

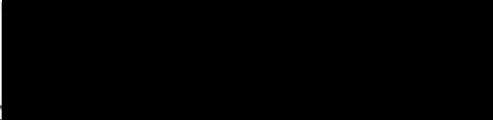
This study was supported by a grant from the
National Institute of Mental Health Grant
Number 5 T24 MH 18547-02.

An Exploratory Study
of Decision-making About Limiting Treatment
in Long-term Care


by
Rosanne Soriano, R.N., B.S.N.

A Thesis
Presented to
The Oregon Health Sciences University
School of Nursing
in partial fulfillment
of the requirements for the degree of
Master of Science
June 8, 1990

APPROVED:


Beverly Hoetter, RN, DNSC, Professor, Thesis Advisor


Joanne Rader, RN, MN, Instructor, Reader


Caroline White, RN, DrPH, Professor, Reader

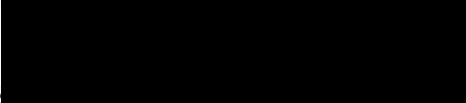

Carol Lindeman, RN, PhD, Dean, School of Nursing

TABLE OF CONTENTS

REVIEW OF LITERATURE	3
Overview	3
Decisions to Limit Treatment	3
Family Involvement in Decision-making	16
The Role of the Nurse in Decision-making About Limiting Treatment for Nursing Home Residents	22
Conclusion	25
CONCEPTUAL FRAMEWORK	28
Introduction	28
The Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research	28
The Triple Contract Theory of Ethics	29
Recommendations of the President's Commission	29
Summary	32
Research Questions	35
METHODS	37
Design	37
Subjects and Setting	37
Instruments	40
Data Collection Procedures	41
Data Analysis	43

DISCUSSION	83
Policies and Practices Concerning Limiting Treatment	83
Roles of the Nurse in Decision-making	85
Limitations of the Study	89
Summary	90
SUMMARY	92
Recommendations for Further Research	95
Recommendations for Nursing Practice	95
Conclusion	98
REFERENCES	99

APPENDICES107
A. Ethical Systems, Religious Traditions, and Western Liberal Political Philosophy107
B. Facility Characteristics Questionnaire112
C. Interview Schedules	114
D. Letters to Research Subjects	133
E. Consent Form	136
 ABSTRACT	 139

LIST OF FIGURES AND TABLES

FIGURE 1. Conceptual Framework for Studying
Decision-making About Limiting Treatment
in Nursing Homes 34

TABLE 1. Levels of Care Provided to Patients
With Dementia of the Alzheimer's Type 14

TABLE 2. Comparison of the Four Facilities
With Policies/Written Materials
Related to Decision-making About
Limiting Treatment 47

TABLE 3. Roles and Functions of the Nurse in
Decision-making About Limiting Treatment. . . .53

TABLE 4. Nurses' Reports of How Judgements Are Made
Regarding Decision-making Capacity of
Nursing Home Residents.77

CHAPTER I

INTRODUCTION

In 1980, there were approximately 2.2 million Americans 85 years old or older. By the year 2000, it is estimated that this "old-old" group will comprise approximately 4.9 million people. In 1982 approximately 1.3 million Americans over the age of 65 lived in nursing homes, half of them aged 85 or older (Schick, 1986). Mortality rates for the population aged 65 and over have steadily declined during this century. However, with increasing age, there is an increasing incidence of chronic disease such as arthritis, hypertension, heart disease, arteriosclerosis, and diabetes as well as hearing and visual impairment (Rabin & Stockton, 1987). Although medical technology can keep patients alive longer, it cannot cure many of the chronic ailments that reduce quality of life in old age.

Increasingly, there is debate about what kinds of treatment are appropriate for elderly persons, especially when they have underlying chronic illnesses. When the elderly person is also incapable of making decisions due to a dementing illness, the problem is compounded. Sixteen percent of nursing home residents have a primary diagnosis of mental disorder or senility and 56% have a chronic mental condition or senility (Schick, 1986).

The nurse in a nursing home has considerable autonomy and responsibility for the day-to-day care of patients and can expect to be faced with dilemmas regarding the kinds of treatment that are appropriate for chronically ill elderly residents, who may also be

mentally impaired. Because of close contact with both residents and their families, the nurse may be asked to assist and advise families making decisions about the possibility of limiting treatment for residents. Unfortunately, there is a lack of nursing research in the area of decision-making about limiting treatment to assist the nurse in this role.

This research project will provide a review of literature relevant to the limitation of treatment of elderly residents in long-term care facilities, the role of the family, and the role of the nurse. It will present a conceptual framework for ethical decision-making, and present a study of policies and practices about decision-making concerning limiting treatment in long-term care facilities in three metropolitan counties in Oregon to determine the policy framework for current practice, identify roles of the nurse, and identify areas for further study.

CHAPTER II

REVIEW OF LITERATURE

Overview

In classical times, when the Hippocratic corpus was written, it was considered unethical merely to prolong life. The functions of medicine were to preserve and to restore health. The physician was to do away with suffering, lessen the violence of illness, and to refuse to treat cases in which he felt that intervention would be useless. The first injunction to prolong life, by Francis Bacon in the sixteenth or seventeenth century, apparently referred to urging physicians to seek cures for yet incurable diseases. Bacon also recommended that means be found to make dying less unpleasant and more comfortable (Amundsen, 1978).

In a contemporary opinion on prolonging the life of an incompetent elderly patient, Lynn (1984) argued that only intervention that could be expected to improve the patient's well-being should be used. Making this determination would require weighing objectives and concerns and these should, as far as possible, reflect the preferences of the individual patient.

Decisions to Limit Treatment

Possible reasons for limiting the treatment offered to patients were listed by Lo and Jonsen (1980). These included futility of the treatment, the wishes of the patient, the patient's quality of life, and the cost of the care and/or limited available resources. They added

that quality of life must be determined by the patient, or if the patient is incompetent, by appropriate decision-makers; in the case of cost or limited resources, this can only be a societal decision, such as limitations on what Medicare will cover.

Besdine (1983) discussed three categories of limited treatment decisions for long-term care residents. These are decisions not to resuscitate, not to hospitalize, and not to treat. Decisions not to treat patients may include decisions about providing nutrition and hydration. Each of these categories will be discussed in more detail.

Do Not Resuscitate

Cardio-pulmonary resuscitation (CPR), in the form of closed chest massage, was introduced in the 1960s (Gulati, Bhan, & Horan, 1983) and was approved by the American Heart Association in 1974 (Youngner, 1987). It was originally intended only for victims of an acute insult who were otherwise well and expected to recover completely (Blackhall, 1987). Over time, the procedure has become refined and technology more sophisticated (Gulati et al). Gradually, the trend has changed, so that current standards of practice in many hospitals dictate that CPR be performed on all patients who have not specifically requested that it be withheld (Lee & Cassel, 1984; Youngner, 1987; Blackhall, 1987). Youngner points out that it is the only medical intervention that can be performed by non-physicians without a physician's order.

In the mid-1970s there was increasing concern that, for certain classifications of patients, CPR imposed more burden than benefit and

that long-term survival rates were low. Concurrently, there was increasing interest in patients' rights. Hospitals and medical societies began establishing guidelines for making decisions to withhold CPR. These generally addressed decision-making for competent patients, for incompetent patients, and procedures for implementing the decision. It is almost universally agreed that competent patients have the right to refuse CPR. For incompetent patients, most guidelines require that family agree to the decision to withhold CPR. Most policies also require documentation in the progress notes of the medical record of factors involved in the decision-making process. All guidelines require that the physician write a medical order to withhold CPR (Lee & Cassel, 1984).

DeBard (1981) conducted a study of CPR covering six years and 1,073 cases. The study results showed that 24% of patients survived to discharge. The average age of these patients was 58. Most cases reflected patients who had a cardiac arrest in the emergency department, so that although DeBard suggested that age should not be a criterion for resuscitation, the study is not reflective of circumstances in a long-term care setting.

Fusgen and Summa (1978) studied resuscitation attempts on 335 patients, of whom 239 were over the age of 60. The average length of survival for all patients was 2.4 days. Twenty four patients (7%) were discharged after four to ten weeks of care. Of these, 18 (5%) survived for at least six months. No direct relationship was found between age

and chance of survival, but the authors stated that multiple pathology does seem to have a negative effect on survival.

Gulati, Bhan, and Horan (1983) reported outcome of attempted CPR in 52 hospitalized elderly patients (mean age 75.6 years). All had been living in the community prior to hospitalization. Patients with chronic illness who were totally dependent on nursing care and those with severe dementia were excluded from this study. Although 14 patients survived initially, five died in the first week after the resuscitation. At the end of a month, nine (17%) were living; of these, seven had been discharged. The authors stated that the outcome is affected by patient selection, speed of the response to the arrest, as well as by the cause of the arrest.

Limitations to the use of CPR have been proposed by Blackhall (1987). He suggested that CPR should not be considered an option for patients to whom it offers no benefit and that families be informed that it may only prolong the dying process and cause the patient to be subjected to more invasive procedures in the stressful environment of an intensive care unit. Besdine (1983) suggested that CPR may not be appropriate for most residents of long-term care facilities. First, there is limited ability to detect and treat an arrest without the technology available in the acute hospital setting. Second, there is the fact that many of the residents have chronic, progressive illness and decline.

Levinson, Shepard, Dunn, and Parker (1987) surveyed 76 nursing

homes in Portland, Oregon. Of the 57 facilities responding, only 23 (41%) had a policy regarding CPR. Respondents from 19 (70%) of the 32 facilities that did not have a policy agreed that a policy was needed.

Several authors stated that having a no-CPR order--also known as a do-not-resuscitate (DNR) order--or another order to limit the kind of treatment offered, should not affect the attentiveness of care (Besdine, 1983; Lee & Cassel, 1984; Lo & Jonsen, 1980; Lo & Dornbrand, 1984). Shelley, Zahorchak, and Gambrill (1987) studied the effect of both having a DNR order and being old by presenting vignettes to 95 staff nurses at four metropolitan sites and measuring attitudes using a Likert scale. They replicated this study with 183 nursing students and 86 intensive care nurses. With all groups, they found that both variables reduced the aggressiveness of care given, but only to the "moderately aggressive range." Their study also found that comfort and rest were given preference over more aggressive measures for patients with DNR orders.

Schwartz and Reilly (1986) surveyed house officers after the death or discharge of patients with DNR orders. Questionnaires on 71 (75%) of 95 instances of DNR decisions were returned. They reported that 27 (38%) of these patients were believed to have received less aggressive care due to having the DNR order. Patients with DNR orders differed from age- and sex-matched controls in having longer hospital stays, residing in long-term care facilities, having metastatic cancer, being incontinent, and having an abnormal mental status on admission.

Do Not Hospitalize

A decision not to hospitalize a resident of a long-term care facility has considerable implications for the kind and aggressiveness of care that will be provided (Lynn, 1986b; Besdine, 1983). Lynn suggested that there is a wide variation in the types of treatment available within long-term care settings which then impose constraints on what can be provided. She offered the example of intravenous therapy, which is available in some, but not all, long-term care facilities. The reasons offered for limiting care to what can be provided in the long-term care setting involve questions of burdens or risks versus benefits. For the demented, elderly person the hospital may be confusing and frightening (Besdine; Rango, 1985; Volicer, Rheaume, Brown, Fabiszewski, & Brady, 1986) and may subject the patient to increased use of restraint (Volicer et al). Hospitalization may increase the risk of falls, infections, and adverse drug reactions (Besdine, 1983). Finally, the medical intervention for which the patient was hospitalized may be painful and invasive (Besdine; Rango).

Do Not Treat

During a visit to a nursing home patient with apparent pneumonia, Hilfiker (1983) took note of his deliberations about the degree of aggressiveness of treatment that would be in her best interest. He reached the conclusion that decisions to withhold treatment were being made, but not being openly discussed. He proposed the need for open discussion so that a consensus could be reached and guidelines

established for such patients.

Hirsh (1983) also addressed the need for guidelines in establishing policies regarding appropriate treatment for terminally ill incompetent patients. He acknowledged that physicians do give instructions that patients should just be kept comfortable, but added that these were not always a part of the medical record. The guidelines he presented, developed by four state medical societies, address orders to withhold CPR, but do not address limiting other kinds of therapy.

Brown and Thompson (1979) conducted a retrospective study of nontreatment of fevers in nine long-term care facilities. During the two year period of the study, 190 of 1256 patients experienced a febrile episode considered to be a serious fever. Eighty one (43%) of these patients did not receive active treatment, defined as treatment with antibiotics, hospitalization, or both. Factors significantly associated with non-treatment included a primary diagnosis of cancer, mental state (alert, confused, or comatose), being bed-ridden and in pain, or notations in the medical record of either general deterioration or plans for non-treatment. Twenty three of the untreated patients had chart notations indicating a non-treatment plan if the patient should develop a serious illness. The best predictor of non-treatment was documentation of general deterioration in the patient's condition. The nurse did not notify the physician in 20 instances of fever. Brown and Thompson considered this to be a deliberate non-treatment decision on the part of the nurse, either autonomously, or because of knowledge of

an undocumented plan to withhold treatment.

Miles and Ryden (1985) surveyed a random sample of long-term care facilities in Minnesota to determine if they accepted orders to limit treatment. They also requested a copy of the facility's policy regarding such orders, if the facility had one. Of 135 facilities responding, 22 had such policies, and 20 sent them. Approximately 70% of the responding facilities accepted DNR orders and 73% accepted limited treatment orders. However, only 14% had a policy on CPR and 16% had a policy regarding limited treatment. Of the 14 facilities with CPR policies, 11 were from facilities attached to hospitals.

Limited treatment protocols emphasized quality of life and recognized the importance of family relationships, comfort, and hygiene as objectives. Nearly half also indicated that another objective was to allow death to occur. Resuscitation and hospitalization were usually either prohibited in the protocol or directed to be addressed by the physician's orders (Miles & Ryden, 1985).

