand that this power of attorney will exist for seven years from the date I execute this document unless I establish a shorter time. If I am unable to make health care decisions for myself when this power of attorney expires, the authority I have granted my attorney-in-fact will continue to exist until the time when I become able to make health care decisions for myself.

I wish to have this power of attorney end before seven years on the following date: _____

6. STATEMENT OF DESIRES.

(With respect to decisions to withhold or withdraw life-sustaining treatment, your attorney-in-fact must make health care decisions that are consistent with your known desires. You can, but are not required to, indicate your desires below. If your desires are unknown, your attorney-in-fact has the duty to act in your best interests; and, under some circumstances, a judicial proceeding may be necessary so that a court can determine the health care decision that is in your best interests. If you wish to indicate your desires, you may INITIAL the statement or statements that reflect your desires and/or write your own statements in the space below.)

(If the statement reflects your desires, initial the box next to the statement.)

1. I desire that my life be prolonged to the greatest extent possible, without regard to my condition, the chances I have for recovery or long-term survival, or the cost of the procedures.

(_____)

2. If I am in a coma which my doctors have reasonably concluded is irreversible, I desire that life-sustaining or prolonging treatments or procedures not be used.

(_____)

3. If I have an incurable or terminal condition or illness and no reasonable hope of long-term recovery or survival, I desire that life-sustaining or prolonging treatments not be used.

(_____)

4. I do not desire treatment to be provided (_____)
and/or continued if the burdens of the
treatment outweigh the expected benefits.
My attorney-in-fact is to consider the relief
of suffering, the preservation or restoration
of functioning, and the quality as well as the
extent of the possible extension of my life.

(If you wish to change your answer, you may do so by drawing
an "X" through the answer you do not want, and circling the
answer you prefer.)

Other or Additional Statements of Desires: _____

7. DESIGNATION OF ALTERNATE ATTORNEY-IN-FACT.

(You are not required to designate any alternative attorney-in-
fact but you may do so. Any alternative attorney-in-fact you
designate will be able to make the same health care decisions
as the attorney-in-fact designated in Paragraph 1 above in the
event that he or she is unable or unwilling to act as your
attorney-in-fact. Also, if the attorney-in-fact designated in
Paragraph 1 is your spouse, his or her designation as your
attorney-in-fact is automatically revoked by law if your marriage
is dissolved.)

If the person designated in Paragraph 1 as my attorney-in-fact
is unable to make health care decisions for me, then I designate
the following persons to serve as my attorney-in-fact to make
health care decisions for me as authorized in this document,
such persons to serve in the order listed below:

A. First Alternative Attorney-in-Fact:

Name: _____

Address: _____

Telephone Number: _____

B. Second Alternative Attorney-in-Fact.

Name: _____

Address: _____

Telephone Number: _____

8. PRIOR DESIGNATIONS REVOKED.

I revoke any prior durable power of attorney for health care.

(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY.)

I sign my name to this Statutory Short Form Durable Power of Attorney for Health Care on _____ at _____
(Date)
_____, _____
(City) (State)

(Signature)

(THIS POWER OF ATTORNEY WILL NOT BE VALID FOR MAKING HEALTH CARE DECISIONS UNLESS IT IS EITHER (1) SIGNED BY AT LEAST TWO QUALIFIED WITNESSES WHO ARE PERSONALLY KNOWN TO YOU AND WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE OR (2) ACKNOWLEDGED BEFORE A NOTARY PUBLIC IN CALIFORNIA.)

CERTIFICATE OF ACKNOWLEDGEMENT OF NOTARY PUBLIC

(You may use acknowledgement before a notary public instead of the statement of witnesses.)

State of California)
County of _____) ss.

On this _____ day of _____, in the year _____,
before me, _____
(here insert name of notary public)

personally appeared _____
(here insert name of principal)

personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is subscribed to this instrument, and acknowledged that he or she executed it. I declare under penalty of perjury that the person whose name is subscribed to this instrument appears to be of sound mind and under no duress, fraud, or undue influence.

NOTARY SEAL

(Signature of Notary Public)

STATEMENT OF WITNESSES

(You should carefully read and follow this witnessing procedure. This document will not be valid unless you comply with the witnessing procedure. If you elect to use witnesses instead of having this document notarized, you must use two qualified adult witnesses. None of the following may be used as a witness: (1) a person you designate as the attorney-in-fact, (2) a health care provider, (3) an employee of a health care provider, (4) the operator of community care facility, (5) an employer of an operator of a community care facility. At least one of the witnesses must make the additional declaration set out following the place where the witnesses sign.)

I declare under penalty of perjury under the laws of California that the principal is personally known to me, that the principal signed or acknowledged this durable power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud, or undue influence, that I am not the person appointed as attorney-in-fact by this document, and that I am not a health care provider, an employee of a health care provider, the operator of a community care facility, nor an employee of an operator of a community care facility.

Signature: _____ Residence Address: _____
Print Name: _____
Date: _____

Signature: _____ Residence Address: _____
Print Name: _____
Date: _____

(AT LEAST ONE OF THE ABOVE WITNESSES MUST ALSO SIGN THE FOLLOWING DECLARATION.)

I declare under penalty of perjury under the laws of California that I am not related to the principal by blood, marriage, or adoption, and to the best of my knowledge I am not entitled to any part of the estate of the principal upon the death of the principal under a will now existing or by operation of law.

Signature: _____
Signature: _____

SPECIAL REQUIREMENTS

(Special additional requirements must be satisfied for this document to be valid if (1) you are a patient in a skilled nursing facility, or (2) you are a conservatee under the Lanterman-Petris-Short Act and you are appointing the conservator as your agent to make health care decisions for you.)

1. If you are a patient in a skilled nursing facility (as defined in Health and Safety Code Section 1250(c)) at least one witness must be a patient advocate or ombudsman. The patient advocate or ombudsman must sign the witness statement and must also sign the following declaration.

I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and am serving as a witness as required by subdivision (a) (2)A of Civil Code 2432.

Signature: _____ Address: _____
 Print Name: _____
 Date: _____

2. If you are a conservatee under the Lanterman-Petris-Short Act (of Division 5 of the Welfare and Institutions Code) and you wish to designate your conservator as your agent to make health care decisions, you must be represented by legal counsel. Your lawyer must sign the following statement:

I have advised my client _____
 (Name)

concerning his or her rights in connection with this matter and the consequences of signing or not signing this durable power of attorney and my client, after being so advised, has executed this durable power of attorney.

APPENDIX F
Sample Living Will

Living Will Directive to Physicians

Directive made this _____ day of _____ (month/year).

I, _____, being of sound mind, willfully and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, and do hereby declare:

If at any time I should have an incurable or irreversible condition caused by injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my attending physician determines that my death is imminent whether or not life-sustaining procedures are utilized or will result within a relatively short time without application of such procedures, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physicians as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.

Other directions: (You may use this space to make other requests of your caregivers.)

This directive shall be in effect until it is revoked.

I understand the full impact of this directive and I am emotionally and mentally competent to make this directive.

I understand that I may revoke this directive at any time.

A duplicate copy of this directive shall have the same force and effect as the original.

Signed _____

City, County, and State of Residence _____

This declarant has been personally known to me and I believe him/her to be of sound mind. I am not related to the declarant by blood or marriage, nor would I be entitled to any portion of the declarant's estate on his/her decease, nor am I the attending physician of the declarant or an employee of the attending physician or a health facility in which the declarant is a patient, or a patient in the health care facility in which the declarant is a patient, or any person who has a claim against any portion of the estate of the declarant upon his/her decease.

Witness _____ Witness _____