1994

Nurses' knowledge of advance directives and their perceived role in discussing end of life issues with patients

Christine Diane Hall
San Jose State University

Follow this and additional works at: https://scholarworks.sjsu.edu/etd_theses

Recommended Citation

Hall, Christine Diane, "Nurses' knowledge of advance directives and their perceived role in discussing end of life issues with patients" (1994). *Master's Theses*. 912.
DOI: <https://doi.org/10.31979/etd.g672-qp3h>
https://scholarworks.sjsu.edu/etd_theses/912

This Thesis is brought to you for free and open access by the Master's Theses and Graduate Research at SJSU ScholarWorks. It has been accepted for inclusion in Master's Theses by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313/761-4700 800/521-0600

Nurses' Knowledge of Advance Directives and Their
Perceived Role in Discussing End of Life Issues with
Patients

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

Christine Diane Hall

December, 1994

UMI Number: 1361170

UMI Microform Edition 1361170
Copyright 1995, by UMI Company. All rights reserved.

**This microform edition is protected against unauthorized
copying under Title 17, United States Code.**

UMI

**300 North Zeeb Road
Ann Arbor, MI 48103**

(c) 1994

Christine Diane Hall

ALL RIGHTS RESERVED

APPROVED FOR THE DEPARTMENT OF NURSING

Virgil Parsons
Virgil Parsons, D.N.Sc., R.N.

Rosemary Mann
Rosemary Mann, J.D., M.S., R.N.

Barbara Parker
Barbara Parker, M.S., R.N.

APPROVED FOR THE UNIVERSITY

Serena H. Stanford

ABSTRACT

Nurses' Knowledge of Advance Directives and Their Perceived Role in Discussing End of Life Issues with Patients

by Christine Diane Hall

This study replicated a study done by Hall (1992) and used a descriptive design to explore nurses' perceptions of their role in discussing end of life issues with patients, nurses' knowledge of advance directives and their attitudes towards end of life issues. This study also explored whether there was a relationship between nurses' perceived role in discussing end of life issues with patients and their years of nursing experience in California.

The findings indicated that, although most nurses' agreed that it was their role to discuss end of life issues with patients, knowledge of advance directives was lacking. The findings were consistent with Hall (1992). A negative weak correlation between nurses' perceived role in discussing end of life issues with patients and their years of nursing experience was shown. Nurses with less experience were more certain about their role.

ACKNOWLEDGEMENTS

I would like to acknowledge the support and encouragement I received from my family, friends and colleagues. Without such, completion of this project would have been difficult.

TABLE OF CONTENTS

	Page
LIST OF TABLES.....	ix
Chapter	
1. INTRODUCTION.....	1
Statement of the Problem.....	2
Research Questions.....	3
Purpose.....	4
Definitions.....	5
Research Design.....	7
Limitations.....	9
2. CONCEPTUAL FRAMEWORK AND	
LITERATURE REVIEW.....	11
Conceptual Framework.....	11
Review of the Literature.....	14
3. METHODOLOGY.....	20
Research Design.....	20
Sample and Setting.....	21
Instrument.....	22
Data Collection.....	23

	Analysis Procedures.....	24
4.	ANALYSIS AND INTERPRETATION OF DATA.....	26
	Introduction.....	26
	Sample.....	26
	Professional Role.....	30
	Nurses' Knowledge.....	34
	Nurses' Attitudes.....	37
	Nurses' Perceived Role and Years of Experience.....	40
	Summary.....	42
5.	CONCLUSIONS AND RECOMMENDATIONS.....	43
	Conclusions.....	43
	Recommendations.....	50
	REFERENCES.....	52
	APPENDIXES	
	A. Directive to Physicians: California Natural Death Act.....	56
	B. Durable Power of Attorney for Health Care Decisions.....	60
	C. Nurse/Patient Communication Survey....	65

D.	Human Subjects-Institutional Review	
	Board Approval.....	70
E.	Institution Approval Letter.....	72
F.	Cover Letter for Research Packet.....	74
G.	Agreement to Participate in Research..	76

LIST OF TABLES

Table		Page
1.	Demographics of Sample.....	28
2.	Nurses' Role Perception in Discussing End of Life Issues with Patients.....	31
3.	Nurses' Knowledge of Advance Directives.....	35
4.	Nurses' Attitudes Towards End of Life Issues....	38
5.	Nurses' Perceived Role in Discussing End of Life Issues with Patients by Years of Experience in Nursing in California.....	41

Chapter 1

INTRODUCTION

Decisions regarding the circumstances of a person's death have belonged exclusively to health professionals until recent years. Patients and families are now demanding more control over health care decisions, including those directly affecting the prolongation of life (Kelner & Bourgeault, 1993). The Patient Self-Determination Act of 1990, requiring all health care institutions receiving government funds to inform patients of their right to be involved in treatment decision making, has further increased the public's awareness and desire to be involved (Meyer, 1993).

Health professionals are being confronted with new dilemmas in trying to accommodate the patient's desire for autonomy during the dying process. The desire to forego life-sustaining treatment is seen as problematic by many health professionals in North America (Kelner & Bourgeault, 1993, p. 757).

The professional nurse's role as a patient advocate is

described by the American Nurses' Association's Code for Nurses (1985). In this role, the nurse is usually aware of the patient's values and belief system and can participate in decision making which fosters the patient's overall best interests (Marchette et al., 1993).

By replicating a study done by Hall (1992), this study was designed to explore professional nurses' perceptions of their role in discussing end of life issues with patients, their knowledge and attitudes toward advance directives and the relationship between nurses' role perception in discussing end of life issues with patients and years of experience in nursing. Also, by using the questionnaire developed by Hall (1992), entitled "Nurse/Patient Communication Survey," reliability and validity for the instrument can begin to be established.

Statement of the Problem

Advanced technology allows for prolonging lives with varying degrees of quality of life (Scott, 1992, p. 52). Public awareness of the need for advance directives has been heightened by the Nancy Cruzan and Karen Quinlan cases where courts were petitioned for permission to stop treatment in

the absence of an advance directive. Health care professionals are being expected to assist patients in self-determination during the dying process (Uhlman, Pearlman & Cain, 1989, p. 707). The nurse as patient advocate is often the voice of the patient's desire for treatment (Corley, Selig & Ferguson, 1993, p. 126). The role of the nurse in relation to the Patient Self-Determination Act of 1990 is still being defined (Meyer, 1993, p. 40). According to a study by Wilkinson (1992), 81% of the nurses surveyed stated they had experienced difficulties in communicating with cancer patients. Research is needed to assist with the planning of education and the establishment of guidelines for nurses in the role of advocate for the patient wanting to discuss end of life issues.

Research Questions

The following research questions were asked:

1. What do nurses perceive as their professional role in discussing end of life issues with patients?
2. To what extent are nurses aware of the existence and uses of advance directives?

3. What are nurses' attitudes toward end of life issues?

4. What is the relationship between nurses' perceptions of their role in discussing end of life issues with patients and years of experience in nursing in California?

Purpose

The purpose of this study was to explore nurses' perceptions of their role in discussing end of life issues with patients and examine their knowledge of advance directives and attitudes towards end of life issues by replicating a study by Hall (1992). Further, this study assisted in establishing reliability and validity for the tool developed by Hall entitled "Nurse/Patient Communication Survey."

Final decisions regarding treatments must be based on the principle of autonomy and competent patient wishes after being given accurate information on diagnosis, treatment options, risks and benefits (Ott, 1986, cited in Marchette et al., 1993). The nurse is directed by the American Nurses' Association's Code for Nurses (1985) to act as a

patient advocate. Marchette et al. (1993) describe the nurse's role to include enhancing the competence of patients and families by educating them about their illness and treatments and by assisting patients in communicating their wishes regarding end of life issues.

As technology increases, the nurse's role as patient advocate regarding end of life issues will become more prevalent. Few guidelines exist to guide health care professionals as they strive to respond to the growing desire of patients to have more control over their own dying (Kelner & Bourgeault, 1993). Studies in this area will assist in planning educational programs focusing on the role of advocate in the area of end of life issues.

Definitions

For the purpose of this study, the following definitions of terms apply:

1. End of life issues refers to issues of death and dying, use of life-sustaining treatment, resuscitation status, quality of life, and use of advance directives (Hall, 1992).

2. Directive to Physicians (Appendix A) is also known as the Living Will. The California Natural Death Act of 1976 authorizes competent adult residents to provide written instructions to physicians to withdraw or withhold life-sustaining treatments in the event of a terminal illness (Martyn & Jacobs, 1984, as cited in Hall, 1992). This declaration becomes operative when (a) communicated to the attending physician, and (b) the patient is diagnosed and certified in writing by the attending physician and a second examining physician to be in a terminal or permanent unconscious condition, and is no longer able to make decisions regarding administration of life-sustaining treatment (Consent Manual, 1993, p. 5).