Nutrition and hydration. Of all the decisions to be made regarding limiting treatment, the decision to withhold artificial nutrition and hydration seems to be one of the most difficult and controversial. The symbolic meaning of nourishment is frequently mentioned when the question is raised (Dresser, 1985). Lynn and Childress (1983) pointed out the psychological links between feeding and loving, and nutritional and emotional satisfaction. However, as with all medical procedures, there are risks and burdens associated with

provision of artificial nutrition and hydration. Because medical means of providing nutrition and hydration are intrusive and carry risks, Dresser (1985) said that they should be considered in the same light as other medical treatments. Artificial hydration can be provided by a peripheral intravenous (IV) infusion. Both Zerwekh (1984) and Billings (1981) have observed that the principal discomfort associated with dehydration in terminally ill patients is thirst and a dry mouth. They recommended that this can be adequately managed by either small amounts of oral fluids or by some other method of moistening the mouth. Billings stated that for a dying patient, intravenous therapy is not indicated to provide comfort. Zerwekh suggested that dehydration may have some benefits for the terminally ill patient by decreasing frequency of urination, decreasing congestion and choking, and decreasing awareness and perception of suffering.

In any case, peripheral IV therapy is only a temporary solution to the problem of inadequate hydration and nutrition. To provide sufficient calories and other nutrients intravenously for an extended period of time, a special kind of intravenous catheter must be inserted into a major vein. This procedure carries some risk, is expensive, increases the risk of infection, and may require that the patient be restrained (Lynn & Childress, 1983).

Tube feeding is another method of providing nutrition or hydration for patients unable to meet their needs by oral feeding. Either a nasogastric (N/G) tube or a gastrostomy (G/T) tube may be used for this

purpose. In a survey of directors of nursing service and medical directors or house physicians in Oregon nursing homes, Watts, Cassel, and Hickam (1986) found that there was general recognition that the burdens to the patient of tube feeding might sometimes outweigh the benefits. The N/G tube is often uncomfortable and annoying to the patient, may have to be reinserted repeatedly in a patient who removes it, may lead to pneumonia, and often requires that the patient be restrained or sedated (Lynn & Childress, 1983; Lo, 1984). The G/T tube requires a surgical procedure to insert and remove (Lynn & Childress).

Norberg, Norberg, and Bexell (1980) described the "double-bind" caregivers experience in feeding patients with advanced dementia. This involved feelings of guilt when they had to force patients to eat or when they had to use invasive methods to feed them. The caregivers also felt guilty when they did not make an aggressive effort to feed their patients. The authors speculated that this might lead to emotional distancing from the patients, affecting the quality of care. Lo (1984) expressed the concern that artificial feeding methods may also cause caregivers to focus on the procedure rather than the patient, depriving the patient of some comforting contact. He recommended that physicians and family should determine the goal of artificial nutrition. This might be prolonging life, providing calories, or providing comfort. If the goal is comfort, he suggested that hand feeding, although it may provide inadequate nutrition, may advance achievement of the overall goal by meeting the patient's psychosocial needs.

Guidelines For Limiting Treatment

Guidelines for limiting treatment to patients in a multi-level geriatric facility were described by Levenson, List, and Zaw-Win (1981). The facility included acute care beds and had a working relationship with a nearby hospital. Decisions were made for each patient about what should be done in the event of critical illness, terminal illness, witnessed cardiac arrest, and unwitnessed cardiac arrest. Four classes of treatment were established ranging from maximum therapeutic effort to comfort-based, supportive care. The protocol included an assessment of the patient's ability to be involved in decision-making. If it was determined that the patient was not capable, the family was asked whether the patient had ever expressed any wishes that would guide decision-making.

A hospice approach was used for patients with dementia of the Alzheimer's type in an intermediate care center attached to a research center and clinic. Five levels of care were established from full resuscitative effort to supportive care only (see Table 1). After a multi-discipline team had evaluated a patient, a care conference that included the family was held, and a decision was reached about an appropriate level of care. Family members were encouraged to express their knowledge of the patient's wishes. The plan of care, based on the level chosen, became part of the patient record. The decision would be reviewed monthly and the family conference might be reconvened if the patient's condition changed or at the family's request

Table 1 Levels of Care Provided to Patients With Dementia of the Alzheimer's Type (adapted from Volicer et al, 1986)

Care Provided	Level 1	2	3	4	5
CPR	x				
Transfer to acute care facility, if needed	x	x			
All usual diagnostic studies and treatment	x	x	x		
All usual treatment except diagnostic studies and antibiotics				x	x
Tube feedings	x	x	x	x	

(Volicer et al, 1986).

Lynn (1986a) voiced concern that such a rigid classification might not meet the objective of keeping patients comfortable, using a urinary tract infection accompanied by severe dysuria as an example. She suggested that time-limited trials of treatment might be an acceptable option, with the treatment being withdrawn if it was felt that the burdens outweighed the benefits.

A group of concerned professionals in Minnesota formed a task force and published recommendations and guidelines for a supportive care plan for residents of long-term care. These guidelines were derived after discussions with various groups concerned about quality of care in the long-term care setting, including physicians, social workers, resident advocates, nursing home professionals, clergy, and those responsible for surveillance of the facilities. Supportive care was defined as provision of care and medical treatment that preserves comfort, hygiene, and dignity, but does not prolong life (Task Force on Supportive Care, 1984).

The guidelines proposed by the Task Force recommended institutional policies regarding issues surrounding supportive care. The decision for supportive care should only be made after thorough discussion with all parties concerned. This should include the resident to the degree that he is able to participate, and should respect his values and philosophy. These discussions should be fully documented. The Task Force recommended the use of advance directives and proxy decision-making by someone who is

aware of the patient's wishes. It also said that each supportive care plan should be individualized and be written as a set of explicit medical orders by the physician stating exactly what would and would not be done.

Finally, the Task Force recommended liberal guidelines for review of the plan: at least every 30 days, when the condition of the resident changes, or when any of those involved in the decision deem it advisable (Task Force on Supportive Care, 1984).

Summary

Decisions are being made to limit the treatment offered to some residents of long-term care facilities. Decision categories include resuscitation, hospitalization, and definitive treatment, including artificial nutrition and hydration. The long-term care setting imposes some constraints on what can be offered. For instance, there may be limited ability to resuscitate a patient and some treatments, such as IV therapy, are not offered in some facilities. Several attempts have been made to develop guidelines for provision of comfort-based, supportive care for chronically ill elders who are mentally-impaired. However, there has been very little research to determine whether such guidelines are being used.

Family Involvement in Decision-making

Societal Expectations

The family is a fundamental institution in our society. As such, it is mandated by society to make choices for its' incompetent members, even though families may use a less exacting standard of decision-making than

the courts would use if no family were available (Veatch, 1984). According to O'Rourke (1988), proxy decision-making by families is a cross-cultural phenomenon. It is presumed that shared love will lead to decisions in the patient's best interests and that the decisions made will reflect the wishes of the patient, if the family knows them, since family members are most likely to be familiar with the patient's previous life-style and attitudes and to best appreciate their present level of suffering (Volicer et al, 1986).

Medical Custom

In the practice of medicine, too, it has been customary to turn to the family to make decisions for patients who are incapable of deciding for themselves (Areen, 1987). The American Medical Association's Council on Ethical and Judicial Affairs specifically mentions the family first in considering who may act on behalf of an incompetent patient (Dickey, 1986). The involvement of family in decision-making for incompetent patients permeates the literature on making limited treatment decisions. There is, of course, the possibility that families might act in bad faith, for whatever motives. That consideration is beyond the scope of this paper and, for purposes of this discussion, it will be assumed that families act in the best interests of their incompetent member.

Four ways in which families might contribute to the decision-making process have been proposed: 1) by providing written evidence of the patient's wishes; 2) by providing insights into the patient's lifestyle; 3) by providing an assessment of what would be in the best interests of the

family; and 4) by providing an assessment of what would be in the best interests of the patient (Sherlock and Dingus, 1985).

In the ideal situation, a surrogate has been appointed in advance by the patient, since the surrogate may be called upon to administer a life or death trust. If that is not the case, the person who knows the patient best should fulfill that trust, usually a spouse or other family member (Uhlmann, Clark, Pearlman, Downs, Addison, and Haining, 1987).

Research on Family Involvement in Decision-making

Lo, McLeod, and Saika (1986) studied three groups of patients to determine if they had considered advance directives or surrogate decision-makers in case they became demented and unable to direct their own care. Two groups had cancer or serious chronic illness; one group was younger than 65 and the other group was 65 years old or over. The third group was 65 years old or over, but without a serious illness. They found that 66% of the 152 patients had given considerable thought to a surrogate decision-maker. Of this group, 79% wanted relatives to serve in this capacity. There was a significant difference by age in that more older patients than younger patients had considered the matter.

Substituted judgment is the attempt to make the decision that the patient would make if able, and is the recommended standard for decision-making. Uhlmann, Pearlman, and Cain (1988) studied the accuracy of spouses as surrogate decision-makers in predicting patients' preferences for CPR and CPR plus a ventilator, given scenarios of baseline health or hypothetical illness. They found that accuracy of the spouses' predictions

did not exceed that predicted by chance in three of six scenarios. They suggested, however, that more detailed scenarios and increased opportunity for discussion regarding such decisions between patients and surrogate decision-makers might increase the level of agreement. They concluded that more research is needed to determine what factors would increase accuracy of substituted judgement.

The Law

Areen (1987) summarized the current legal status of family involvement in decisions to withhold treatment. Court decisions in five states, including Arizona, California, Connecticut, Florida, and Washington, have authorized families to make decisions to withhold or forego treatment. Massachusetts courts have recognized the rights of families only insofar as to approve a DNR order. Eleven states have statutes allowing families to withdraw or forego life-prolonging treatments for certain types of patients. In nine of these states the patient must be considered to be terminal as well as incapable of making a decision. Most of the statutes mandate providing comfort care but there is disagreement on whether artificial hydration and nutrition is life-prolonging or a comfort measure. In Oregon, nutrition must be provided to patients as long as it is determined that the patient can medically tolerate it.

Most state statutes establish a priority list of family members from whom consent can be obtained to withhold or withdraw treatment: 1) a court-appointed guardian, 2) spouse, 3) adult child or majority of adult children, 4) either parent. Other states add siblings, nearest living

relative, and one state requires that all family members that can reasonably be contacted be in agreement. The statutes generally do not address what standard the family is to use in making such a decision (Areen, 1987).

The courts use two standards in order to make decisions. The first is commonly referred to as substituted judgement. This is an attempt to reach the decision the patient would have made, if competent. It uses written directives or other written evidence of the patient's wishes which might include a living will, a written communication to an attorney, physician, or even part of a letter written to a friend or family member. The next best testimony would include verbal statements that the patient had made at a prior time that would indicate his/her wishes. Lacking such information, the second of the two standards, often called best interest, may be used by the courts. Under this standard, the surrogate decision-maker is asked to weigh the burdens and the benefits of treatment and make a determination of what would be in the patient's best interest (Dresser, 1985; Sherlock & Dingus, 1985).

Families and Nursing Homes

There is very little research on the involvement of families with residents of long-term care facilities and it is agreed that research in this area is much needed (Brody, 1986; Hirst & Metcalf, 1986). Smith and Bengtson (1979) interviewed 100 residents of a multi-level care facility and the adult child most involved with each resident to discover the effect of institutionalization on the relationship. They found continued

closeness, renewed closeness, or discovery of new love and affection in 70% of the families studied. Ten percent were involved, but described the involvement as quantity rather than quality interaction and 20% continued a former pattern of separateness.

Brody (1986) identified nine roles fulfilled by family members of non-institutionalized elderly. These included sharing a home or helping the elder maintain a home, giving personal care, providing medically related care, instrumental services, financial support, money management, affective support, mediation and advocacy with formal systems, and participation in decision-making. According to Brody, advocacy/mediation and participation in decision-making continue once the elder is institutionalized but the roles are not well defined; not only is there little information on what families do, there is general disagreement about what they should do.

Pratt, Schmall, Wright, and Cleland (1985) studied perceived burden in 240 caregivers to Alzheimer's disease patients. Thirty eight percent of the patients were in institutions at the time of the study. No significant differences were found in burden scores between this group of caregivers and the group with the patient living in the community. They suggested that this might be due to feelings of failure and guilt at having to relinquish the care of their relative to an institution. However, it would be interesting to study the effect of decision-making and advocacy responsibilities on perceived burden. It may be that these responsibilities contribute to the perceived burden of the caregivers.

Summary

The legal system reflects the cultural expectation that families are the best decision-makers for their members who are unable to make decisions for themselves. Current medical practice also relies on the family when making decisions about treatment for mentally-impaired elderly. However, little is known about the way that families are involved in these decisions when the elder is a resident of a long-term care facility.

The Role of the Nurse in Decision-making About Limiting Treatment for Nursing Home Residents

A review of the literature suggests a somewhat different role for the nurse in long-term care than is usual in acute care settings. The nurse functions with more autonomy in long-term care (Watts, Cassel, & Hickam, 1986) with responsibility for the day-to-day maintenance of the patient (Curran, 1985; Thompson, Pender, & Hoffman-Schmitt, 1987). Patients are seldom seen by physicians except when there is a change in their condition (Curran; Watts, Cassel, & Hickam). According to Brown and Thompson (1979), nurses in long-term care have considerable responsibility for decision-making and often influence the decision made by the physicians when consulted. They suggested that this may be due to their close proximity to the situation, opportunity for communication with the patient and the family, and their long experience with the patient.

Cassel & Jameton (1981) noted that management of the severely demented patient is documented in the nursing literature rather than the medical literature and added that it is unfortunate that more physicians do

not read the nursing literature. When considering decisions to limit treatment for these patients, there is general agreement that the nurse, as the one closest to the patient and his family both emotionally and physically, is in the best position to know their wishes (Lo, 1984; Bandman & Bandman, 1979; Olson, 1981). The nurse can also best assess the patient's level of enjoyment or suffering (Rango, 1985; Watts, Cassel, & Hickam, 1986). The nurse is a logical person to be involved in the decision-making process since it is the nurse who will have to implement the plan of care (Lo, 1984; Rango, 1985) and may be called upon to answer questions and explain decisions (Lo).