3. Durable Power of Attorney for Health Care Decisions (Appendix B) is a legal document allowing a person to designate someone to make health care decisions for him if he becomes unable to give informed consent (California Association of Hospitals and Health Systems, 1993, pp. 2-3). This document exists for an unlimited period of time, unless the individual limits its duration in the document (Consent Manual, 1993)

Research Design

This study explored nurses' perceptions of their role in discussing end of life issues with patients, nurses' attitudes towards end of life issues and their knowledge of advance directives. Whether there is a relationship between nurses' perceived role in discussing end of life issues with patients and their years of nursing experience in California was also examined.

The sample population was comprised of registered nurses who worked in one of five medical-surgical in-patient nursing units at a 172 bed acute care community hospital in central California. All full-time, part-time and per diem registered nurses currently working on medical-surgical units at this hospital were included. Participation was voluntary and anonymous.

This was a descriptive survey study. A 39 item questionnaire, entitled "Nurse/Patient Communication Survey," using a fixed response, Likert scale, addressed the variables of role perception, knowledge of Durable Power of Attorney for Health Care Decisions, and attitudes toward end of life issues. There was no attempt by this researcher to

control variables.

Reasonable efforts were made to obtain permission from Hall (1992) for the use of the questionnaire entitled "Nurse/Patient Communication Survey" (Appendix C). This researcher was unable to contact Hall after 3 months of effort. This unpublished questionnaire was used, giving proper credit to Hall for developing this important tool.

Nurses received the research packet in their unit mailboxes. This research packet included an agreement to participate (Appendix G), a cover letter (Appendix F), the questionnaire, and a sealable envelope for return.

The questionnaire responses were analyzed using descriptive statistics, including frequencies and percentages. The data were also tested for a statistically significant relationship between role perception and years of nursing experience using the chi square and Cramer's V test. Reliability and validity of the questionnaire, "Nurse/Patient Communication Survey," were also examined.

Limitations

The following limitations were identified as applying to this study:

1. The instrument lacks established validity and reliability, because it was developed for a study which used a small sample.

2. The sample came from a small community hospital, and the results may not be generalizable to a larger, more diverse population.

3. The participants were asked to volunteer. There may be differences in responses from those volunteering and those who chose not to volunteer. Respondents may have answered questions with a bias toward socially acceptable answers.

4. The lack of randomization also limits the ability to generalize the findings to a larger population.

As the public demands for autonomy in health care decisions increase, the need for improved education and guidelines for nurses will become more apparent. This study suggests the need for further research in the nurse's role in discussing end of life issues with patients which may

assist in developing guidelines and standards for
nurse/patient communication.

Chapter 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

This study was based on the conceptual framework of universal moral principles outlined by Beauchamp and Childress (1989). The ability to prolong life due to advanced technology and resuscitation has led to many ethical dilemmas requiring that ethical principles be applied to the problem solving process (Nicholson, 1991). The four basic ethical principles are (a) respect for autonomy, (b) beneficence, (c) nonmaleficence, and (d) justice.

Respect for Autonomy

The concept of autonomy includes the concepts of respect for persons and autonomy (Silva, 1990, p. 40). According to Beauchamp and Childress (1989), the concept of respect for persons focuses on humans as moral agents. The philosopher, Kant, states that humans deserve this respect because of their possession of a rational will that allows them to act morally (Silva, 1990, p. 54). The Code for

Nurses (American Nurses' Association, 1985) outlines "Respect for Human Dignity" as a fundamental principle of nursing. Nurses are morally obligated to respect human existence and the individuality of all persons who are recipients of nursing (American Nurses' Association, 1985, p. 2). The Code for Nurses (American Nurses' Association, 1985) requires nurses to tell clients the truth about their nursing care and to discontinue any treatment a responsible client objects to having performed. Respect for persons refers to recognizing, appreciating, and giving due consideration to a person's beliefs, capacities, judgements, and perspectives (Silva, 1990, p. 44).

The principle of autonomy or self-determination is a patient's right to determine what will or will not be done for him (Jurchak, 1990, p. 457). Autonomy can mean either a self-governing person or acting in a self-governing manner (Silva, 1990, p. 45). Crucial to autonomous actions is understanding. Silva (1990) points out the problem of misunderstanding in the area of informed consents.

When the concept of respect for persons and autonomy are put together, they infer respect for the autonomous

person. The autonomous person perceives himself as being capable of carrying out autonomous actions (Silva, 1990, p. 54).

Beneficence

The principle of beneficence is founded in the idea that morality is associated with a concern for human welfare (Beauchamp & Childress, 1989). Beneficence is also one of the universal moral principles upon which the Code for Nurses (American Nurses' Association, 1985) was based.

The concept of beneficence includes prevention of harm, removal of harm, and the promotion of good. Prevention of harm means taking measures against a possible or probable event. Removal of harm means elimination of an existing situation where injury, impairment, or disability has occurred. Promotion of good refers to the contribution to the welfare of others (Silva, 1990, p. 59).

Nonmaleficence

The concept of nonmaleficence refers to the idea of "do no harm." The Code for Nurses (American Nurses' Association, 1985) states that the nurse acts to safeguard clients and protect them from risk and harm. Nonmaleficence

is a moral action in which others are spared actual harm. It refers to not harming others, as well as not putting others at risk for harm (Silva, 1990).

Justice

The principle of justice refers to giving each person his due. Persons with equal characteristics should be treated equally. A common agreement regarding the principle of justice is that equals should be treated equally and unequals unequally (Silva, 1990, pp. 54-68). The Code for Nurses (American Nurses' Association, 1985) refers to treating all persons fairly.

Review of the Literature

The nursing literature did not reveal any studies dealing specifically with nurses' perception of their role in discussing end of life issues with patients. Wilkinson's (1992) research did ask nurses if they thought it was their role to talk with patients about their feelings. The majority answered "yes." Marchette et al. (1993) called for further study in the area of how nurses feel about patient autonomy and their perception of the meaning of support of the patient in end of life issues.

The literature was found to be consistent in identifying nurses as key health professionals who are in an ideal position to discuss end of life issues with patients, families and other health professionals (Nicholson, 1991, p. 64P). Gill, a fellow in the Annenberg Washington Program (a think tank specializing in public policy and communication), writes that hospitals should encourage their nurses to discuss advance directives with patients due to the nurses' preparation (Meyer, 1993, p. 40).

According to Meyer (1993), nurses play a pivotal role in life threatening illness by assuring that the patients' wishes are respected. The American Nurses' Association's Code for Nurses with Interpretive Statements (1985) clearly outlines the nurse's role of patient advocate. Discussion of end of life issues often occurs more naturally with nurses, as opposed to other health professionals, due to their unique relationship with the patient (Yarling & McElmurry, 1993, p. 5). As outlined by Ryder (1992), the nurse-patient relationship naturally provides the foundation for discussing end of life issues with patients, and these issues are appropriate topics for discussion.

A 1985 study conducted for the Howard Community Health Plan and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioral Research revealed a change in public attitudes over the last 10 years. Of those surveyed, 85% stated they believed patients with terminal diseases ought to be able to tell their physicians to let them die when no cure is available. If participants became incompetent, 64% wanted a family member to make end of life decisions for them (Evans, 1990, p. 24A).

Advance Directives

The passing of the Self-Determination Act in 1990 has furthered public awareness and education of their rights for autonomy by mandating institutions receiving federal funding to provide education to the public on advance directives. This includes written information about the right to be involved in treatment and to formulate an advance directive (Meyer, 1993, p. 40).

The California Natural Death Act of 1976 established a procedure whereby an individual may declare in writing a desire that life-sustaining procedures be withheld or

withdrawn in instances of terminal condition or permanent unconscious condition (Consent Manual, 1993). This Directive to Physicians (Appendix A) is commonly called a living will and is the most common tool used for protecting one's autonomy (Byock, 1991, p. 7). This declaration becomes operative when (a) communicated to the patient's attending physician, and (b) the patient is diagnosed and certified in writing by the attending physician and a second examining physician to be in a terminal or permanent unconscious condition, and is no longer able to make decisions regarding administration of life-sustaining treatment (Consent Manual, 1993, p. 5).

The Durable Power of Attorney for Health Care Decisions (Appendix B) allows an individual to choose another person to make health care decisions for him if, for any reason, he is unable to speak for himself. Unlike the living will, this document allows for health care desires to be directed in any situation in which you are unable to make your own decisions, not just in the case of coma or terminal illness. (California Medical Association, 1992). The Durable Power of Attorney for Health Care Decisions is more flexible than

the living will because it does not limit the conditions for which it applies (Evans, 1990). The Durable Power of Attorney for Health Decisions exists for an unlimited period of time unless the individual limits its duration in the document (Consent Manual, 1993). Forms printed prior to January 1, 1992, generally expire at the end of 7 years (California Medical Association, 1992).

If no document or directions are available, the concept of "substitute judgement" is invoked requiring those well acquainted with the desires and values of the incapacitated person to provide direction in the decision making process (Byock, 1991, p. 7). This concept was invoked by the courts for cases, such as the Cruzan case (Cruzan v. Director, 1990).

Nancy Cruzan was in a persistent vegetative state following a 1983 automobile accident. She was being fed through a gastrostomy tube. The family requested the feedings be stopped when they were informed by physicians that Nancy would not recover from her coma. A trial court decision upholding the family's request was appealed to the Missouri Supreme Court. This court ruled that without clear

and convincing evidence that the patient would wish treatment terminated, the state could not allow it. The United States Supreme Court upheld this ruling in a 1990 decision (Cruzan v. Director, 1990). This decision also recognized that where a person has clearly made his wishes known, a right to die may exist (Killian, 1990). Although the Supreme Court denied Nancy Cruzan's family's wishes, it affirmed the rights of competent adults to refuse treatment and did not require the patient to be in a terminal state (Evans, 1990, p. 24A).

As public awareness regarding advance directives increases, nurses will be expected to be knowledgeable in this area (Ulhman, Pearlman & Cain, 1989). Nursing interventions should be directed toward allowing the patient to retain decision making authority in care as long as possible (Turner, 1992, p. 701).

Chapter 3

METHODOLOGY

This study was designed to explore nurses' perceptions of their role in discussing end of life issues with patients, nurses' knowledge of advance directives and their attitudes towards end of life issues. This study also explored whether there is a relationship between nurses' perceived role in discussing end of life issues with patients and their years of nursing experience.

Research Design

A cross-sectional, descriptive survey research design was used for this study. The questionnaire, entitled "Nurse/Patient Communication Survey," measured role perception, knowledge of Durable Power of Attorney for Health Care Decisions, and attitudes toward end of life issues (Hall, 1992). A questionnaire with a fixed Likert scale for responses simplified the respondent's answers for easier analysis. Using a survey questionnaire also eliminated interviewer bias, because there was no interviewer using verbal and non-verbal communication which

may have led the respondent to answer in a particular way. This research design allowed for complete anonymity, which was important due to the sensitive nature of death and dying issues (LoBiondo-Wood & Haber, 1990, p. 238). Underlying this study was the assumption that participants would respond honestly without social desirability pressure, since responses were anonymous.

Sample and Setting

The sample population included registered nurses who worked on one of five medical-surgical, in-patient nursing units at a 172 bed acute care community hospital in central California. Nurses who worked on in-patient medical-surgical units were chosen because of the broad-spectrum of diagnoses they encounter and the high patient and family contact they have. The in-patient nursing units included intensive care, cardiac step-down, oncology, orthopedic, and medical-surgical units. All full-time, part-time and per diem registered nurses currently working on a medical-surgical unit at this hospital were included.

Instrument

The instrument used for this study was a 39 question survey entitled "Nurse/Patient Communication Survey" (Appendix C). The first 25 questions addressed the variables of role perception, knowledge of Durable Power of Attorney for Health Care Decisions, and attitudes toward end of life issues. A fixed response, Likert scale asked the respondents to answer each question by choosing one of the following responses: strongly agree, agree, unsure, disagree, and strongly disagree. Each of these responses was assigned a number. Participants were asked to circle the number that most closely corresponded to their response. The last 14 questions addressed demographic information, including age, religion, number of years experience in nursing in California, and information related to knowledge and use of Durable Power of Attorney for Health Care Decisions.

The research packet given to each participant included a cover letter (Appendix F), an agreement to participate (Appendix G), the questionnaire and a sealable envelope.

Data Collection

Approval for this study was obtained from the San Jose State University Human Subjects-Institutional Review Board (Appendix D). Permission was obtained from the Vice-President of Nursing of the hospital where the sample nurses worked (Appendix E). Reasonable efforts were made to obtain permission from Hall for the use of the questionnaire entitled "Nurse/Patient Communication Survey" (Appendix C). This researcher was unable to contact Hall after 3 months of effort. This unpublished questionnaire was used, with appreciation to Hall (1992) for developing this valuable instrument.

Nurses working in the five medical-surgical units received the research packet in their unit mailboxes. The cover letter identified the investigator as a student in a master's program at San Jose State University and explained that participation was voluntary and anonymous. This researcher held an information meeting to answer questions and explain the research study in a hospital classroom on the first day of the collection period. This researcher was also available in the hospital during the collection period

for questions. The questionnaires in sealed envelopes were collected in collection box. The agreement to participate was not collected. A statement on this agreement instructed the participant that completion of the survey was an indication of consent. This assured anonymity of the respondent. The return questionnaires remained in the possession of this researcher at all times.

Analysis Procedures

The questionnaire responses were analyzed using descriptive statistics, including frequencies and percentages. The data were also tested for a statistically significant relationship between role perception and years of nursing experience in California using the chi square and Cramer's V test.

Reliability of the questionnaire, "Nurse/Patient Communication Survey," was examined by determining stability. Stability refers to obtaining the same results from repeated administrations of the instrument (LoBiondo-Wood & Haber, 1990, p. 256) and was measured by comparing results obtained by Hall (1992) with those from this study. Validity was assessed for face validity; that is, an

assessment that the tool measures what it is intended to measure (LoBiondo-Wood & Haber, 1990, p. 251).

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

Introduction

This study used a descriptive survey design to explore nurses' perceptions of their role in discussing end of life issues with patients, nurses' knowledge of advance directives and their attitudes towards end of life issues. This study also explored whether there is a relationship between nurses' perceived role in discussing end of life issues with patients and their years of nursing experience in California. This study was a replication of a study done by Hall (1992). The sample consisted of 75 registered nurses who worked on one of five medical-surgical units at a community hospital in central California. The questionnaire, entitled "Nurse/Patient Communication Survey," included 39 questions. Twenty-five questions used a fixed response, Likert scale, and 14 questions asking for demographic information were open-ended.

Sample

The sample consisted of 75 respondents, mostly females

(96%). The age of respondents ranged from 24 to 54 years, with the mean age being 39 years old. The majority professed a protestant religion (44%), while 27% of the sample were Catholic. The majority of the sample (60%) had an associate degree as the highest level of nursing education. Only 20% of the sample had bachelor of science degrees, 14% had diplomas from a nursing school, and 3% held a master's degree. Most of the nurses responding to the survey worked on a general medical-surgical nursing unit (59%), while 21% worked in an intensive care unit and 16% worked on a medical oncology unit. Years of nursing experience in California ranged from 1 year to 30 years, with most respondents (17) reporting 2 years of experience.

This study sample is similar to Hall's (1992) in the areas of gender, age, religion, years of experience in nursing and type of unit. The samples differ in size and highest degree obtained. The 1992 study sample of 26 reported 35% of the respondents held a Bachelor of Science in Nursing degree, while this study sample of 75 reported only 20% held a Bachelor of Science in Nursing degree.

Table 1

Demographics of Sample (n=75)

	n	%
<u>Gender</u>		
Male	2	3
Female	72	96
Missing	1	1
<u>Age</u>		
24-30	13	17
31-40	29	39
41-50	26	35
51-60	5	6
Missing	2	3
<u>Religion</u>		
Protestant	33	44
Catholic	20	27
Other	3	4
None	11	15
Missing	8	11

Table 1 continued

	n	%
<hr/>		
Education		
Diploma	11	15
Associate Degree	45	60
Bachelor of Science in Nursing	15	20
Master of Science in Nursing	2	3
Missing	1	1
<u>Nursing Speciality</u>		
Medical/Surgical	40	53
Intensive Care/Step down Unit	16	21
Oncology	14	19
Orthopedic	5	3
Missing	3	4
<u>Years Nursing Experience in California</u>		
1-5	39	52
6-10	10	13
11-15	12	16
16-20	6	8
Greater than 20	7	9
Missing	1	1

Table 1 continued

	n	%
<hr/>		
<u>Unit Assigned</u>		
Medical/Surgical	44	60
Intensive Care/Step-down Unit	16	21
Oncology	12	16
Orthopedic	1	1
Missing	2	3

Note: Percentages are rounded and may not total 100 %.

Professional Role

Questions 9-19 on the survey (Appendix C) addressed the first research question, "What do nurses perceive as their professional role in discussing end of life issues with patients?" The responses of agree and strongly agree were grouped together, as were the responses of disagree and strongly disagree (Table 2). Frequencies and percentages of responses were tabulated and used in the discussion of responses to questions 9 through 19.