Watts, Cassel, and Hickam (1986) surveyed directors of nursing service and house officers or medical directors of Oregon nursing homes. The respondents, 124 physicians and 157 nurses, had been presented with three scenarios in which the age, mental status, and enjoyment of life of hypothetical patients varied, to determine attitudes towards tube feeding. They found that the nurses favored tube feeding more often than physicians. There was a non-significant trend against tube feeding with increasing years of experience for both nurses and physicians. Among patient variables, enjoyment was the strongest predictor, followed by patient age for responses from both professions. The patient's mental status was found to affect decisions made by physicians, but not by nurses. The authors speculated that nurses may have more contact with demented elderly patients and may be less willing to associate dementia with lack of enjoyment or poor quality of life. They also noted that feeding patients is one of the

primary nursing functions in long-term care and that nurses form attachments to the patients whom they feed.

The Nurse as Advocate

Brock (1982) listed six roles nurses may enact in their relationship to patients. One of these is patient advocate. Lumpp (1979) stated that the advocacy relationship has two components, fidelity and reverence. Reverence refers to awe or respect for individual dignity and personhood. Fidelity reflects the nurse's covenant or agreement to serve the patient's interests. This requires that the nurse know the patient's values and goals.

According to Gadow (1979), the primary focus of advocacy should be helping patients to exercise their freedom of self-determination. For the severely demented patient, this may be interpreted to mean that the nurse must find a way for the patient's values and goals to be considered, as decisions about care are being made. Miller (1972) saw nurses as having a legitimate role in the process of decision-making for residents of institutions, since they essentially live with those residents on a day-to-day basis, and come to assume a relationship similar to family. He recommended that the institution, represented by nursing staff, function as an advocate of the patient.

Summary

The nurse in long-term care is likely to be more autonomous and to have a closer relationship with patients and their families than the nurse in the acute care setting. Because of this, the nurse may have a role in

decision-making as patient advocate.

Conclusion

In the rapidly growing bio-ethical literature, there is very little specific to the long-term care setting. Considerable research has been done on CPR in acute settings. The consensus seems to be that while age itself may not be a factor affecting successful outcome, underlying chronic illness and speed of response to an arrest both affect outcome. The population in long-term care is at risk on all three counts. Two studies indicated that less than half of long-term care facilities have DNR policies.

Brown and Thompson (1979) conducted the only known study of decisions not to treat residents in long-term care. They assumed that non-reporting of febrile episodes of long-term care patients were deliberate non-treatment decisions on the part of the nurse. That seems to be a questionable assumption. However, other literature does support non-treatment decision-making in long-term care facilities. Several articles described levels of care on a hierarchy from full resuscitative effort to comfort-based, supportive care. A group in Minnesota developed a set of guidelines for supportive care plans. One study (Miles & Ryden, 1985) found that 16% of long-term care facilities had policies regarding limited treatment care plans. In all, very little is known about how decision-making regarding limited treatment of residents of long-term care facilities occurs.

Few studies have been done regarding the involvement of families of

residents of long-term care facilities. One study (Smith & Bengtson, 1979) found that most families continued a positive relationship with their institutionalized member. Brody (1986) reported that family roles as advocates or mediators and decision-makers continued after placement of the impaired elder in an institutionalization. Although Pratt et al (1985) found that perceived burden on the part of caregivers continued after institutionalization of their family member, contributing factors are not known. The possibility exists that decision-making, the life or death trust described by Uhlmann et al (1987), contributes to perceived burden.

Cultural expectations and current practice dictate that family should be involved in decision-making for incompetent patients. One study confirmed that most patients want family members to serve as surrogate decision-makers (Lo, McCleod, & Saika, 1986). Both state statutes and court decisions have upheld the rights of families to make decisions for patients unable to decide for themselves. Although the courts use the standards of substituted judgement and best interest, there are no guidelines specified for families to use in making such decisions.

It is suggested that nurses in long-term care settings are more autonomous than their counterparts in acute care settings. However, it is not known how much responsibility or involvement the nurse may have in decision-making for long-term care residents. Because the long-term care nurse is in close proximity to patients for an extended period of time, it is assumed that there is increased likelihood of developing awareness of the patients' values and goals and those of the family. Whether this

assumption is valid is not known. There are no studies describing the role of the nurse in helping families with decision-making for mentally impaired elderly residents in long-term care. However, several authors have suggested that the nurse assumes an advocacy role for the long-term care resident (Brock, 1982; Gadow, 1979; Miller, 1972).

CHAPTER III CONCEPTUAL FRAMEWORK

Introduction

Ethical decision-making is a complex and difficult process. In part, this is due to the lack of a common framework. There are two major ethical systems or theories that may be used. In addition, decision-making will be affected by the religious traditions of the decision-makers and the prevailing political philosophy (see Appendix A). The values and goals of those involved in the decision will be weighed within the system that is chosen.

This section will present the recommendations of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research relevant to decision-making for patients in long-term care facilities. It will suggest that these recommendations are congruent with the triple contract theory of ethics proposed by Veatch (1981) to resolve differences in ethical frameworks.

The Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

In 1983 the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research submitted an additional report, Deciding to Forego Life-Sustaining Treatment, to those originally commissioned. It was an outgrowth of earlier studies of the issue of informed consent and the definition of death. Pertinent topics in the

report include guidelines for decision-making, recommendations for institutional policy, and a discussion of supportive care for dying patients.

The Triple Contract Theory of Ethics

Veatch (1981) proposed the triple contract theory as a solution to reconciling diverse ethical frameworks used to consider the ethics of the physician-patient relationship. The contract, to be negotiated between the physician and the patient, would have three levels. The first level of the contract would agree on the basic principles and system to be used between any two people to make an ethical decision. For this level, Veatch suggested the use of an objective test in which the decision-makers consider whether they would be willing to have the same decision made for themselves. The second level of the contract specifies the role-specific duties and obligations of the professional to the patient. The third level of the contract is a negotiated agreement between the individual professional and the individual patient to determine the exact terms of the relationship in their particular case. The report of the President's Commission seems to be recommending policies that would establish such a third level contract between patients or their surrogates, and the caretaking facility.

Recommendations of the President's Commission

Guidelines for Decision-making

In keeping with its' earlier recommendations, the President's Commission recommended that decision-making should be a joint effort of the

patient and the care-providers, and that decisions should be made voluntarily. Only a patient having decision-making capacity can make such a voluntary decision. Determining the decision-making capacity or incapacity of the patient requires taking into account the abilities of the patient, the requirements of the decision-making task, and the consequences of the decision. The patient must be able to understand information relevant to the decision, must be able to communicate with the care providers, and must be able to reason and consider alternatives relative to his goals and values in life.

For patients who do not have the capacity to make their own decisions, the President's Commission (1983) recommended that a surrogate decision-maker should be appointed. They noted that this will usually be a family member, and, in most instances, the procedure for appointing such a surrogate will take place outside of the legal system. The surrogate, taking into account the values and goals of the patient, should then try to reach the same decision that the patient would have made, had he retained decision-making capacity.

Institutional Policy

Facility policies should take into account the fact that institutionalization and the institution impose some constraints on the patient. Since institutionalization itself imposes constraints on the patient, it should be determined if the patient has alternatives to being in the institution. Since the range of services available in a given institution may be determined by the reimbursement available to it,

constraints on the range of options available to the patient may be imposed by placement in a particular facility. Because there is such a wide variation among long-term care facilities, the President's Commission (1983) suggested that each facility should have the obligation to inform residents and their families about facility policies and practices, their philosophy or biases, and any constraints--both before residents are admitted, and during their stay.

Policies in long-term care facilities should promote good decision-making, including consideration of who determines decision-making capacity or incapacity, what standards will be used, and how surrogate decision-makers will be determined. These policies should conform to the guidelines suggested above (President's Commission, 1983). To the present, the availability of decision-making protocols has not been a consideration in evaluating the quality of long-term care facilities.

Supportive Care for Dying Patients

The President's Commission (1983) recommended goals for supportive care of dying patients. These included competent care--including diagnosis, treatment, and prognosis--, control of symptoms, promoting the ability of the patient to advance his life goals, maintaining trust, providing help to the patient's significant others, and the use of a team approach to comprehensively meet the patient's needs. Meeting these goals would require a care plan taking into account the physiology of organ-system failure. It is also important that communication be maintained with the patient and the family, so that decision-making can be enhanced

throughout the dying process.

Summary

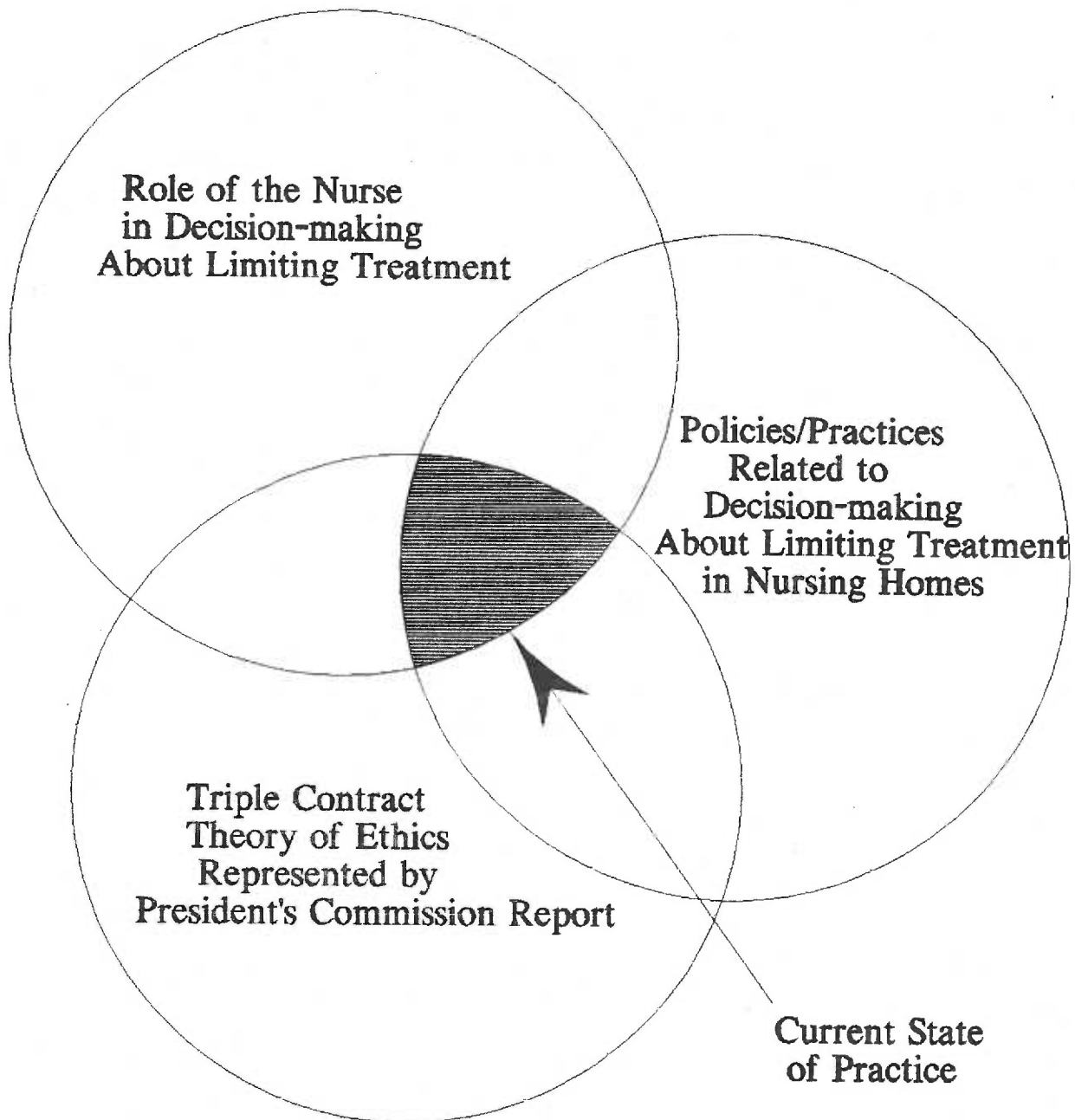
Decision-making for incompetent patients is made difficult by the diverse ethical systems and principles that can be used to make such decisions. The factors being weighed may be considered within either of two major ethical systems, and will be affected by the religious and philosophical ideology of the decision-maker. For this reason, it is important for decision-makers to be familiar with the values and life goals of the patient for whom the decisions are being made. The recommendations of the President's Commission (1983) are consistent with the third or negotiated level of Veatch's (1981) triple contract theory of ethics.

The President's Commission (1983) recommended that long-term care facilities inform residents and their families of their philosophies of care and make them aware of constraints imposed by institutionalization and the limits of the particular institution. The Commission recommended that facilities develop policies which provide for determination of decision-making capacity and outline a system for designation of a surrogate decision-maker. Facilities should also develop care plans which address the needs of dying patients and their families, allowing for communication throughout the dying process.

The literature reviewed for this paper reflects an awareness that limited treatment decisions are being made for elderly persons, many of whom are mentally-impaired, in long-term care facilities. The literature also suggests a role for the nurse in long-term care facilities as a

patient advocate in such decision-making. The President's Commission provides a framework for making decisions for mentally-impaired patients in long-term care facilities.

This paper proposes research that would explore the overlap of these areas, represented figuratively in Figure 1, and answer questions about limited treatment policy, the role of the nurse in decision-making, and how policies compare to the guidelines established by the President's Commission.



**FIGURE 1. Conceptual Framework for Studying Decision-making
About Limiting Treatment in Nursing Homes**

Research Questions

This paper proposes an exploratory study of policies and nursing practice in long-term care facilities to answer the following research questions:

1. To what extent do nursing home facilities have guidelines, standards, or policies about making decisions to limit treatment to residents?
 - a. What is the content of the guidelines standards, or policies?
 - b. What similarities or differences exist in the guidelines, standards, or policies across facilities?
 - c. Is the content congruent with the guidelines of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research?
2. What are the roles of the nurse in making decisions to limit treatment to residents in nursing homes?
 - a. In what ways are nurses involved in making decisions about limiting treatment to nursing home residents?
 - b. Are the roles congruent with the facility's written or stated guidelines, standards, or policies?
 - c. Are the roles congruent with the guidelines proposed by the President's Commission for the Study of Ethical

Problems in Medicine and Biomedical and Behavioral
Research?