Of the nurses sampled, the majority (80%) agreed or strongly agreed that it was within their professional role to discuss end of life issues with patients, and 37% were

Table 2

Nurses: Role Perception in Discussing End of Life Issues
with Patients (n=75)

Question	Agree/ Strongly Agree	Unsure	Disagree/ Strongly Disagree
	n	n	n
	%	%	%
It is within my professional	60	12	3
role to discuss end of life	80	16	4
issues with my patients.			
I am comfortable discussing	54	8	13
end of life issues with my	72	11	17
patients.			
I do not initiate	28	10	36
discussions of end of life	37	13	48
issues with my patients.	Missing-1		

Table 2 continued

Question	Agree/ Strongly Agree	Unsure	Disagree/ Strongly Disagree
	n	n	n
	%	%	%
I discuss end of life	54	5	14
issues with my patients	72	7	19
only when they indicate	Missing-2		
a desire to do so.			
It is appropriate for the	75		
physician to discuss end of	100		
life issues with patients.			
It is appropriate for nurses	61	13	1
to discuss end of life	81	17	1
issues with patients.			
Most of my patients would	38	24	12
be comfortable discussing	51	32	16
end of life issues with me.			

Table 2 continued

Question	Agree/ Strongly Agree	Unsure	Disagree/ Strongly Disagree
	n	n	n
	%	%	%
Most patients have discussed	28	18	29
end of life issues with at	37	24	39
least one significant other.			
Initiating discussions of	24	21	30
end of life issues with	32	28	40
patients causes them anxiety.			
Patients want to talk about	31	18	25
end of life issues.	41	24	53
	Missing-1		
Physicians do not want nurses	20	28	27
to discuss end of life issues	27	37	36
with patients.			

Note: Percentages are rounded and may not total 100%.

unsure if physicians wanted nurses to discuss end of life issues with patients. Whereas 51% of the nurses agreed or strongly agreed that patients would be comfortable discussing end of life issues with them, 32% were unsure and 16% disagreed or strongly disagreed.

Only 37% of the nurses agreed or strongly agreed that most patients have discussed end of life issues with a significant other. In addition, only 41% of nurses agreed or strongly agreed that patients want to discuss end of life issues. Responses to this set of questions were similar to the responses obtained by Hall (1992).

Nurses' Knowledge

The second research question, "To what extent are nurses aware of the existence of and uses for Durable Power of Attorney for Health Care Decisions?" was addressed by questions 20-25 on the survey. Frequencies and percentages of responses were tabulated (Table 3).

Sixty percent of the respondents agreed or strongly agreed that the Living Will was a legal document. Although the Durable Power of Attorney for Health Care Decisions is more comprehensive than the Directive to Physicians, only

Table 3

Nurses' Knowledge of Advance Directives (n=75)

Question	Agree/	Unsure	Disagree/
	Strongly		Strongly
	Agree		disagree
	n	n	n
	%	%	%
Directive to Physician, or	45	17	12
Living Will, is a legal	60	22	16
document.	Missing=1		
The best time to discuss	75		
and document advance	100		
directives is before ill.			
Directive to Physician is	27	36	12
more comprehensive than	36	48	16
Durable Power of Attorney			
for Health Care Decisions.			
I have a good working	32	20	
knowledge of Durable Power	43	27	31
of Attorney for Health Care.			

Table 3 continued

Question	Agree/	Unsure	Disagree/
	Strongly		Strongly
	Agree		Disagree
	n	n	n
	%	%	%
Durable Power of Attorney	70	4	
for Health Care Decisions is	93	5	
a legal document allowing	Missing=1		
naming of surrogate decision			
maker.			
A valid Durable Power of	26	35	12
Attorney provides	35	47	16
immunity for physicians	Missing=2		
who honor its terms.			

Note: Percentages are rounded and may not total 100%.

16% of the nurses recognized this. While the majority of respondents (93%) agreed with the correct definition of the Durable Power of Attorney for Health Care Decisions, only

43% agreed or strongly agreed that they had a good working knowledge of this document. In addition, only 35% of the nurses recognized physician immunity as an important part of the Durable Power of Attorney for Health Care Decisions. These results are comparable to the results obtained by Hall (1992).

Nurses' Attitudes

The third research question, "What are nurses' attitudes toward end of life issues?," was addressed by questions 1-8 on the survey. Frequencies and percentages were tabulated (Table 4).

The majority of respondents (72%) disagreed or strongly disagreed that human life should be preserved at all cost, while 65% of the nurses agreed or strongly agreed that preservation of life is a basic principle of medical ethics. All of the respondents agreed or strongly agreed that patients should participate in their health care decisions, and the majority (97%) agreed or strongly agreed that every competent adult has a right to decide what should be done with his own body. Also, all the nurses agreed or strongly agreed that every competent adult is entitled to refuse

Table 4

Nurses' Attitudes Towards End of Life Issues (n=75)

Question	Agree/	Unsure	Disagree/
	Strongly		Strongly
	Agree		Disagree
	n	n	n
	%	%	%
Human Life should be	11	10	54
preserved at all cost.	15	13	72
Patients should participate	75		
in their health care	100		
decisions.			
Competent adult has the	73	1	1
right to decide what should	97	1	1
done with his own body.			
Competent adult is entitled	75		
to refuse recommended	100		
medical treatment.			

Table 4 continued

Question	Agree/ Strongly Agree	Unsure	Disagree/ Strongly Disagree
	n	n	n
	%	%	%
A basic principle of	49	11	14
medical ethics is the	65	15	19
preservation of life.	Missing=1		
The average layperson has	10	8	57
adequate knowledge of	13	11	76
medical technology and			
ways life can be extended.			
If unable to regain a	64	9	2
meaningful life, I would wish	85	12	3
to avoid extension of my life.			
I expect to share in	74		1
decisions about my health care.	99		1

Note: Percentages are rounded and may not total 100%.

medical treatment. A majority of respondents (76%) did not feel the average person had adequate knowledge of medical technology.

A majority of nurses (85%) would wish to avoid artificial extension of their lives, and 99% of the nurses responding expected to participate in decisions about their health care. These results were similar to those obtained by Hall (1992).

Nurses' Perceived Role and Years of Experience

The fourth research question, "What is the relationship between nurses' perception of their role in discussing end of life issues with patients and years of experience in nursing in California?," was answered by doing non-parametric statistics. The category, years of experience, was changed from continuous data to categorical data by condensing the information into groups (Table 5). A chi square was performed and the cell frequency assumption failed with greater than 25% of the cells having less than five entries. The chi square is unstable, lacking external validity and cannot, therefore, be reported. The Cramer's V was then calculated at .296. This showed a negative, weak

correlation between years of experience in nursing in California and perception of role in discussing end of life issues with patients (Table 5).

Table 5

Nurses' perceived Role in Discussing End of Life Issues with Patients by Years of Experience in Nursing in California
(n=75)

Years Experience					
	1-5	6-10	11-15	16-20	>20
<u>Role</u>					
Strongly Disagree/Disagree	1	1		1	
Unsure	7	2	3		
Strongly Agree/Agree	31	7	9	5	7

Summary

This chapter discussed the survey results as they related to the research questions dealing with nurses' perceptions of their role in discussing end of life issues with patients, the extent nurses are aware of the existence and uses of advance directives, nurses' attitudes toward end of life issues, and the relationship between years of nursing experience in California and nurses' perception of their role in discussing end of life issues with their patients. Conclusions and recommendations based on the results are presented in Chapter 5.

Chapter 5

CONCLUSIONS

This study used a descriptive survey design to explore nurses' perceptions of their role in discussing end of life issues with patients, nurses' knowledge of advance directives and their attitudes towards end of life issues. This study also explored whether there is a relationship between nurses' perceived role in discussing end of life issues with patients and their years of nursing experience in California.

The sample, 75 registered nurses who worked on one of five medical surgical units at a community hospital in central California, answered the 39 item questionnaire entitled " Nurse/Patient Communication Survey." Fourteen opened ended questions asked for demographic data, while 25 used a fixed response, Likert scale and addressed nurses' knowledge of advance directives and attitudes and role perception regarding end of life issues.

Sample

This study sample was similar in age, gender, religion

and years of nursing experience to the sample used in Hall (1992). This study sample differed from Hall (1992) in size and education. Hall's study (1992) had a sample size of 26, as compared to a sample size of 75 for this study. A majority of respondents in the 1992 study reported the highest degree obtained was a bachelor of science degree. A majority (60%) of respondents in this study had an associate degree as the highest degree obtained. The high percentage of nurses in this study with an associate degree as the highest degree obtained may be due to the close proximity of an associate degree program to the survey hospital. The community hospital used in this study also has a financial affiliation with the near-by associate degree program, which may influence recruitment and hiring practices of the survey hospital.

Professional Role

The majority of nurses (80%) agreed or strongly agreed that it was within their professional role to discuss end of life issues with patients, and most (72%) stated they felt comfortable doing this. The majority of nurses (72%) initiated discussions of end of life issues only when their

patients indicated a desire to do so. All of the nurses agreed or strongly agreed that it was appropriate for the physician to discuss end of life issues with patients, while a smaller majority (81%) agreed or strongly agreed that it was appropriate for the nurse to discuss end of life issues with patients. Thirty-seven percent of the nurses were unsure if physicians wanted nurses to discuss end of life issues with patients. Only 51% of nurses agreed or strongly agreed that patients would be comfortable discussing end of life issues, and only 41% agreed or strongly agreed that patients want to discuss end of life issues.

These findings are consistent with the results from Hall (1992). Although the majority of nurses reported being comfortable discussing end of life issues, other studies found contrasting information. Most nurses believe it is the nurses' role to talk with patients about their feelings; however, Wilkinson's study (1992) found that most nurses (81%) reported difficulty communicating with cancer patients. Wilkinson's study (1992) also reported that the majority of those surveyed did not want to get involved in talking in depth with patients about their feelings and

emotions. Time constraints and training in communication about difficult subjects may contribute to these results.

All of the nurses agreed or strongly agreed that it is the physician's role to discuss end of life issues with patients, and a majority agreed or strongly agreed that it was the nurse's role. Most nurses (72%) initiate discussions of end of life issues with patients only when the patient indicates a desire to do so. A recent study (Kelner & Bourgeault, 1993) reported that when questioned, only about half of the physicians stated they routinely discussed control of dying with the elderly or very ill patients. When patients are facing death or uncertain treatment, most agree it is more difficult to discuss end of life issues. Doctors and nurses recommend that discussions of control of dying take place early, in the physician's office (Kelner & Bourgeault, 1993).

This study and Hall (1992) reported a minority of nurses agreeing or strongly agreeing that patients want to discuss end of life issues. Other studies indicate that most patients want to have control over their dying (Kelner & Bourgeault, 1993). Health professionals should strive to

create an environment which encourages open communication about patients concerns, especially regarding end of life issues. Uncertainty about whether physicians want nurses to discuss end of life issues with patients may contribute to a majority of nurses (72%) initiating discussions of end of life issues only when the patient indicates a desire to do so.

A negative, weak correlation was found between years of nursing experience in California and role perception in discussing end of life issues with patients. Nurses with less experience reported more certainty in their role of discussing end of life issues. Corley, Selig, and Ferguson (1993) also found that participation on ethical decision making was negatively related to age and years of work experience. Younger nurses with less experience were more likely to participate in ethical decision making. This may represent a trend in nursing curricula. As the role of the nurse expands, nursing programs have expanded their course content to include role expectations and communication skills geared to assist the nurse in dealing more effectively with patient autonomy and the many choices

available to patients.

Nurses' Knowledge

The majority of nurses did not identify the key components of the Directive to Physicians or Living Will. While the majority of nurses (93%) were able to correctly define the Durable Power of Attorney for Health Care Decisions, only 35% of nurses identified physician immunity as a component, and only 43% stated they had a good working knowledge of the Durable Power of Attorney for Health care decisions. Hall (1992) identified the possibility that the questions defining the Durable Power of Attorney for Health Care Decisions were leading and may account for the majority correctly defining the document, yet reporting they did not have a good working knowledge of it. This researcher agrees.

This lack of knowledge, consistent with Hall's research (1992), indicates a need to provide guidelines for nursing education about advance directives to nursing students and practicing nurses. Most nurses believe it is their role to discuss end of life issues with patients. Further preparation is needed to more completely fulfill this role

expectation.

Nurses' Attitudes

The majority of nurses (72%) disagreed or strongly disagreed that human life should be preserved at all cost. The majority of nurses also agreed or strongly agreed that competent adults have the right to decide what should be done with their body, including refusal of treatment. Most (76%) disagreed or strongly disagreed that the lay person has adequate knowledge of medical technology, including ways to extend life. Most nurses would not want to extend their lives if unable to regain a meaningful life and would expect to share in decisions about their health care.

The majority of physicians and nurses believe that patients should control the circumstances of their dying, and most believe that patients have a right to refuse treatment. Factors influencing the health professional's view of the patient's control include: (a) patient circumstances; (b) professional's moral scruples and legal concerns; and (c) the type of interventions patients may request. The desire to forego treatment is seen as most problematic for most health professionals (Kelner &

Bourgeault, 1993). According to Nicholson (1991), nurses should be aware of the basic principles of the ethics of resuscitation, such as honoring the patient's wishes, in order to assist the patient and be more comfortable in implementing the patient's decision.

The nurses' role as patient advocate includes providing necessary information to the patient, to enable the patient to make an informed choice. As most nurses believe that the average layperson does not possess adequate knowledge of medical technology and ways life can be extended, it becomes important to develop ways to assist the nurse in this challenging role. Although the majority (81%) of the respondents did not have a Durable Power of Attorney for Health Care Decisions, it is advocated that this is one way to improve knowledge and comfort level of nurses in assisting patients in discussing end of life issues (Evans, 1990).

Recommendations

Based on the findings from this study, the following recommendations are made:

1. Further research, as a qualitative study, to

identify themes of communication barriers to discussing end of life issues may be useful in developing guidelines for nursing education.

2. Revise the survey tool, "Nurse/Patient Communication Survey," to include a revision of questions 20-25, dealing with the nurses' knowledge. These questions may be leading and inaccurately reflect the knowledge level of the participant.

3. Expand sample in size and nursing speciality to identify trends in nursing practice.

The results of this study indicated that nurses believe it is their role to discuss end of life issues with patients. Responses to this survey also indicated that nurses' knowledge of advance directives was lacking. Educational programs and standards for discussing end of life issues with patients are needed to assist nurses in clinical medical-surgical settings deal effectively with end of life discussions with patients.

REFERENCES

- American Nurses' Association. (1985). Code for nurses with interpretive statements. Kansas City, MO: Author.
- Beauchamp, T. L., & Childress, J. F. (1989). Principles of biomedical ethics (3rd ed.). New York: Oxford University Press.
- Byock, I. R. (1991). Tools for autonomy. American Journal of Hospice and Palliative Care, 8(5), 6-8.
- California Medical Association. (1992). Your health care: Who will decide when you can't?. San Francisco, CA: Author.
- Consent manual: A reference for consent and related health care law. (1993). Sacramento, CA: California Association of Hospitals and Health Systems.
- Corley, M. C., Selig, P., & Ferguson, C. (1993). Critical care nurse participation in ethical and work decisions. Critical Care Nurse, 7(3), 120-126.
- Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 (1990).
- Evans, S. A. (1990). Who lives, who dies, who decides? Heart

and Lung, 19(5), 21A-24A.

Hall, P. L. (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.

Jurchak, M. (1990). Competence and the nurse-patient relationship. Critical Care Nursing Clinics of North America, 2, 453-459.

Kelner, M. J., & Bourgeault, I. L. (1993). Patient control over dying: Responses of health care professionals. Social Science Medicine, 36, 757-765.

Killian, W. H. (1990). Knowledge of living will laws essential. The American Nurse, 10(4), 33.

LoBiondo-Wood, G., & Haber, J. (1990). Nursing research: Methods, critical appraisal, and utilization (2nd ed.). St. Louis, MO: C. V. Mosby Company.

Marchette, L., Box, N., Hennessy, M., Wasserlauf, M., Arnall, B., Copeland, D., & Habib, K. (1993). Nurses' perceptions of the support of patient autonomy in do-not-resuscitate (dnr) decisions.

- International Journal of Nursing Studies, 30(1), 37-49.
- Meyer, C. (1993). End-of-life care: Patients' choices, nurses' challenges. American Journal of Nursing, 93(2), 40-46.
- Nicholson, L. G. (1991). The ethics of limiting treatment: DNR decisions. Nursing Management, 22(2), 64H-64P.
- Ryder, R. L. (1992). End-of-life issues: A practice perspective. Journal of Professional Nursing, 8, 199.
- Scott, J. L. (1992). Ethical issues: A Washington perspective. Nursing Management, 23(1), 52-56.
- Silva, M. C. (1990). Ethical decision making in nursing administration. Norwalk, CT: Appleton & Lange.
- Turner, J. T. (1992). Nursing care of the terminal lung cancer patient. Nursing Clinics of North America, 27, 691-702.
- Uhlman, R. F., Pearlman, R. A., & Cain, K. C. (1989). Understanding of elderly patients' resuscitation preferences by physicians and nurses. Western

Journal of Medicine, 150, 705-707.

Wilkinson, S. (1992). Confusions and challenges.