CHAPTER IV

METHODS

Design

Because of the lack of research in this area, an exploratory study was undertaken. Survey methods were used to interview nursing personnel in nursing home facilities licensed to provide skilled care. Interviews were conducted in person instead of by telephone because it has been suggested that this method establishes a rapport that yields a better response (Polit & Hungler, 1987). Although this limited the size of the sample that could be studied, the sensitive nature of the subject seemed to warrant the use of personal interviews. Respondents were asked about the ways in which they have been involved in decision-making about limiting treatment. A copy of the facility's policy on decision-making about life-sustaining treatment was solicited from the facility that had one. Other materials related to decision-making about limiting treatment were solicited from facilities where they were being used.

Subjects and Setting

A current list of long-term care facilities providing skilled or intermediate levels of nursing care was obtained from the Area Agencies on Aging for three metropolitan counties in Oregon. To increase the likelihood that the staff had had experience with decision-making about limiting treatment, the sample was limited to facilities licensed to provide skilled care. It was assumed that these facilities would employ more licensed staff and have the ability to provide a wider range of

options in terms of treatments. Two of the twenty skilled facilities were excluded from the list of potential study sites; one facility cares only for children and the other was the facility where the investigator is employed.

Subject Selection

Subject selection was done in two stages. In the first stage, the director of nursing (DNS) in each of the potential study facilities was contacted by phone and the study was explained. If the DNS agreed to participate, she was asked to suggest one or more nurses in the facility who could be contacted to make up the other half of the dyad. An attempt was made to obtain phone numbers for the nurses and contact them separately, in order to prevent any feelings of coercion related to participation of the DNS. However, this was not possible, since facilities did not give out staff phone numbers. Therefore, the nurses were also contacted at the facility. It was explained to both the DNS and the nurse that facilities would be included in the pool of potential sites if both the DNS and a nurse in the facility agreed to participate. There was only one facility in which it was not possible to obtain verbal consent from both the DNS and one nurse.

In the second stage of subject selection, the 17 remaining facilities were included in a random drawing. The first nine facilities on the list were designated as study facilities. The DNS in one of these facilities decided against participating in the study at the time she was contacted to schedule the interview. The next facility on the randomized list was

selected to replace this facility.

Sample Characteristics

The sample of facilities was heterogeneous in terms of bed capacity, sponsorship, and profit status. Total bed capacities ranged from 64 to 281 with a mean of 133. Five (56%) of the facilities were non-profit and four (44%) were run for profit. Three (33.3%) of the facilities were part of a multi-facility chain, two (22.2%) were private corporations, two (22.2%) were sponsored by hospitals, and two (22.2%) were sponsored by religious groups. The geographic distribution was representative of the sampling frame with 78% of the sample selected from the county that had 80% of the total number of facilities and 11% of the sample from each of the other counties which had 10% each of the total number of facilities.

Description of Subjects

The subjects were dyads consisting of the Director of Nursing Service (DNS) or the Assistant Director and one Patient Care Manager nurse (PCM) from each long-term care facility chosen to participate in the study. The DNS from each facility selected for the study was asked to recommend nurses from the facility who had had experience with making decisions about limiting treatment. Subjects were allowed to choose the location where they were interviewed; all elected to be interviewed at the facility where they worked. Total long-term care experience of the DNS ranged from 3 to 17 years, with a mean of 8.7 years. One had only served as DNS in her facility for one week; the longest time as DNS at a facility was 10.5 years. One (11.1%) of the DNS had a master's degree in nursing, four

(44.4%) had bachelor's degrees, two (22.2%) had associate degrees, and two (22.2%) were graduates of diploma programs.

The mean length of long-term care experience for the PCMs was 9.77 years, ranging from 6 to 17 years. Length of time as PCM in the study facility ranged from a few weeks to 7 years, with a mean of 2.9 years. Four (44.4%) of the PCMs were responsible for Medicare units, three (33.3%) were responsible for all of the facility units, and two (22.2%) were responsible for intermediate (ICF) level patients. One, who also served as education director, had a master's degree in nursing, two (22.2%) had bachelor's degrees, two (22.2%) had associate degrees, and four (44.4%) had diplomas in nursing.

Instruments

Interview schedules were developed and used for the interviews to ensure that the same areas of content were covered in the same way in each facility. The schedules were pretested in a long-term care facility for clarity, ability to elicit the desired information, and to determine the approximate length of time required for the interviews.

A questionnaire (see Appendix B) filled out by the DNS prior to the interview was used to collect descriptive information about the facility. Interview schedules (see Appendix C) consisting of both open and closed-ended questions were developed by the investigator and used to guide semi-structured interviews with the DNS and the nurse in each facility. A standardized introduction was included that provided an example of decision-making about limiting treatment. The interview guides for

the DNS and the PCM were identical except for a question for the DNS about notifying residents and families about services and differences in questions about facility policy and ethics committees that reflected assumptions about the differing roles of the PCM and the DNS. The interview asked about family conferences, experiences with decision-making about limiting treatment in the facility, policy regarding such decision-making, determination of decision-making capacity for patients, and supportive care of dying patients. Both the DNS and the PCM were also asked to respond to a vignette describing a patient for whom limited treatment might be considered.

The DNS was asked what information was given to families about what care could be provided in the facility. Both interviews included questions about whether there was an ethics committee in the facility. The DNS was asked about composition of the ethics committee, if the facility had one. Although both interviews asked whether there were policies or guidelines for decision-making about limiting treatment, the interview with the DNS asked how they were developed and the interview with the PCM asked for a description of them.

Data Collection Procedures

In one facility, the DNS agreed to participate if the interview could be done the same day; in this facility consent was obtained and the facility characteristics questionnaire was filled out prior to beginning the interview. In all other facilities letters (see Appendix D) and consent forms (see Appendix E) were mailed to the subjects after calling

the study facilities to schedule the interviews. The letters explained the study and the approximate time involved, and contained a reminder of the date and time of the interview. A short questionnaire describing facility characteristics was included with the material sent to the DNS so that it could be filled out before the interview.

Separate interviews were conducted with the DNS and the PCM and recorded on audio tape after confirming or obtaining informed consent, including permission to tape record the interview. Prior to beginning the interview, a verbal agreement was made with the interviewee that the interview could be terminated and the facility eliminated from participation in the study if either participant determined that continuing the interview might elicit information that would jeopardize the confidential nature of the interview. Code numbers were used to identify the interview schedules, audio tapes, and any written materials obtained from the facility. In order to maintain privacy and confidentiality, identifying information on materials was eliminated. The audio tapes were erased after data analysis was completed.

Data included descriptive information for each facility including facility size (number of beds), designated skill level, any affiliation with another institution, such as a hospital, teaching institution, or a religious organization, and whether the facility is profit or non-profit. The interviews with the DNS and the PCM elicited information about policies and current practices regarding limited treatment decision-making and supportive care. A standardized vignette was also used to determine how

nurses are involved in decision-making about limited treatment. A copy of the material on decision-making and the policy on life-sustaining treatment was obtained from the facility that had them.

Data Analysis

Data were analyzed both quantitatively and qualitatively. Research Question #1 was addressed using descriptive statistics to analyze the frequency with which facilities had written guidelines, standards, or policies relating to limited treatment and had written supportive care plans. The content of the written materials was described, compared across facilities, and compared with the guidelines of the President's Commission. Specific points of comparison with the President's Commission guidelines included: 1) informing patients and their families of limitations of the facility, 2) a means for determining decision-making capacity on the part of the patient, 3) a means for designating surrogate decision-makers, 4) joint decision-making involving the patient or a surrogate, health care providers, and the patient's family and 5) the use of care plans (including notations in the nursing notes) to address the needs of dying patients who would be receiving comfort-based, supportive care.

Research Question #2 was addressed using content analysis of material from the interviews with the DNS and the PCM. Notes were taken during the interviews and the audio tapes were reviewed to retrieve additional relevant material that could be used to derive information about the roles of the nurse, the nurse's interaction with families, and the nature of the

decision-making process. Categories were developed to describe the nurse's role in the decision-making process. Comparisons were made between the written guidelines, standards, or policies and actual practice, and between actual practice and the guidelines suggested by the President's Commission. The nature of the supportive care described by nurses was categorized and described.

CHAPTER V

FINDINGS

The findings will be discussed in relation to the research questions. For each question, a summary of the findings will be presented, followed by a more detailed description.

Research Question #1

Research Question #1 asked: "To what extent do nursing home facilities have guidelines, standards, or policies about making decisions to limit treatment to residents? The content of the policies, standards, or guidelines, similarities or differences among facilities, and their congruence with the guidelines of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research will be discussed. In addition, comments of nurses about the need for and use of policies are presented.

Summary of Findings

Four of the nine study facilities had written materials pertaining to decision making about limiting treatment. Two of them provided specifically for involvement of the resident or using knowledge of the resident's wishes. Written materials from three of the facilities specifically mentioned providing comfort, but none provided criteria that could be used to develop supportive care plans. In only one facility did the policy provide a means for determining decision-making capacity of the resident and guidelines for selection of a surrogate decision-maker. In all nine facilities, in varying degrees, practice reflected joint

involvement of families, resident, and health care providers in the decision-making process.

Content of Guidelines, Standards, or Policies

The content of written materials from the four facilities having them is summarized in Table 2. Only one of the facilities (Facility A) had a complete written policy regarding limitation of treatment. Written information accompanying the policy informed residents and/or families of treatment options and defined terms. The policy stated that the resident would be considered the primary decision-maker for health care decisions. It urged advance planning--ideally prior to admission--in terms of both consideration of the resident's wishes regarding life-sustaining treatment options and a choice of surrogate decision-maker should the resident become incapable of making decisions. For residents becoming incompetent as decision-makers without designating a surrogate, the policy provided a hierarchy of surrogate decision-makers based on their relationship to the resident and stated that surrogate decision-makers were to be guided by their knowledge of the resident's wishes. The policy recommended that consideration of resuscitation status and plans for treatment of medical complications should involve the facility staff, the resident, the family, and the physician. Included was a statement that the usual procedure would be to provide nutrition and hydration naturally except where the purpose of providing artificial nutrition/hydration was restorative. The

Table 2

Comparison of the Four Facilities With Policies or Written Materials
Related to Decision-making about Limiting Treatment

	Facilities			
	A	B	C	D
Written policy	Yes	No	C.P.R. only	No
Treatment options discussed with family	Yes	Yes	No	Yes
Decisions based on resident's wishes	Yes	Yes	No	No
Means for determining decision-making capacity	No	Yes	No	No
Encourage advance planning	Yes	No	No	No
Means for choosing surrogate	Yes	No	No	No
Supportive care mentioned	Yes	Yes	Yes	No

policy allowed for the withdrawal of medications other than those to provide comfort if it was the wish of the resident not to prolong dying. The policy stated that comfort measures and supportive care would be provided to residents even if life-sustaining treatment was withheld or withdrawn.

Congruence With Guidelines from President's Commission

The policy in Facility A is congruent with the guidelines of the President's Commission in informing residents and families of what is available in the facility, in providing a means for designating surrogate decision-makers, and in suggesting joint decision-making involving the resident, the family, and health care professionals. Although the policy mandates provision of supportive, comfort-based care for the dying, it does not specify what this would include. It does not suggest criteria for determining decision-making capacity of the resident.

Comparison of congruence with other facilities having written materials. Facility B, although it did not yet have a written policy, had developed forms that meet some of the criteria suggested by the President's Commission. An ethics committee in the facility was in the process of developing guidelines for CPR and continuing treatment.

At the time of admission, a list of treatment options in case of an acute change in condition is presented to the family. Families are encouraged to discuss these with facility staff, including social service and nursing staff, and to select options based on their knowledge of the resident's wishes. A copy of the form is sent to the

physician with an accompanying letter stating that the family will consult with the physician. After the form has been signed, the physician is requested to write corresponding orders on the resident's medical record and to provide a statement about the resident's competence in decision-making.

This process provides the family with information about what is available in the facility, provides for the physician to make a determination of the resident's decision-making capacity, and encourages involvement of the family, facility staff, and the physician in the decision-making process. There are no guidelines for designation of a surrogate decision-maker. There is no discussion of supportive care, although one of the options is the provision of "comfort measures only" in the nursing home.

Facility C had a briefly worded policy that discussed resuscitation procedures in the facility. It stated that full resuscitative measures could not be provided in the facility, that resuscitation would be discussed with family and physician, that family and physician would be consulted in case of a change in condition, and that residents would be kept comfortable at all times. This policy informs residents and families of one limitation in ability to provide service. Although it does not provide details, it suggests the need to provide supportive care for the dying. It also recognizes that decision-making will involve facility staff, physician, and family. It does not recognize or provide for involvement of the resident, provide a means of determining the resident's ability to participate, or establish

guidelines for choosing a surrogate decision-maker.

Facility D provided only a form on which the physician was to indicate preferences regarding resuscitation, mechanical ventilation, N/G tube feeding, and IV fluids, and a space where the physician could indicate with whom he had discussed the options, and a space where family members or a guardian could sign. Although this suggested the need to involve family in the decision-making process, it did not meet the criteria established by the President's Commission in the area of joint decision-making, or address decision-making capacity, designation of a surrogate decision-maker, or discuss meeting the needs of dying residents. According to the PCM, in actual practice in Facility D, the family was encouraged to make a decision about a decision-maker at the time of admission and the staff spent considerable time discussing treatment options with families and residents.

Nurses Perceptions About Policies

When nurses were asked whether they thought policies about limiting treatment were needed, two main concerns emerged. One related to concern at the corporate level. One DNS said, "It's opening a bag of worms 'cause the corporation would say that you'd always have to do everything." Another DNS said, "My understanding is that it's a concern that if we set up a system, that one, we could be accused of coercion; secondly, because states haven't been real consistent....I think it's the fear of litigation." In another facility, a policy regarding withdrawal of nutrition and hydration had been revoked and the facility had been advised to refer each case to the corporate attorney.