Nursing Times, 88(35), 24-28.

Yarling, R. R., & McElmurry, B. J. (1983). Rethinking
the nurses' role in "do not resuscitate" orders: A
clinical policy proposal in nursing ethics.

Advances in Nursing Science, 5(4), 1-12.

APPENDIX A

Directive to Physicians:
California Natural Death Act

CALIFORNIA NATURAL DEATH ACT

Guidelines for Signers

The DECLARATION allows you to instruct your doctor not to use artificial methods to extend the natural process of dying. Before signing the DECLARATION, you may ask advice from anyone you wish, but you do not have to see a lawyer or have the DECLARATION certified by a notary public. If you sign the DECLARATION, talk it over with your doctor and ask that it be made a part of your medical record.

The DECLARATION must be WITNESSED by two adults, at least one of whom is not mentioned in your will and would have no claim to your estate. The DECLARATION may NOT be witnessed by a health care provider (for example, a doctor or a hospital), an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly. If you are in a SKILLED NURSING FACILITY or a LONG-TERM HEALTH CARE FACILITY at the time you sign the DECLARATION, one of your two witnesses MUST be a "patient advocate" or "ombudsman" designated by the state Department of Aging.

You may sign a DECLARATION if you are at least 18 years old and of sound mind, acting of your own free will in the presence of two qualified witnesses. No one may force you to sign a DECLARATION. No one may deny you insurance or health care services because you have chosen not to sign it. If you *do* sign the DECLARATION, it will not affect your insurance or any other rights you may have to accept or reject medical treatment.

The DECLARATION becomes operative when (a) it is communicated to the attending physician, and (b) you are diagnosed and certified in writing by the attending physician and a second physician who has personally examined you that you are in a terminal condition or permanent unconscious condition and no longer able to make decisions regarding administration of life-sustaining treatment. The DECLARATION is not operative during pregnancy.

You may revoke the DECLARATION at any time, even in the final stages of a terminal illness, in any manner. No matter how you revoke the DECLARATION, be sure your doctor is told of your decision. The revocation is effective upon its communication to the attending physician or other health care provider by you or by a witness to the revocation.

Declaration

Declaration made this _____ day of (month, year)_____.

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

- If I should have an incurable or irreversible condition that has been diagnosed by two physicians and that will either (1) result in my death within a relatively short time without the administration of life-sustaining treatment, or (2) has produced an irreversible coma or persistent vegetative state, and I am no longer able to make decisions regarding my medical treatment, then I direct my attending physician, pursuant to the Natural Death Act of California, to withhold or withdraw treatment, including artificially administered nutrition and hydration, that only prolongs the process of dying or the irreversible coma or persistent vegetative state and is not necessary for my comfort or to alleviate pain.
- If I have been diagnosed as pregnant, and that diagnosis is known to my physician, this declaration shall have no force or effect during my pregnancy.
- In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this Declaration be honored by my family, and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences of such refusal.
- I understand the full import of this Declaration and I am emotionally and mentally competent to make this Declaration.

Signature: _____

Address: _____

The declarant voluntarily signed this writing in my presence. I am not a health care provider, an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly.

Witness: _____

Address: _____

The declarant voluntarily signed this writing in my presence. I am not entitled to any portion of the estate of the declarant upon his or her death under any will or codicil thereto of the declarant now existing or by operation of law. I am not a health care provider, an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly.

Witness: _____

Address: _____

This Declaration complies in form with the "Natural Death Act," California Health and Safety Code sections 7185 et seq.

Summary and Guidelines for Physicians

INTRODUCTION

A person who is at least 18 years of age, of sound mind, and acting on his or her own free will may sign a DECLARATION as contained in the California "Natural Death Act." This Act permits a person to give legal effect to his/her wishes to avoid artificial prolongation of the dying process. It also imposes certain obligations -- and provides certain protections -- for a physician dealing with a person presenting a DECLARATION. A physician or other health care provider who is furnished a copy of the declaration shall make it a part of the declarant's medical record and, if unwilling to comply with the declaration, promptly so advise the declarant, and take all reasonable steps as promptly as practicable to transfer care of the declarant to another physician or health care provider who is willing to do so.

SIGNATURE AND WITNESSES

To be effective, the DECLARATION must be signed by the patient and witnessed by two persons, at least one of whom is not mentioned in the patient's will and is not a potential claimant to his/her estate. Witnesses may not be involved in the patient's medical care. Thus, the DECLARATION cannot be witnessed by you or any of your employees. Likewise it should not be witnessed by any other physician or his/her employees, or the employees of any health facility. In addition, if the patient is in a skilled nursing facility or a long-term health care facility at the time of signing, a "patient advocate" or "ombudsman" (designated by the state Department of Aging) *MUST* be a witness.

The DECLARATION is effective indefinitely. A person signing a DECLARATION should, if possible, present the document to his/her physician so that it can be made a part of his/her current medical record.

EFFECT OF A DECLARATION

Upon receipt of a DECLARATION from a patient the attending physician should make a good faith effort to determine whether the DECLARATION meets legal requirements. The DECLARATION should be made a part of the patient's medical record.

If you do not wish to carry out the DECLARATION of a patient, you are required to take all reasonable steps as promptly as practicable to transfer care of the patient to a physician who is willing to comply with the DECLARATION. If you do not transfer such a patient, you may be found guilty of a misdemeanor. If you do carry out the DECLARATION, you are protected from civil and criminal liability in the absence of knowledge of the revocation of the DECLARATION.

A DECLARATION becomes operative when (a) it is communicated to the attending physician, and (b) the patient is certified in writing by the attending physician and a second physician who has personally examined the patient to be in a terminal condition or permanent unconscious condition and no longer able to make decisions regarding administration of life-sustaining treatment. At this time the attending physician MUST record this determination and the DECLARATION in the patient's medical record.

The DECLARATION is not to be given effect until you have determined that death is imminent, whether or not "life-sustaining procedures" are utilized. Such procedures include mechanical or other "artificial" means which sustain vital functions only to postpone the moment of death. These do not include medications or procedures deemed necessary to alleviate pain.

The DECLARATION is not operative during pregnancy.

REVOCATION

A patient may revoke the DECLARATION at any time regardless of his/her mental or physical condition, in any manner. The revocation is effective upon its communication to the attending physician or other health care provider by the patient or by a witness to the revocation. Should you receive such revocation from or on behalf of a patient who has previously signed a DECLARATION, enter that information promptly and prominently in the patient's current medical record.

OTHER RIGHTS

No person may be forced to sign a DECLARATION. A person who has not signed a DECLARATION may not be denied health care or health insurance. The DECLARATION has no effect on any insurance policy and does not limit a person's right to accept or reject health care of any kind.

PRECAUTIONS

A person who knowingly conceals or destroys a valid DECLARATION is guilty of a misdemeanor. A person who forges or falsifies a DECLARATION, or who withholds knowledge of a revocation of a DECLARATION, may be guilty of unlawful homicide.

SUMMARY

Withholding "life-sustaining procedures" in compliance with a DECLARATION is not euthanasia or "mercy killing." The DECLARATION is not a "Living Will." The DECLARATION is merely a method, recognized under California law, by which a physician may respect a patient's instruction to permit an imminent death to proceed naturally.

Verification of Declaration

I am the attending physician for (name of patient) _____.

I have read the attached Declaration, executed by the patient. To the best of my knowledge, the Declaration conforms to the requirements of the law having been signed by the patient and by two witnesses, at least one of whom is not mentioned in the patient's will and would have no claim to the patient's estate. No witness is a health care provider, an employee of a health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, or an employee of an operator of a residential care facility for the elderly. If the patient is in a SKILLED NURSING FACILITY or a LONG-TERM HEALTH CARE FACILITY at the time he or she signs the DECLARATION, one of the two witnesses MUST be a "patient advocate" or "ombudsman" designated by the state Department of Aging.

Date: _____

Signature: _____
(physician)

COPIES: You should keep the executed original document and give a photocopy to your doctor and to members of your family. The photocopies of this document that you give to your doctor and to members of your family can be relied upon as though they were originals.

APPENDIX B

Durable Power of Attorney for Health Care Decisions

California Medical Association
DURABLE POWER OF ATTORNEY FOR HEALTH CARE DECISIONS
(California Civil Code Sections 2410- 2444)

1

WARNING TO PERSON EXECUTING THIS DOCUMENT

This is an important legal document. Before executing this document, you should know these important facts:

This document gives the person you designate as your agent (the attorney-in-fact) the power to make health care decisions for you. Your agent must act consistently with your desires as stated in this document or otherwise made known.

Except as you otherwise specify in this document, this document gives your agent power to consent to your doctor not giving treatment or stopping treatment necessary to keep you alive.

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 or withheld if you object at the time.

This document gives your agent authority to consent, to refuse to consent, or to withdraw consent to any care, treatment, service, or procedure to maintain, diagnose, or treat a physical or mental condition. This power is subject to any statement of your desires and any limitations that you include in this document. You may

state in this document any types of treatment that you do not desire. In addition, a court can take away the power of your agent to make health care decisions for you if your agent (1) authorizes anything that is illegal, (2) acts contrary to your known desires or (3) where your desires are not known, does anything that is clearly contrary to your best interests.

This power will exist for an indefinite period of time unless you limit its duration in this document.

You have the right to revoke the authority of your agent by notifying your agent or your treating doctor, hospital, or other health care provider orally or in writing of the revocation.

Your agent has the right to examine your medical records and to consent to their disclosure unless you limit this right in this document.

Unless you otherwise specify in this document, this document gives your agent the power after you die to (1) authorize an autopsy, (2) donate your body or parts thereof for transplant or therapeutic or educational or scientific purposes, and (3) direct the disposition of your remains.

If there is anything in this document that you do not understand, you should ask a lawyer to explain it to you.

1. 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 below to make health care decisions for me as allowed by Sections 2410 to 2444, inclusive, of the California Civil Code. This power of attorney shall not be affected by my subsequent incapacity. I hereby revoke any prior durable power of attorney for health care. I am a California resident who is at least 18 years old, of sound mind, and acting of my own free will.

2. APPOINTMENT OF HEALTH CARE AGENT

(Fill in below the name, address and telephone number of the person you wish to make health care decisions for you if you become incapacitated. You should make sure that this person agrees to accept this responsibility. The following may not serve as your agent: (1) your treating health care provider; (2) an operator of a community care facility or residential care facility for the elderly; or (3) an employee of your treating health care provider, a community care facility, or a residential care facility for the elderly, unless that employee is related to you by blood, marriage or adoption. If you are a conservatee under the Lanterman-Petris-Short Act (the law governing involuntary commitment to a mental health facility) and you wish to appoint your conservator as your agent, you must consult a lawyer, who must sign and attach a special declaration for this document to be valid.)

I, _____, hereby appoint
 (insert your name)

Name _____

Address _____

Work Telephone (_____) _____ Home Telephone (_____) _____

as my agent (attorney-in-fact) to make health care decisions for me as authorized in this document. I understand that this power of attorney will be effective for an indefinite period of time unless I revoke it or limit its duration below.

(Optional) This power of attorney shall expire on the following date: _____

© California Medical Association 1992 (revised)

3. AUTHORITY OF AGENT

If I become incapable of giving informed consent to health care decisions, I grant my agent full power and authority to make those decisions for me, subject to any statements of desires or limitations set forth below. Unless I have limited my agent's authority in this document, that authority shall include the right to consent, refuse consent, or withdraw consent to any medical care, treatment, service, or procedure; to receive and to consent to the release of medical information; to authorize an autopsy to determine the cause of my death; to make a gift of all or part of my body; and to direct the disposition of my remains, subject to any instructions I have given in a written contract for funeral services, my will or by some other method. I understand that, by law, my agent may not consent to any of the following: commitment to a mental health treatment facility, convulsive treatment, psychosurgery, sterilization or abortion.

4. MEDICAL TREATMENT DESIRES AND LIMITATIONS (OPTIONAL)

(Your agent must make health care decisions that are consistent with your known desires. You can, but are not required to, state your desires about the kinds of medical care you do or do not want, including your desires concerning life-sustaining treatment. If you do not want your agent to have the authority to make certain decisions, you must write a statement to that effect in the space provided below; otherwise, your agent will have the broad powers to make health care decisions for you that are outlined in paragraph 3 above. In either case, it is important that you discuss your health care desires with the person you appoint as your agent.)

(Following are three general statements about withholding and removal of life-sustaining treatment. If, after carefully reading all of these statements, you agree with one of them, you may initial that statement. If you wish to add to one of the printed statements, or to write your own instead, you may do so in the space provided.)

I do not want efforts made to prolong my life and I do not want life-sustaining treatment to be provided or continued: (1) if I am in an irreversible coma or persistent vegetative state; or (2) if I am terminally ill and the application of life-sustaining procedures would serve only to artificially delay the moment of my death; or (3) under any other circumstances where the burdens of the treatment outweigh the expected benefits. I want my agent to consider the relief of suffering and the quality as well as the extent of the possible extension of my life in making decisions concerning life-sustaining treatment.

If this statement reflects your desires, initial here: _____

I want efforts made to prolong my life and I want life-sustaining treatment to be provided unless I am in a coma or persistent vegetative state which my doctor reasonably believes to be irreversible. Once my doctor has concluded that I will remain unconscious for the rest of my life, I do not want life-sustaining treatment to be provided or continued.

If this statement reflects your desires, initial here: _____

I want efforts made to prolong my life and I want life-sustaining treatment to be provided even if I am in an irreversible coma or persistent vegetative state.

If this statement reflects your desires, initial here: _____

Other or additional statements of medical treatment desires and limitations: _____

(You may attach additional pages if you need more space to complete your statements. Each additional page must be dated and signed at the same time you date and sign this document.)

5. APPOINTMENT OF ALTERNATE AGENTS (OPTIONAL)

(You may appoint alternate agents to make health care decisions for you in case the person you appointed in Paragraph 2 is unable or unwilling to do so.)

If the person named as my agent in Paragraph 2 is not available or willing to make health care decisions for me as authorized in this document, I appoint the following persons to do so, listed in the order they should be asked:

First Alternate Agent: Name _____ Work Telephone (_____) _____

Address _____ Home Telephone (_____) _____

Second Alternate Agent: Name _____ Work Telephone (_____) _____

Address _____ Home Telephone (_____) _____

6. USE OF COPIES

I hereby authorize that photocopies of this document can be relied upon by my agent and others as though they were originals.

DATE AND SIGNATURE OF PRINCIPAL

(You must date and sign this power of attorney.)

I sign my name to this Durable Power of Attorney for Health Care as _____
 _____ (City) _____ (State)
 on _____
 _____ (Date) _____ (Signature of Principal)

STATEMENT OF WITNESSES

(This power of attorney will not be valid for making health care decisions unless it is either (1) signed by two qualified adult witnesses who are personally known to you (or to whom you present evidence of your identity) and who are present when you sign or acknowledge your signature or (2) acknowledged before a notary public in California. If you elect to use witnesses rather than a notary public, the law provides that none of the following may be used: (1) the persons you have appointed as your agent and alternate agents, (2) a health care provider or an employee of a health care provider, or (3) an operator or employee of a community care facility or residential care facility for the elderly. Additionally, at least one of the witnesses cannot be related to you by blood, marriage or adoption, or be named in your will. IF YOU ARE A PATIENT IN A SKILLED NURSING FACILITY, ONE OF THE WITNESSES MUST BE A PATIENT ADVOCATE OR OMBUDSMAN.)

I declare under penalty of perjury under the laws of California that the person who signed or acknowledged this document is personally known to me to be the principal, or that the identity of the principal was proved to me by convincing evidence,* 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 or a residential care facility for the elderly, nor an employee of an operator of a community care facility or residential care facility for the elderly.

Signature _____	Signature _____
Print name _____	Print name _____
Date _____	Date _____
Residence Address _____	Residence Address _____

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

I further 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: _____

*The law allows one or more of the following forms of identification as convincing evidence of identity: a California driver's license or identification card or U.S. passport that is current or has been issued within five years, or any of the following if the document is current or has been issued within five years, contains a photograph and description of the person named on it, is signed by the person, and bears a serial or other identifying number: a foreign passport that has been stamped by the U.S. Immigration and Naturalization Service; a driver's license issued by another state or by an authorized Canadian or Mexican agency; or an identification card issued by another state or by any branch of the U.S. armed forces. If the principal is a patient in a skilled nursing facility, a patient advocate or ombudsman may rely on the representations of family members or the administrator or staff of the facility as convincing evidence of identity if the patient advocate or ombudsman believes that the representations provide a reasonable basis for determining the identity of the principal.

SPECIAL REQUIREMENT: STATEMENT OF PATIENT ADVOCATE OR OMBUDSMAN

(If you are a patient in a skilled nursing facility, a patient advocate or ombudsman must sign the Statement of Witnesses above and must also sign the following declaration.)

I further 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 (f) of Civil Code Section 2432.

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

CERTIFICATE OF ACKNOWLEDGMENT OF NOTARY PUBLIC

(Acknowledgment before a notary public is not required if you have elected to have two qualified witnesses sign above. If you are a patient in a skilled nursing facility, you must have a patient advocate or ombudsman sign the Statement of Witnesses on page 3 and the Statement of Patient Advocate or Ombudsman above)

State of California)

) ss.