A second major area of concern about written policies was the necessity of allowing for individuality. "That is something that should not be put in writing because each situation has to be handled every minute and every day as uniquely--you cannot, you just cannot decide that everybody's going to be treated the same way," said one PCM. The DNS in another facility expressed concern about decisions being made at the time of admission:

I think it almost has to be an on-time thing because people, when they first come, they cannot make that decision....They really have a difficult decision just making the transfer, admitting their patient from the hospital to here...It's kind of like giving too much information to the person at the same time. They're overwhelmed. When they're ready for the information, then something needs to be discussed with them. And individually discussed, because everyone is different.

Another DNS said, "It has to be individualized, I think. If the director of nurses or the charge nurse communicates with the relatives, I don't think there is a need for it" [a written policy about decision-making].

Research Question #2

Research Question #2 asked, "What are the roles of the nurse in making decisions to limit treatment to residents in nursing homes?" Nurses' roles in decision-making about limiting treatment will be described in this section; in addition an analysis of their congruence with facility guidelines, standards, or policies and with the guidelines proposed by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research will be presented.

Summary of Findings

Five categories of nursing roles related to the instrumental process of decision-making about limiting treatment were identified by qualitative analysis of audio-taped interviews with the DNS and one PCM from each nursing home. These included facilitator, liaison, member of a decision-making team, documenter, and patient advocate. (See Table 3.) These roles were congruent with the written policy in the one facility found to have a policy. Nursing practice was found to be congruent with the guidelines of the President's Commission in the areas of promotion of joint decision-making and construction of care plans for dying residents. Nurses gave evidence of exercising vigilance in the matter of surrogate decision-makers. Although nurses seemed to advocate for participation of the resident in the decision-making process, there was no indication that nurses used objective means for determining the ability of residents to participate in decision-making. Because personnel in the admitting or social service departments usually

Table 3

Roles and Functions of the Nurse
in Decision-making about Limiting Treatment.

<u>Role</u>	<u>Function</u>
-------------	-----------------

Facilitator

- Raise the topic of limiting treatment
- Discuss treatment options with families
- Sanction decisions made by families
- Notify families of situations requiring decision-making
- Review and confirm prior decisions
- Support decisions that have been made

Liaison

- Refer families to physician
- Serve as communication link between resident, family, physician,
and facility staff

Member of the decision-making team

- Cooperate with other facility staff in assisting families with the
decision-making process

Documenter

- Document the decision-making process

Patient advocate

- Advocate for the wishes of the patient
- Advocate for appropriate decision-makers
- Advocate for treatment changes
- Monitor the quality of decision-making

discussed limitations of the facility, nurses did not usually have a role in this area, unless transfer to acute care was being considered.

Nursing Roles

Nursing involvement in the decision-making process. Nurses' involvement in the decision-making process incorporates two major functions. The first, which will be discussed very briefly, is monitoring of the patient's condition for indications of the need for decision-making and remaining sensitive to the individual needs of different families and the ways in which these change.

A recurring theme in discussing decision-making with nurses was the importance of knowing the resident and the family. "I think you've got to know your patient and if it's somebody that's been here a long time and I know the family, I think I know what they want" (PCM). "We do a lot of talking with our families" (DNS). "I usually have real good rapport with the spouse or that and we talk daily or sometimes two or three times a day" (PCM). When the nurse has identified an actual or potential problem necessitating decision-making, this knowledge may enhance sensitivity to the individual needs in each case. The options that are considered and the decision that is made may be based more on this awareness of individual needs and preferences than strictly on medical indications. In one instance related by a DNS, the resident was hospitalized, although treatment could have been provided in the nursing home: "She needed antibiotics which we could have done here, but for the family's peace of mind, hospitalization was a better choice."

The second function is supporting the more instrumental process of

decision-making to ensure that all concerned arrive at the best possible decision. The nursing roles related to the instrumental aspects of decision-making were examined in three ways: 1) by using the answer to a question about whether the nurse had initiated discussion of limiting treatment, 2) by transcribing relevant anecdotal portions of the audio tapes, and 3) by transcribing responses to the hypothetical case presented in the interview.

That nurses had a clinical practice base from which to respond is partially reflected in their response to, "Can you recall instances when you have been the one who raised the issue of limiting treatment by asking families if they wanted certain kinds of treatments?" Fourteen (78%) of the 18 nurses responded "Yes." Thirteen (72%) of the nurses had discussed hospitalization and antibiotics, 12 (67%) had discussed IVs and tube feedings, and 11 (61%) had discussed resuscitation. Resuscitation status had sometimes been pre-determined at admission by either the physician, social service person, or admitting clerk.

The role of the nurse as facilitator in the decision-making process. In the role of facilitator, the nurse might raise the topic of limiting treatment, discuss the options with families, sanction family decisions, notify families of changes in condition that might lead to decision-making, review and confirm prior decisions, or support decisions that had already been made.

Nurses sometimes facilitated decision-making about limiting treatment by raising the topic. In some cases, CPR had been discussed by the physician prior to admission to the nursing home or before the

patient was discharged from a hospital. It was also discussed at the time of admission by admission personnel or social service personnel in many facilities. However, sometimes it was left to the nurse to raise the issue. As one DNS stated, "It's a disservice to relatives if that's not done." This might take the form of an individual discussion, described by another DNS: "If they don't [come in with an order for no-code], then I ask the family and then I ask them to sign a directive-to-physician that spells out everything." The topic might also be raised as part of an admission conference with the resident's family:

If the form isn't signed at that time [admission], the nurses will talk with the family. We try to set up a family conference within a few days, a week, after the person's been here, too, and it would be brought up at that time (DNS).

In another instance, a DNS raised the subject of CPR with a family member who was having difficulty accepting the impending death of a terminally ill resident and hadn't been able to make a decision about starting resuscitation:

She hadn't made up her mind about the CPR and he was dying and I finally said to her, 'You have to make a decision'....We talked about it for a while and she realized he was dying.

Nurses wanted to know how to plan for the residents in their care: If someone who's admitted, say in a pretty critical condition and we have a no-code, then it's immediate grounds for me to perk up my ears and to

meet with that family and find out just where we're coming from and how much we're going to do (DNS).

Nurses also raised the issue to try to ensure that the best quality decision would be made:

It might be a patient that has chronic illnesses, is rather debilitated, and the family is going out of the country and those type of decisions might be left to someone who might not have the authority. And so I've said, 'Before you go, here is something we need to discuss, and how do you feel about this?' and brought out our procedural plan, talked to them about it, and had them make their decisions (PCM).

Another way that nurses functioned in the facilitator role was by discussing treatment options. In some instances the family raised the issue and had already made a decision:

Families have discussed this with me, especially if a patient has been to the hospital and has been critically ill, and they say, 'I don't want mom or dad or whoever it is to go back to the hospital again. This is just too traumatic for them, their quality of life is not such that we wish them to continue' (PCM).

Nurses might also respond to questions from family members. "They've asked sometimes what the alternatives are, if the fact of the matter is the patient is not eating, 'What are the alternatives for a patient who does not eat?'"(PCM). One DNS said that her role in the family conference was "being there to answer questions, to let them know what

it would mean if they didn't have a tube, or what benefit it would be if there was one." Nurses stressed that the actual decision was left up to the family or the resident:

I can only tell them what's out there and available and what it would mean....When the family's having a hard time, yeah, I will talk to them about making the decision. All you can do is tell them the facts, you can't sway them one way or the other. The only thing you can tell them is 'This is what I have and this is what it will do,'...so that it might help make that decision a little easier (PCM).

In responding to families, nurses also mentioned their concern that families need to be fully informed about the decisions they are making:

A lot of families think that full code means that you are just going to do CPR and if they live, fine and if they don't, that's fine, too; they don't understand that it means 911, ambulances, lights flashing, going to the hospital, intubation, respirators. Part of the nurse's function is to be sure the family knows that, and hopefully that will have been discussed prior to this becoming a crisis, emotion-laden situation, so that the family can make that decision in a rational manner (PCM).

In another instance, the issue was tube feeding and the DNS described the importance of discussing the options so that:

Those people looking at making those decisions for the

resident know the pros and cons of treatment or non-treatment and that the patient's comfort is considered. For instance, some people linger for a long time without a tube feeding and can have skin breakdown. So the family needs to know that without that protein that they're at risk for skin breakdown.

Another function the nurse may perform as facilitator is to sanction decisions the family is making. In this instance the nurse is considered an authority by virtue of personal and professional experience with decision-making and provides a frame of reference within which decisions may be made. In the following instance the family asks what the nurse, a DNS, would do in the same situation:

You know, they'll ask you, and most of them feel good if you, as an R.N. would tell them exactly how you feel, yourself. And I would say, 'This is my personal feeling'....And they always appreciate it when I say that.

A PCM also said, "A lot of times they'll ask, 'Well, what would you do?' and I tell them it has to be their decision or sometimes I give them-- 'Well, I would send them to the hospital.'" Sometimes the family might ask the nurse about a decision they were considering. "The family come to me and express their concerns and say, 'This is the way I feel,' and ask, 'Do you have a problem with that?' And I say, 'No, I do not' (PCM).

Nurses facilitated decision-making by notifying families of changes in a resident's condition and asking what the family wanted to

be done. Whenever possible, nurses tried to anticipate changes and give families time to consider options. One DNS said, "Sometimes the nurses will become involved with the family and talk about the different options that are available, if the patient's not doing well." An example was given by a PCM:

If we evaluated a patient and their hydration status hasn't been good for over a period of time, we will discuss with the family just to make sure that we are in synch with what is the best course to take for them and how their feelings would be if we were to come to a question of whether or not an IV should be placed.

Another nurse, a DNS, mentioned presenting both sides of the issue of tube feeding:

If the resident has been alert and has been taking an active part in the life around them, even though it's not the greatest in the world, a lot of times the family will opt to have a tube and we're going to support them in every way, even though the person has had a change or deterioration. Because quite often, if we can get them to eat a little better, we can bring up their quality a bit, and we discuss that with them. We let them know that quite often, because they haven't been eating as well for a while, their quality's gone down, so if we can get some food back into them, they may not have to keep the tube feedings for a long time. They'll just get their strength back and they'll be

able to start eating again. So we let them know both sides as much as we can, as much as we know.

Even when the change was more acute, nurses seemed to present the situation in terms of options:

What we do, if a patient is really bad...then we call the family and see if they want us to transfer the patient [to the hospital] and most of the time the family will just say, 'Just keep them in the nursing home; don't send them anywhere.' Or if they say, 'Yes,' then we ship the patient right away (DNS).

If it's somebody that's terminal, has cancer, and all of a sudden their lungs become congested, I immediately bring it up with the family whether or not they have thought about doing antibiotics where there's a pneumonia or whether they--whether that person has thought about them dying by systems or whether they want them to die from a secondary infection (PCM).

This also involved clarifying intentions:

If the family come[s] in and they've been called because there's been a dramatic change, they will say, 'Please, I don't want anything done,' and I say, 'Please, what do you mean when you say you don't want anything done?' We must be specific.

A DNS described leading families through the specifics:

If they say, no, I don't want any quote CPR or heroics, then

we try and lead them down the path; what do you consider to be--do you want CPR, no CPR; IVs, no IVs; N/G, no N/G; antibiotics, no antibiotics; comfort measures only?

Another important aspect of the facilitator role was reviewing and confirming decisions that had been made, including advising the family that they could change their minds about decisions. "We remind them that they can change their mind at any moment" (PCM). Also, when there was a change in condition, nurses provided the opportunity to review and update decisions. "If a person's condition changes, we try to make sure that the family's wishes are still the ones that were stated previously" (PCM).

There's been several times when the decision's been made for no hospitalization when the patient has been stable and then something comes about where it needs immediate attention and then sometimes there's, 'Well, yes, let's hospitalize her this time.' And so I always try to clarify, 'Now, you had stated before no hospitalizations. I just want to clarify that with you' (PCM).

Finally, nurses facilitated decision-making by supporting families in the decisions, once they had been made. After the nurse had discussed options and tried to ensure that the decisions that were made were informed decisions, an assurance of support might be given: "I kind of discuss with them their options. And I always tell them, whatever their decision is, I'm going to support it, I'll do it" (DNS). Another DNS said she tried to, "be supportive to them that they've made

the best decision for that family member, and it may be a difficult decision to make, but in the end, we'll support that decision."

The liaison role of the nurse in decision-making. Another important role of the nurse in decision-making is liaison. One of the strategies of the liaison role was referral of the decision-making situation to the physician. This might result from a nursing judgement that treatment options needed to be discussed. "There have been a couple of occasions when it's been my feeling that it [discussion of CPR] needs to be done, but I always take it to the physician and ask the physician to deal with that" (PCM). The nurse might still be involved in the decision-making process as part of a decision-making team. A DNS, referring to resuscitation status, said, "We contact the physician and ask that he discuss it. That's not something I ask my nurses to do. They can be involved in the discussion in the family conference setting, but I feel it's a physician-family issue." A probable family conference was also mentioned by a DNS in the following instance of referral to a physician:

If we're noticing a continual decline in their appetite, or they're losing weight, we can not get them to eat orally...the nursing staff will discuss it with the doctor, what's happening, and the doctor will talk with the family about it and we will usually have a family conference to discuss it also.

Another major function of the nurse in the liaison role was to

provide a vital communication link between all of those involved in decision-making. The importance of having someone who knows what all of the parties to any decision are thinking was suggested by a PCM:

A lot of times you get yourself in a catch-22 situation where you clarify with the doctor...first, and they say, 'Well, yes, let's admit this patient to the hospital, let's start an IV,' and the family says, 'Well, no, we don't really want that,' and you have to call the doctor back and so it's very nice to have all your information...before a situation comes about.

One PCM described her role in a very difficult decision-making process, which was eventually referred to the ethics committee:

I was sort of the liaison person who talked to the family and talked to the physician and coordinated so that they each knew what the other person thought and wanted to be done for this resident and took that information to the administrator and the director of nursing and then I was present at the ethics committee meeting.

Another PCM explained the importance of keeping the whole team informed:

I like to let the DNS know when there's a change, because sometimes somebody else might know something you don't, like social service could have a recall of when a family really wants this done or doesn't want that, when they've had time to do a one-to-one, if it's a relatively new patient, that they've discussed this, and we all work pretty close

together here.

Physicians seemed to rely on the nurse in the liaison role. One PCM said, "Many times I've called the physician and he'll say, 'I want you to call the family and ask them what their wishes are and I will go along with whatever they want.'" Another related:

Doctor will call me and say, 'The family just contacted me and they're having some difficulty understanding some things and they need to be talked to,' and so I'll go and call them and call them in and talk to them and then pick up the phone and call the doctor and tell the doctor exactly where we're at with it.

When families had discussed their wishes with the nurse, the nurse might communicate it to other members of the team, as described by a PCM:

The information [about treatment wishes] would come to me from the family, usually, and then I would let the doctor know. I also would relay the information to social services, because they might not always be involved in the discussion. We try to keep a close working communication with them.

Nurses also related instances of promoting communication among family members, for example asking:

If at any point they had discussed with their mother what her desires were, if this should come in question, and what they feel. Lots of times there's been conflicting type things among many siblings or that type of thing. And I

would probably ask them if they would discuss this among family and let us know. I'd also pass along any information given by the physician (PCM).

A DNS described an instance where her knowledge of the family's wishes prevented hospitalization of a resident, to which the family was opposed:

She developed a temp[erature] and the doctor called and said, 'I want her hospitalized,' and I said, 'I think we'd better wait. First, I think we'd better get hold of the daughter. I know exactly how she feels. She does not, she was adamant she does not want this patient hospitalized.' So I intervened, telling this doctor, you know, can we wait on hospitalization half an hour until I can get hold of her. And she was indeed grateful. And then she, in turn, talked to the doctor and said, 'I refuse to have her sent to the hospital.'

The role of the nurse as a member of the decision-making team. In their role as a member of a decision-making team, nurses reported working closely with families and the social service department in decision-making. One PCM described decision-making as a team effort:

I think our decision-making for limiting treatment in the facility is a combination. It's not just one person who makes the decision. We have a fairly good team and social services is always involved and, more often than not, the

Director of Nurses is involved also. It's a real team approach. Everybody is able to put in a little bit of input. The decision to approach the family is usually a team decision.

A DNS in another facility also described the importance of input from as many people as possible:

When it comes to this "difficult decision" [a form designed by the facility on which families or the resident can indicate treatments they do or do not wish] we don't do it usually on an individual basis. We will meet with social services, the nurse, myself, and the family members so it's not just one person discussing this with them, it's so we can get input from all of them, all areas.

The role of the nurse as documenter in decision-making. Although most facilities seemed to rely on written orders from the physician, documentation was mentioned as one of the roles of the nurse. The PCM in one facility said, "In the nursing notes, we would mention discussed with family their wishes, patient's wishes," and the DNS in another facility said, "I think it [the decision-making process] all needs to be well documented."

The role of the nurse as patient advocate in decision-making. Nurses assumed the role of patient advocate in several ways. They tried to ensure that the wishes that were carried out were those of the patient. One DNS described her concerns about decisions not to treat with antibiotics:

If a family member said, you know, 'If mom develops pneumonia, I don't want you to treat it,' and they're not that person's guardian, then I have a problem with that. You know, mom needs to be the one to have something to put into that decision.

Nurses also tried to ensure that those who were making decisions for residents were the most appropriate decision-makers. "Sometimes if we see a need to get someone a court-appointed guardian, if there's a problem with friends meddling and taking over, then we'd suggest that they get a guardian and initiate that procedure (DNS).

Nurses advocated for treatment changes for residents. This might be advocacy for more treatment, for more appropriate treatment, or for less treatment if the treatment was perceived by the nurse as being futile and uncomfortable for the resident. In one instance, a PCM identified a resident whose quality of life might be improved by improved hydration:

I had a patient come in with a fractured hip that was not healing at all and had severe dementia, and had had previous to the fracture, and she was getting very dehydrated, extremely agitated, so I requested we hydrate her. Maybe that would decrease some of her agitation. So, since they finally decided this was an ongoing problem prior to the fractured hip, that they would place a G/T tube in. And they put it in and she's just had a remarkable turnaround....The family had a hard time making the

decision, but once they did, they knew it was the right decision.

In another instance, when a patient became comatose after seizures, and the DNS in the facility advocated for hydration, the outcome was not so clear cut:

The grand-daughter came and I asked her what she wanted done. She didn't want an N/G tube, didn't want anything done. I said, 'Well, you know, she hasn't taken anything. Can we give her some IVs just to hydrate her?' She kind of paused for a little while, then she said, 'Well, we can't really starve her to death, can we?' So we started IV on her and she's still on IVs at 60ccs per hour. And the doctor had discussed this with the granddaughter and grandson, what they want. So today they're supposed to discuss about an N/G tube because she has been on IVs for about a month and she's still here.

Nurses might also advocate for less treatment, especially if the treatment was futile and causing the patient discomfort:

The poor man was in pain, just had lots and lots of problems, on all kinds of IVs and pain control and that kind of stuff and the doctor was ordering blood tests continually, found out that he needed some packed cells...and that in order to do that we had to send him next door, which meant an expense for the family because Medicare doesn't pay for it, a very difficult transfer for the

patient because anything caused severe pain, and I just said, 'Why are we doing this? I know we're to get him comfortable, but this isn't a comfort measure.'...I called the family and the family was very much in agreement with me and they did not want him sent over either. You're just prolonging the inevitable (PCM).

Another incident described by a PCM also involved transfer of a patient:

I had a patient last wintertime that had developed pneumonia, went into the hospital, which was very appropriate, came back to us about 10 days later and the doctor was way over in the other end of town...and this doctor insisted on seeing her late in the afternoon and I felt the woman was in no condition to go over and we were trying to get her changed to a doctor locally who could either come to see her...I didn't want her to leave the facility....It took a while, but we did finally get a local doctor....I felt it was my responsibility not to send her in. And we started another course of antibiotic treatment on her just by p.o. [oral] medicines.

Another form of advocacy is the monitoring of decisions that are being made. In one facility, the DNS was part of a discussion committee convened by the facility staff to consider a request by a family to remove a resident's feeding tube:

We do not have a formal ethics committee but in a decision like that, we do have the house physician, my assistant

director, and myself, and the administrator and another nurse served as a discussion committee on this, so we don't have anything formal, but on an individual decision, we'd group again.

Roles of the nurse identified in the hypothetical case. Responses to a hypothetical case of an elderly women with dementia who became comatose after an apparent stroke, confirmed most of the roles identified in the other anecdotal material. All of the nurses said that they would notify the physician and the family of the resident's change in condition. Since the physician might not be immediately available, the nurse might ask either the physician or the family about what would be done for the resident. If prior decisions had been made, the nurse might review and confirm those decisions with either the family or the physician. The nurse would then convey that information to the other party. An offer might be made to set up a family conference. One PCM said:

If I had gotten directly in touch with [the physician] and he wanted to know what the family wanted to have done, I would tell him that I hadn't contacted them yet, 'I will, and ask them.' If I called the physician, but was not able to get in contact with him right away, I would call the family and discuss with them-- let them know that there was a change in the condition, what it looked like it might possibly be, and then probably ask, 'What do you want us to do at this point? Do you want us to have her transported to

the hospital, if the physician wants that?'"

A DNS said that she would notify "the physician first, because we would want to know what kind of actions he wants us to take." Then the nurse would notify the family:

Initially we would say there's been this change in her condition, that we've contacted the physician and these are the decisions he's made in regard to her care. We would recommend that she contact the physician and we'd ask if she'd like to meet with our team to review the change in the condition.

The DNS in another facility described both the ideal and the real situation:

They [the family] would be told what has happened over the last few days, what her status is, and most likely what the physician is doing at this point in time....If the physician has said, 'We're not going to hospitalize her, we're not going to do anything,' then the family needs to know that. I mean, we need to know, are they comfortable with that, is that their wishes?...[IVs and tube feedings] again should be initiated by the physician. I would assume that the physician is going to talk with the family. I would think the ideal scenario is for the physician to see the resident, evaluate her, talk with the family, let them know the prognosis, let them know what options are available, including hydration, N/Gs, what are the chances of that. If

he doesn't want to do that, and the family asks, 'What are her chances?' or, 'We don't want her hospitalized,' then we need to pick up the ball on that....If the family indicates that they don't want things done or do want things done, then I would need to talk with the physician.

In response to a question about what philosophy nurses would use or help others use in making decisions for the patient in the hypothetical case, a DNS mentioned providing information and supporting the decisions that had been made. "I will certainly support whatever the outcome is and I'll certainly be glad to participate in any way in giving information based on my knowledge of what's going on."

These examples include roles for the nurse as facilitator, liaison, member of the decision-making team, and advocate. Documentation was not mentioned in responses to the hypothetical case.

Congruence of Nursing Roles/Practice With Facility Guidelines

Nursing practice in Facility A, the only facility with a written policy to guide decision-making about limiting treatment, was congruent with facility policy. Residents were considered to be the primary decision-makers and surrogate decision-makers were to be guided by the wishes of the resident whenever possible. When asked about the factors considered in making a decision, the first factor mentioned by the PCM was the resident's wishes. When family members were concerned that residents expressing a desire to limit treatment were not mentally competent:

The home, the nurses, the social service department, all get

sort of caught in the middle and we work very hard to try to get the family member to see what the resident wants and to work out something that we can both, or that they can both be happy with" (DNS).

Their policy also advocated advanced planning for surrogate decision-making. The DNS said, "We also encourage families to have a living will, especially if their resident is alert, you know, in the beginning, is to have something like that, talk with the resident so that they're aware of what their family member would want." The policy suggested a hierarchy of decision-makers based on legal precedent and the DNS said, "We have...a little over a year ago formed an ethics committee and came up with some guidelines that would help families to make a decision and help us to follow, you know, to help the families, to help us understand....It was taken basically from law on who they considered to be the closest, next-of-kin."

Finally, the policy stated that a primary concern of the facility is to provide comfort for the resident. The first decision-making factor mentioned by the DNS in the facility was the comfort of the resident. The PCM, when asked about benefits versus burdens as a factor in decision-making said, "I think in most every case, the prime, the main consideration has been the comfort of the resident."

Nursing staff also encouraged joint decision-making, as recommended by their policy:

Since the [family conference] meeting is usually conducted, led by social services, they will bring it up first and

then...input will be given from the nurses, just basically to answer questions and help them to make a decision.

Oftentimes, too, when this decision becomes necessary, we have whatever physician talk with the family also (DNS).

Congruence of Nursing Roles/Practice With Guidelines of the President's Commission

The roles of the nurse identified in all facilities are congruent with the guidelines of the President's in that they promote joint decision-making and negotiated agreement. The other areas of comparison with the President's guidelines were addressed by specific questions in the interview guide. These include: 1) informing patients and their families of limitations of the facility, 2) a means for determining decision-making capacity on the part of the resident, 3) a means for designating a surrogate decision-maker, and 4) the use of care plans to address the needs of dying residents and their families. Additional data for the last two items was obtained from responses to the hypothetical case.

Limitations of the facility. Because the facilities studied were all skilled nursing facilities, they could provide quite sophisticated care. Patients were often admitted to these facilities precisely because the facility could take them when they required IV therapy or tube feedings. In addition, the nurses were not usually involved in the pre-admission process. The admitting or social service department usually handled this. Nursing generally had little or no role in informing families about the limitations of the facility.

Means of determination of decision-making capacity. Nurses were asked "How do you determine if a resident in this facility is able to participate in decision-making?" (See Table 4.) Ten of the nurses gave answers that indicated they used their own judgment. "If they are alert most of the time and oriented most of the time; there are some that are just slightly confused" (DNS). "If they are alert and oriented we talk to them and ask them, and that's just kind of...you know who is and who isn't" (DNS). Nursing judgement was included with other ways of determining decision-making capacity by another three nurses. Two of the nurses indicated that a decision about the resident's ability to participate in decision-making was made by the physician. One nurse said that this was based on the admitting physician's statement about whether the patient is capable of understanding the diagnosis. One DNS said, "I rely on the physician to make that decision; we don't make those kind of decisions. We certainly have input from what we see on a day-to-day basis, but the decision is the physician's." A PCM said, "We've just now started sending out with our doctor's orders, is the patient cognitively intact and address...what their cognitive level is." Six of the nurses specifically mentioned including the resident in the decision-making process. There was recognition that the level of awareness could change. "A patient could be oriented very well in the morning and by afternoon is completely unaware of what's going on" (PCM). Nurses also believed that even a confused resident might be able to participate in decision-making. "It's strange that some of the people can be quite demented in a lot of things, but when you talk to

Table 4
Nurses Reports of How Judgements Are Made
Regarding Decision-Making Capacity
of Nursing Home Residents

<u>Source(s) of Judgement</u>	<u>N</u>	<u>%</u>
Nursing judgment	10	56
Nursing judgment, physician judgment, family judgment, having guardian/conservator	2	11
Physician judgment	2	11
Physician judgment, family judgment	2	11
Physician judgment, having guardian/conservator	1	5.5
Nursing judgement, family judgement	1	5.5
N = 18		100%

them about what they want to have done for themselves, it's suddenly like they become very clear" (DNS). Another DNS said, "I think you have patients that are somewhat demented, but they can still understand, and then they should participate." Even if the resident could not express wishes, one PCM said, "Even on a limited basis, we take into consideration the...resident's wishes."

Nurses gave evidence of trying to interpret resident's wishes. "Even those who are unable to verbally communicate, they can still let us know when life is not what they really want it to be and they're not happy with it" (PCM). Another PCM said:

Each one is an individual case and you've got to stop and figure out how the family's feeling and how the patient feels about it and you can tell when they close their mouth and purse their lips together, they don't want it-- what their thoughts are.

Finally, nurses consulted with families to try to determine "what the family knows about what the patient would want" (DNS) and to "try to figure out what they patient would have wanted if they were able to-- if they had voiced whether or not they would want these kind of things" (DNS).