County of _____)

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)

COPIES

YOUR AGENT MAY NEED THIS DOCUMENT IMMEDIATELY IN CASE OF AN EMERGENCY. YOU SHOULD KEEP THE COMPLETED ORIGINAL AND GIVE PHOTOCOPIES OF THE COMPLETED ORIGINAL TO (1) YOUR AGENT AND ALTERNATE AGENTS, (2) YOUR PERSONAL PHYSICIAN, AND (3) MEMBERS OF YOUR FAMILY AND ANY OTHER PERSONS WHO MIGHT BE CALLED IN THE EVENT OF A MEDICAL EMERGENCY. THE LAW PERMITS THAT PHOTOCOPIES OF THE COMPLETED DOCUMENT CAN BE RELIED UPON AS THOUGH THEY WERE ORIGINALS.

APPENDIX C

Nurse/Patient Communication Survey

NURSE/PATIENT COMMUNICATION SURVEY

Please use the following number scale to respond to statements 1-22. Circle the number in the appropriate column to indicate your degree of agreement or disagreement with each statement.

5-strongly agree 4-agree 3-unsure 2-disagree 1-strongly disagree

		Strongly Agree		Unsure		Strongly disagree
1.	Human life should be preserved at all costs.	5	4	3	2	1
2.	Patients should participate in their health care decisions.	5	4	3	2	1
3.	Every competent adult has the right to decide what should be done with his or her own body.	5	4	3	2	1
4.	A competent adult is entitled to refuse recommended medical treatment despite the opinions of others that such treatment is in his or her best interest.	5	4	3	2	1
5.	A basic principle of medical ethics is the preservation of life.	5	4	3	2	1
6.	The average layperson has an adequate knowledge of medical technology and is aware of many of the ways in which life can be artificially extended.	5	4	3	2	1
7.	In the event that an illness made it very unlikely that I would regain a meaningful quality of life, I would wish to avoid artificial extension of my life.	5	4	3	2	1
8.	I expect to participate or share in making decisions about my health care.	5	4	3	2	1

For questions 9-19, the term "end of life issues" refers to issues of death and dying, use of life-sustaining treatment, resuscitation status, quality of life, and use of advance directives.

		Strongly Agree		Unsure		Strongly Disagree
9.	It is within my professional role to discuss end of life issues with my patients.	5	4	3	2	1
10.	I am comfortable discussing end of life issues with my patients.	5	4	3	2	1
11.	I do not initiate discussions of end of life issues with my patients.	5	4	3	2	1
12.	I generally discuss end of life issues with my patients only when they indicate a desire to do so.	5	4	3	2	1
13.	It is appropriate for a physician to discuss end of life issues with his or her patient.	5	4	3	2	1
14.	It is appropriate for a nurse to discuss end of life issues with his or her patient.	5	4	3	2	1
15.	I believe most of my patients would be comfortable discussing end of life issues with me.	5	4	3	2	1
16.	I believe most of my patients have already discussed end of life issues with at least one family member or significant other.	5	4	3	2	1
17.	Initiating discussions of end of life issues with my patients causes them increased anxiety.	5	4	3	2	1
18.	In general, patients want to talk about end of life issues.	5	4	3	2	1
19.	I believe that physicians do not want nurses to discuss end of life issues with their patients.	5	4	3	2	1
20.	A Directive to Physician, often erroneously referred to as a Living Will, is a legal document in the state of California.	5	4	3	2	1

		Strongly Agree		Unsure		Strongly Disagree
21.	Ideally, the best time for an individual to discuss and document advance directives with appropriate persons is before one becomes ill.	5	4	3	2	1
22.	The Directive to Physician is more comprehensive in scope than the Durable Power of Attorney for Health Care Decisions.	5	4	3	2	1
23.	I have a good working knowledge of the Durable Power of Attorney for Health Care Decisions.	5	4	3	2	1
24.	The Durable Power of Attorney for Health Care Decisions is a legal document that allows an individual to specify his or her health care wishes and to designate another person to make health care decisions for that individual in the event that the individual is no longer able to make his or her own decisions.	5	4	3	2	1
25.	A validly executed Durable Power of Attorney for Health Care Decisions is intended to provide immunity from civil and criminal liability to a physician who agrees to subordinate his or her own judgment to that of the designated attorney-in-fact.	5	4	3	2	1

Please answer the following questions by writing in the space provided:

26. Age _____ 27. Sex _____ 28. Religion _____
29. Professional title: _____
30. Nursing specialty: _____
31. Type of unit where you work: _____
32. Number of years you have practiced in California: _____
33. Highest degree obtained in nursing: _____
34. Overall, approximate percentage of patients for whom you provide care that are older than 65 years old: _____

35. Does your institution have an ethics committee? yes__no__unsure__
36. If so, what type of ethics committee(s)? Please check appropriate types:
Nursing_____ Medical_____
Other(Please specify)_____
37. Do you have a valid Durable Power of Attorney for Health Care Decisions document for yourself? yes_____ no_____
38. Do you have a valid Directive to Physician document for yourself? .
yes_____ no_____
39. Have you recommended the use of the Durable Power of Attorney for Health Care Decisions to one or more patients in the last 12 months?
yes_____ no_____

Please use the remainder of this paper for any additional comments you would like to make regarding this questionnaire and it's contents. Thank you for your assistance.

APPENDIX D

Human Subjects-Institutional Review Board 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: Christine Hall
311 Sirena Del Mar
Marina, CA

FROM: Serena W. Stanford *Serena W. Stanford*
AAVP, Graduate Studies and Research

DATE: May 17, 1994

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

"Nurses' Knowledge of Advance Directives and Their Perceived Role"

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 projects, 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 projects 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 E

Institution Approval Letter

Community Hospital of the Monterey Peninsula

AGREEMENT TO PARTICIPATE IN RESEARCH AT SAN JOSE STATE UNIVERSITY

Responsible Investigator: Christine Hall RN, BSN

NURSES' KNOWLEDGE OF ADVANCE DIRECTIVES AND THEIR PERCEIVED ROLE IN DISCUSSING END OF LIFE ISSUES WITH PATIENTS

Christine Hall has permission to conduct research at Community Hospital of the Monterey Peninsula to answer the following research questions:

1. What do nurses' perceive as their professional role in discussing end of life issues with patients?
2. What are nurses' attitudes toward end of life issues?
3. To what extent are nurses aware of the existence and uses of the advance directives?
4. What is the relationship between nurses' perception of their role in discussing end of life issues with patients and years experience in nursing?

This study will utilize the questionnaire "Nurse/Patient Communication Survey" and will be conducted from June through December 1994.

Mary Ann Washington RN, Vice-President

1-10-94, 1994
Date

APPENDIX F

Cover Letter for Research Packet

To Participating Nurses,

The attached questionnaire is part of my thesis project for my Master of Science degree at San Jose State University. I would very much appreciate your participation and input regarding this study.

Please read the attached agreement to participate in research at San Jose State University. Completion of the survey indicates voluntary agreement to participate. This survey is anonymous. If you agree to participate, please return the survey to the covered box on Garden South.

You may decide not to participate at any time.

Thank you for your assistance with this project.

Christine Hall, BSN

APPENDIX G

Agreement to Participate in Research

School of Applied Arts and Sciences • Department of Nursing • Graduate Program
One Washington Square • San Jose, California 95192-0037 • 408/924-3134

Agreement to Participate in Research

Responsible Investigator: Christine Hall

Title of Questionnaire: Nurse/Patient Communication Survey

I have been asked to participate in a research study that is investigating nurse/patient communication related to end of life issues.

I UNDERSTAND THAT:

- 1) I will be asked to complete an ANONYMOUS 4-page questionnaire that will be collected and returned in a sealed envelope to the researcher. Total time for my participation should be less than 20 minutes.
- 2) There are no anticipated risks for participation in this study.
- 3) A possible benefit to me is receiving information about tools that can be used by myself and my patients for documenting health care wishes.
- 4) The results of this study may be published, by my identity will remain anonymous and confidential throughout this study. My privacy or my job status will in no way be affected by my participation in this study.
- 5) I will receive no compensation for my participation in this study.
- 6) Any questions about my participation in this study will be answered by Christine Hall (408) 625-4750. Complaints about the procedures may be presented to Dr. Coleen Saylor, Graduate Coordinator (408) 924-3131. For questions or complaints about research subjects' rights or research related injury, contact Serena Stanford, Ph.D., Associate Vice President of Graduate Studies and Research at (408) 924-2480.
- 7) My consent is given voluntarily without being coerced; I may refuse to participate in this study or in any part of this study without prejudice to my relations with San Jose State University or the institution at which I am employed.

I have made a decision whether or not to participate. Return of the survey indicates voluntary agreement to participate in this research.