In summary, there is a lack of objective criteria for determining decision-making capacity. Unlike other areas of the interview where nurses answered readily, this was an area where nurses had to stop and consider before giving an answer. Even in the facility which had a

written policy regarding limitation of treatment, there were no criteria for determining decision-making capacity, although the policy did address the area of choosing a surrogate decision-maker. However, it was obvious that nurses in all facilities were making judgements about residents' ability to participate in decision-making and made efforts to involve resident's in the decision-making process either directly or by involving families.

Means for designating a surrogate decision-maker. Nurses were asked, "How do you determine who will make decisions for a resident in this facility if the resident is unable to make decisions?" Overall, it seems this is a family decision. As one nurse said, "Usually the families are pretty emphatic about who is the responsible party, they're very positive about letting me know who to contact" (PCM).

Although family was mentioned most frequently, only one facility (Facility A) had guidelines that would help to determine which family member would serve as surrogate decision-maker. In two other instances, it was indicated that a decision was made at the time of admission, but no criteria were provided.

The DNS in the facility with the written policy described the reasons for developing the policy. "Part of this was brought about because we have brothers, sisters, and they may not agree and the poor resident gets caught in the middle." The PCM in another facility said that the staff tried to "work with family soon after admit to determine [the decision-maker] and resolve conflicts."

Another problem that resulted from a lack of guidelines for

appointing decision-makers is that the person called in case of a change in condition was often the one listed as the responsible party. As one PCM related, "It might be somebody who is financially responsible, like an auditor or trustee, but they are not morally responsible, as they put it." In other cases, the responsibility fell to family members who didn't know the resident. One DNS gave an example: "It's a third cousin that they haven't seen in twenty years."

In summary, the nurse's role in the area of determination of a decision-maker seems to be one of advocacy, exercising vigilance to make sure that any conflicts are resolved and that an appropriate person is making decisions for the resident. Protocols for determination of a decision-maker were unavailable in most of the facilities surveyed.

Care plans to address the needs of dying residents and their families. None of the nurses reported that their facilities had standardized care plans to address the needs of patients who were receiving supportive care while dying. However, all of them reported that individualized care plans would be developed to meet the needs of each patient. Nurses were asked what would be done for a patient receiving supportive care and for the family and were also asked, later in the interview what would be done for a patient and her family in a hypothetical case. Probes asked if oxygen, suctioning, and antibiotics would be included in supportive care for the resident, if these had not been mentioned by the nurse. The data from the question and the hypothetical case were combined.

The most frequently mentioned components of supportive care were

fluids or hydration (14), pain control (13), turning (13), skin care (12), oral care (9), positioning (8), nutrition (7), basic nursing care or ADLs (7), suctioning (5), oxygen (5), and medications (4). Other components were emotional support (2), visits from clergy (2), sensory stimulation (2), toileting (2), and activities (2). When specifically asked about suctioning and oxygen, those nurses who had not mentioned them said that they would be considered a part of supportive care if they were necessary. Most nurses also agreed that antibiotics would be part of supportive care, but five added that this would depend on the family's wishes. When asked what would not be included, most nurses said that there was nothing that would be automatically excluded. There was agreement from several nurses that the plan needed to be very specific. "We ask for specifics [from the physician]" (DNS). "What is not included needs to be spelled out really well" (PCM). What is not included is "as specified by doctor" (DNS).

The most frequently mentioned components of the plan for families were to provide support (8) and to keep them informed or explain what was happening (7). Nurses also enlisted social services to help the family (3) and served as liaison with the physician (3). Even at this point, one PCM said the plan would "give them the opportunity to discuss and/or change their viewpoints about treatment at any time" (PCM).

In summary, the plans for supportive care are congruent with the guidelines proposed by the President's Commission in that they provide for symptom control, maintain communication with the resident and the family, and provide help to the patient's significant others. To some

extent, it is also a team approach, as recommended by the Commission; the nurse's role is to develop and implement the plan and serve as liaison between resident, family, physician, clergy, and social service department.

CHAPTER VI

DISCUSSION

This chapter will compare the study findings regarding policies and practices concerning limiting treatment to the literature reviewed in Chapter II. The multiple roles of the nurse found in this study will be discussed and possible explanations for the findings presented. Limitations of the study will be discussed.

Policies and Practices Concerning Limiting Treatment

Policies About Limiting Treatment

Because of the small number of facilities included in the study, comparisons with other studies should be interpreted cautiously. In this study of nine skilled nursing facilities, one (11%) of the facilities surveyed had a policy that discussed limiting treatment. This is roughly comparable to Miles and Rydens' (1985) findings that 16% of a sample of 135 nursing homes in Minnesota had policies concerning limiting treatment. Miles and Ryden studied both skilled and intermediate care facilities and found that policies were more common in skilled facilities. They also found that policies were more common in facilities with ethics committees, facilities serving as clinical practice sites for students and facilities operated by churches. They found no relationship between profit status and having a policy concerning limiting treatment.

In this study, both the facility with a written policy and the facility in the process of developing a policy had ethics committees, served as clinical practice sites for students, had religious

sponsorship (different in each facility), and were non-profit. Noteworthy is that the ethics committees in both facilities were formed, in part, to develop such policies.

Interestingly, when nurses in this study were asked what philosophy they would use or help others use in decision-making, only one nurse mentioned the philosophy of the facility in which she worked. This may reflect the lack of a philosophy statement which might be helpful in decision-making, a lack of awareness of such a philosophy, or may reflect an emphasis on individuality in our culture.

The written policy in the one facility in this study specified that the resident should be primary decision-maker, and that if a surrogate decision-maker is necessary, their decision should be guided by their knowledge of the resident's wishes. The Miles and Ryden (1985) study found that only 25% of the policies specified the resident as primary decision-maker.

Practice Regarding Resuscitation

Practice regarding decision-making about resuscitation in the study facilities was generally consistent with the guidelines that have been recommended for hospitals (Lee & Cassel, 1984). The family is consulted and the physician writes an order to withhold CPR and documents the decision in the resident's medical record. Nursing practice also reflects Blackhall's (1987) recommendation that CPR should not be considered an option for those it cannot benefit, and that families should be advised of the risk of the procedure's prolonging dying and exposing the resident to more stressful interventions.

Family Involvement in Decision-making

Of the four ways families might be involved in decision-making suggested by Sherlock & Dingus (1985), two were apparent in what nurses in this study described. Families did provide written evidence of residents' wishes in the form of "living will" or "directive to physician" documents. Families also provided their assessments of what was in the best interest of the resident. There were no clear cut instances of families providing insights into the resident's lifestyle, goals, or values. There were also no instances described where families based decisions on what was in the family's best interest. The study may have been too small, or the interview guide inadequate to identify instances in which families specifically discussed resident's lifestyle, goals and values.

Roles of the Nurse in Decision-making

The nurses interviewed for this study seemed very interested in the topic of decision-making about limiting treatment and indicated that it is a significant clinical aspect of nursing in a nursing home. Several nurses mentioned that the hypothetical case was typical of situations that they frequently encountered in their facilities.

As suggested by the literature (Watts, Cassel, & Hickam, 1986; Brown & Thompson, 1979) the nurses did seem to function quite autonomously in the area of decision-making about limiting treatment.

Although limiting treatment is the terminology used in the literature, nurses in this study seemed uncomfortable with it. One nurse denied that any treatment was limited for any resident, although

she had discussed the question of whether certain kinds of treatment were appropriate for certain residents. In discussing these issues, nurses seemed more comfortable with language that discussed treatment options.

Multiple Roles for the Nurse

In addition to identifying several ways in which nurses enact the advocate role (Gadow, 1979; Miller, 1972) suggested by the literature, this study identified four other roles of the nurse in decision-making about limiting treatment. These included facilitator, liaison, member of the decision-making team, and documenter.

Discussion of Nursing Roles

Possible explanations. Although the study was too small to draw conclusions, some possible explanations for the findings will be discussed. Because physicians visit residents infrequently (Curran, 1985; Watts, Cassel, & Hickam, 1986), it is the nurse who is available to families and who is aware of the day-to-day changes in residents' condition (Curran; Thompson, Pender, & Hoffman-Schmitt, 1987). In the investigator's experience, residents are usually cared for by the same nursing staff, so that families have consistent communication and the opportunity to build a relationship with the nurse. Because of this accessibility, knowledge about the resident's ongoing condition, and the likelihood of an established relationship with families, the nurse may be the person to whom families turn for help with decision-making. These factors may help to explain the roles of the nurse as facilitator and liaison.

Nurses seemed concerned about ensuring the best quality of decision-making about treatment options. One aspect of this concern was the need to explain the consequences of the treatment options that were being considered. Lo (1984) and Rango (1985) suggested that nurses should be involved in decision-making because they will have to implement the plan of care. Nurses in this study indicated that they may have more awareness of the consequences of the decision than does the physician. Since nurses will be living with the consequences of any decision that is made, they have an investment in making sure that the decision has been carefully made and that families are aware of the consequences of the decision. One nurse said that she discussed options with families because she believed most physicians did not adequately discuss the consequences of treatment decisions. In contrast, in another facility, nurses explained that they were comfortable with referring decisions about limiting treatment to physicians because their physicians were experts in gerontology and very sensitive to such issues. This would seem to indicate that nurses make a judgment about who can best explain the options and their consequences to families and this judgment may determine whether the nurse enacts the role of facilitator or refers the decision to the physician in the role of liaison.

Miller (1972) and Lumpp (1979) suggested that the nurse is the person most likely to be aware of a resident's goals and values and can use this knowledge to advocate for the resident in decision-making. However, the results of this study suggest a somewhat different role for

the nurse. The nurses in this study facilitated decision-making by helping families to use their knowledge of the resident, which may have included an awareness of the resident's goals, values, and wishes. The nurse was recognized as an authority by virtue of her nursing knowledge and experience with other residents with similar problems and other families making similar decisions. As an authority on the cultural norms in the nursing home, the nurse provided a framework within which the family could use their knowledge about the resident to reach a decision.

Nursing roles and the President's Commission Guidelines. The nursing roles identified in the study were congruent with the recommendation that decision-making should be a joint process. Nurses also provided evidence of developing care plans for dying residents that met their needs for symptom control and maintained or promoted communication and involvement with family members. Because social service or admitting departments were usually involved in providing pre-admission information to residents and their families, nurses were not involved in informing families of limitations of the facilities. On the contrary, in this study nurses mentioned informing families that many procedures could be performed within the nursing home, thus avoiding the trauma of transfer to an acute facility.

Nurses seemed to have problems when asked to identify ways in which they determined the ability of residents to participate in decision-making. Several factors may contribute to this. Because decisions about activities of daily living are routinely made for many

residents by nursing staff, residents' actual decision-making abilities may not be considered. Nurses may give preference to beneficence over autonomy. However, nurses in this study reported trying to involve residents in the decision-making process whenever possible. None of the nurses mentioned using tests of cognitive ability such as the Mini-mental State (Folstein, Folstein, & McHugh, 1975) or the Short Portable Mental Status Questionnaire (Pfeiffer, 1975). Possibly an important reason for difficulty with this issue is that neither the medical nor the legal profession has been able to agree on a standard to determine the competence of an individual to make decisions about their care. As one of the nurses mentioned, even residents who are quite demented may express strong, rational-seeming preferences about treatment.

Another problem area was the designation of a surrogate decision-maker. Although some nurses did report vigilance regarding appropriate decision-makers, there seemed to be no requirement that the decision-maker be one that the resident had chosen. One factor may be the need of the facility to have a responsible party for financial purposes. The responsible party may also be assumed to be an appropriate surrogate decision-maker. Another factor may be a reluctance on the part of most people to consider the possibility of mental or physical deterioration, and consequently, a failure to plan for such a contingency.

Limitations of the Study

This study is limited by virtue of its cross-sectional design. Because of increasing interest in the topic of decision-making about limiting treatment reflected in recent literature, policies and

practices might be expected to change fairly rapidly. Miles and Ryden (1985) found that the majority of policies about limiting treatment had been recently instituted in the facilities that had them. In this study, one facility had instituted its policy within the past year and another was in the process of developing a policy. The study is also limited by its small size, including nine nursing homes and 18 nurses. Only facilities licensed to provide skilled care were included in the study which limits the generalizability of the findings to facilities that provide intermediate and residential levels of care.

Considering the sensitive nature of the topics, nurses were surprisingly forthcoming in their willingness to discuss decision-making about limiting treatment. However, there is still a possibility that the information shared by the nurses may have been subject to a response bias based on social desirability. Finally, the qualitative data regarding roles of the nurse is limited by the biases of the investigator, since she has been employed in long-term care for 6 years. However, this may also have facilitated the rapport established with subjects and their willingness to be candid in their comments.

Summary

The findings of the present study are consistent with existing literature concerning the characteristics of nursing homes that had policies about limiting treatment. Decision-making practices are also consistent with existing recommendations for decision-making about CPR. Congruence with recommendations of the President's Commission was found in the areas of joint decision-making and care plans for dying

residents. Current practice does not reflect the President's Commission recommendations on determining decision-making capacity of residents or designating a surrogate decision-maker.

The roles of the nurse identified in this study are more numerous and complex than the suggested role of advocate found in the literature. This study seems to indicate that nurses rely on families' knowledge about residents rather than the nurse's knowledge of resident's goals and values. Results of this study seem to confirm that families rely on nurses because nurses are more available than physicians in long-term care facilities, but also suggest that nurses may be more willing to discuss the consequences of the options that are being discussed. These factors contribute to nursing roles as facilitator, member of the decision-making team, liaison and advocate.

The study is limited by its small sample size, cross-sectional nature, the possibility of a social desirability response bias, and potential biases of the investigator.

CHAPTER VII

SUMMARY

Nurses in nursing homes are responsible for the day-to-day care of elderly persons, who often have multiple chronic illnesses. Because of frequent, close contact with nursing home residents and their families, the nurse may be involved in discussions about the appropriateness of treatments that are being considered for residents. These discussions may lead to decision-making about limiting treatment.

Decisions about limiting treatment in the nursing home may include decisions not to resuscitate a resident, not to hospitalize a resident, or not to provide specific treatments. Some of the most difficult decisions may involve the provision of nutrition and hydration by artificial means. The reasons for limiting treatment may include the wishes of the resident, possible futility of the treatment, consideration of relative burdens and benefits, and the quality of life of the resident.

The literature reports attempts to develop guidelines for limiting treatment in long-term care facilities including the use of specified levels of care, the use of a hospice approach, and the development of guidelines for supportive care that would provide for hygiene, comfort, and dignity, but would not prolong life. Both the law and medical custom have recognized families as parties to the decision-making process and as surrogate decision-makers when the patient is incapable of making decisions.

Decision-making about limiting treatment involves ethical

concerns. The difficulty of decision-making about limiting treatment may be complicated by the existence of different ethical systems or frameworks that may be used. Guidelines for decision-making in nursing homes suggested by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recommend the use of the life goals and values of the resident for whom the decisions are being made.

In this study, a survey was conducted in nine of the 20 nursing homes licensed to provide skilled care in three metropolitan counties in Oregon. Eighteen nurses, including the Director of Nursing Service or her assistant, and one Patient Care Manager nurse from each of the facilities, were interviewed using an interview guide developed by the investigator. This study was intended to determine the extent and content of policies, standards or guidelines about limiting treatment in nursing homes and to identify roles of the nurse in the decision-making process. Guidelines developed by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1983 were used as a standard for purposes of examining policies and practices concerning decision-making about limiting treatment.

One of the nine nursing homes was found to have a policy that discussed limiting treatment; another was in the process of developing a policy. All of the nurses provided evidence that the decision-making process was a joint effort of professional staff and the resident or family, as recommended by the President's Commission. However, only one

facility was found to have criteria for determining the decision-making capacity of residents and only one facility had a procedure for appointing a surrogate decision-maker. Two facilities specified that the resident should be the primary decision-maker or that the resident's wishes should be used to guide decision-making, as recommended by the President's Commission. Although all of the facilities were providing supportive care to dying residents, none had specific guidelines for developing supportive care plans, as suggested by the President's Commission.

All of the nurses had had experience with decision-making about limiting treatment. Within the year prior to the study, fourteen (78%) of the nurses had raised the issue of limiting treatment with families. Hospitalization had been discussed by 13 (72%), intravenous fluids or tube feedings to provide hydration/nutrition had been discussed by 12 (67%) and resuscitation had been discussed by 11 (61%) of the nurses in this study. Resuscitation status had often been determined prior to admission, especially if the resident had been transferred from a hospital. When nurses were not involved in initiating discussions pertaining to limiting treatment, they might be involved in other ways.

The roles of the nurse in decision-making about limiting treatment that were identified in this study included facilitator, liaison, member of a decision-making team, documenter, and patient advocate. As facilitator the nurse might raise the topic of limiting treatment, discuss options, sanction decisions, notify family of changes in the resident's status, review and confirm prior decisions, or support a

decision that had been made. As liaison, the nurse might refer the situation to the physician or serve as a communication link between all interested parties. Nurses fulfilled the role of advocate by ensuring that the decisions that were made reflected the wishes and values of the resident, and that they were made by an appropriate decision-maker. Nurses also advocated for treatment changes for residents including more treatment or more appropriate treatment of a resident, or in the case of treatment that was futile and painful, discontinuation of treatment or alternate treatment.

Recommendations for Further Research

Because of the small size of this study, not enough data were available to determine whether differences existed between the roles of the DNS and PCM, what factors affected the role the nurse assumed, and whether all of the nurses enacted all of the roles. In addition this study did not examine the roles of staff nurses. Further research is needed to confirm or reexamine the roles that were identified, perhaps using quantitative approaches. Future studies might also explore possible differences between roles of the Director of Nursing Service, the Patient Care Manager, and the other staff nurses. Further research might also explore the factors that determine which role the nurse will enact in a given situation.

Recommendations for Nursing Practice

Utilization of the findings of the present study should take into account the small sample size, cross-sectional nature of the data, possible social desirability response bias on the part of subjects, and

the potential biases of the investigator in analyzing the qualitative data. However, several recommendations will be made based on the findings of this study.

Developing Guidelines or Policies

One of the ways nurses might ensure that the best decisions are made for the residents in their care is by developing policies or guidelines about decision-making. In addition to the guidelines presented by the President's Commission, guidelines for developing such policies are suggested by Ryden and Miles (1987). Statements about the goals and philosophy of the institution, if available, might provide a useful framework. Nurses working for corporate facilities might try to demonstrate that policies and guidelines can be written that will promote considered decision-making and still protect the corporation.

There are several areas that require special attention. If a facility chooses not to allow limitation of treatment, residents and their families should be so advised, since this is a constraint on the kind of care offered. Attention also needs to be given to the concern that the decision-making process should allow for individual needs in each instance. Although advance planning should be encouraged, frequent review and update should be part of the protocol and readiness to discuss issues should also be considered.

Decision-making capacity. Although there are no universally accepted standards for determining decision-making capacity, nurses need to be aware of the possibility that they are making judgements about whether or not residents are able to participate in decision-making

about their health care. If nurses are making such judgments, they should make sure that they are using objective criteria and that they do involve the resident in the decision-making process to the degree possible. These judgements and the criteria on which they are based need to be documented in the resident's medical record.

At the policy level, nurses need to work with other health and legal professionals to develop policies or guidelines that will ensure self-determination of the resident in decision-making. To be congruent with the President's Commission guidelines, these should specify that the resident be the primary decision-maker and that decisions made by surrogates be based on the wishes of the resident, as much as they are known. The decision-making process needs to be fully documented, including the basis for decisions made by surrogates.

Consideration of residents' wishes. Nurses in this study did indicate that they asked families about their knowledge of what the resident would want when considering options, and advance planning for decision-making was encouraged in some facilities. Because some research has questioned the accuracy of families' ability to predict treatment decisions (Uhlman, Pearlman, & Cain, 1988), more consideration may need to be given to interviewing the resident and the family about specific wishes. Ideally the resident could indicate preferences. If not, family should be asked to provide justification for their beliefs about the resident's wishes. Nurses should continue to serve as patient advocates and try to ensure that the interests of residents are being served.

Presenting options. Since one of the functions of the nurse in the facilitator role is presenting options, nurses must make sure that they are presenting all of the available options. Nurses, who may not think of themselves as powerful or influential, may nevertheless be perceived as authorities by residents and families. Therefore, nurses need to be scrupulous in distinguishing between facts and personal opinion when presenting options to families. Nurses must also examine their own feelings and be aware that they may need to present options that are contrary to their own values or beliefs. If the nurse does not feel that this can be done objectively or comfortably, another staff member might be asked to discuss treatment options with the family. If there are options that would be contrary to the philosophy or policy of the facility, this should be explained to those involved in decision-making, and the alternatives, such as transfer to another facility, or home care, should be presented.

Conclusion

Nursing home nurses are involved in assisting families as they make decisions about treatment options and consider the possibility of limiting treatment to residents in nursing homes. Nurses need to become involved in developing policies that will provide a framework for careful decision-making. Nurses also need to examine their own practice related to decision-making about limiting treatment as they enact the roles of facilitator, liaison, member of the decision-making team, documenter, and patient advocate.

References

- Amundsen, D.W. (1978). The physician's obligation to prolong life: A medical duty without classical roots. Hastings Center Report, 8(4), 23-30.
- Areen, J. (1987). The legal status of consent obtained from families of adult patients to withhold or withdraw treatment. Journal of the American Medical Association, 258, 229-235.
- Bandman, E.L., & Bandman, B. (1979). The nurse's role in protecting the patient's right to live or die. Advances in Nursing Science, 1(3), 21-35.
- Besdine, R. W. (1983). Decisions to withhold treatment from nursing home residents. Journal of the American Geriatrics Society, 31, 602-606.
- Billings, J.A. (1985). Comfort measures for the terminally ill: Is dehydration painful? Journal of the American Geriatrics Society, 33, 808-810.
- Blackhall, L.J. (1987). Must we always use CPR? New England Journal of Medicine, 317, 1281-1285.
- Brock, D.W. (1982). The nurse-patient relation: Some rights and duties. In Beauchamp, T.L., & Walters, L. (Eds.), Contemporary Issues in Bioethics (2nd ed.) (pp. 142-148). Belmont, CA: Wadsworth Publishing Company.

- Brody, E.M. (1986). The role of the family in nursing homes: Implications for research and public policy. In Harper, M.S., & Lebowitz, B.D. (Eds.), Mental illness in nursing homes: Agenda for research (pp. 159-179). Rockville, MD: U.S. Department of Health and Human Services, National Institute of Mental Health.
- Brown, N.K., & Thompson, D.J. (1979). Nontreatment of fevers in extended-care facilities. New England Journal of Medicine, 300, 1246-1250.
- Cassel, C.K., & Jameton, A.L. (1981). Dementia in the elderly: An analysis of medical responsibility. Annals of Internal Medicine, 94, 802-807.
- Curran, W.J. (1985). Defining appropriate medical care: providing nutrients and hydration for the dying. New England Journal of Medicine, 313, 940-942.
- DeBard, M.L. (1981). Cardiopulmonary resuscitation: Analysis of six years' experience and review of the literature. Annals of Emergency Medicine, 10, 408-416.
- Dickey, N.W. (1986). AMA Council on Ethical and Judicial Affairs. Journal of the American Medical Association, 256, 471.
- Dresser, R. (1985). When patients resist feeding: Medical, ethical, and legal considerations. Journal of the American Geriatrics Society, 33, 790-794.

- Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). Mini-mental State: A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research, 12, 189-198.
- Fusgen, I., & Summa, J.D. (1978). How much sense is there in an attempt to resuscitate an aged person? Gerontology, 24, 37-45.
- Gadow, S. (1979). Advocacy nursing and new meanings of aging. Nursing Clinics of North America, 14(1), 81-91.
- Gulati, R.S., & Bhan, G.L. (1983). Cardiopulmonary resuscitation of old people. Lancet, 2(8344), 267-269.
- Hilfiker, D. (1983). Allowing the debilitated to die. New England Journal of Medicine, 308, 716-719.
- Hirsh, H. (1983). Guidelines for withholding treatment in the terminally ill. Nursing Homes, 32(4), 25-26.
- Hirst, S.P., & Metcalf, B.J. (1986). Learning needs of caregivers. Journal of Gerontological Nursing, 12(4), 24-28. ✕
- Lee, M.A., & Cassel, C.K. (1984). The ethical and legal framework for the decision not to resuscitate. Western Journal of Medicine, 140(1), 117-122.
- Levenson, S.A., List, N.D., & Zaw-Win, B. (1981). Ethical considerations in critical and terminal illness in the elderly. Journal of the American Geriatrics Society, 12, 563-567.

- Levinson, W., Shepard, M.A., Dunn, P.M., & Parker, D.F. (1987).
Cardiopulmonary resuscitation in long-term care facilities: A
survey of do-not-resuscitate orders in nursing homes. Journal
of the American Geriatrics Society, 35, 1059-1062.
- Lo, B. (1984). The death of Clarence Herbert: Withdrawing care is
not murder. Annals of Internal Medicine, 101, 248-251.
- Lo, B., & Dornbrand, L. (1984). Guiding the hand that feeds: Caring
for the demented elderly. New England Journal of Medicine, 311,
402-404.
- Lo, B., & Jonsen, A.R. (1980). Clinical decisions to limit
treatment. Annals of Internal Medicine, 93, 764-768.
- Lo, B., McLeod, G.A., & Saika, M.A. (1986). Patient attitudes to
discussing life-sustaining treatment. Archives of Internal
Medicine, 146, 1613-1615.
- Lumpp, F. (1979). The role of the nurse in the bioethical decision-
making process. Nursing Clinics of North America, 14(1), 13-21. X
- Lynn, J. (1984). Brief and appendix for amicus curiae: The American
Geriatrics Society in the matter of Claire C. Conroy. Journal
of the American Geriatrics Society, 32, 915-922.
- Lynn, J. (1986a). Dying and dementia. Journal of the American
Medical Association, 256, 2244-2245.
- Lynn, J. (1986b). Ethical issues in caring for elderly residents of
nursing homes. Primary Care, 13, 295-306.

- Lynn, J., & Childress, J.F. (1983). Must patients always be given food and water? The Hastings Center Report, 13(5), 17-21.
- Merritt, T.L. (1987). Equality for the elderly incompetent: A proposal for dignified death. Stanford Law Review, 39, 689-736.
- Miles, S.H., & Ryden, M.B. (1985). Limited treatment policies in long-term care facilities. Journal of the American Geriatrics Society, 33, 707-711. X
- Miller, M.B. (1972). Therapeutic decision making and institutional advocacy in caring for the ill aged. Journal of the American Geriatrics Society, 20, 585-592.
- Norberg, A., Norberg, B., & Bexell, G. (1980). Ethical problems in feeding patients with advanced dementia. British Medical Journal, 281, 847-848.
- Olson, J. (1981). To treat or to allow to die: An ethical dilemma in gerontological nursing. Journal of Gerontological Nursing, 7, 141-147.
- O'Rourke, K. (1988). Nancy Beth Cruzan: A case of proxy consent. St. Louis University Medical Center, Center for Health Care Ethics, March 1988.
- Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. Journal of the American Geriatrics Society, 23, 433-441.

- Polit, D.F., & Hungler, B.P. (1987). Nursing Research (3rd ed.). New York: J.B. Lippincott.
- Pratt, C.C., Schmall, V.L., Wright, S., & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. Family Relations, 34, 27-33.
- 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.
- Rabin, D.L., & Stockton, P. (1987). Long-term care for the elderly: A factbook. New York: Oxford University Press.
- Rango, N. (1985). The nursing home resident with dementia: Clinical care, ethics, and policy implications. Annals of Internal Medicine, 102, 835-841.
- Ryden, M., & Miles, S. (1987). Limiting treatment in long term care facilities: The need for policies or guidelines. Journal of Long-term Care Administration, 15(1), 23-26.
- Schick, F.L. (1986). Statistical Handbook on Aging Americans. Phoenix, AZ: Oryx Press.
- Schwartz, D.A., & Reilly, P. (1986). The choice not to be resuscitated. Journal of the American Geriatrics Society, 34, 807-811.
- Shelley, S.I., Zahorchak, R.M., & Gambrill, C.D.S. (1987). Aggressiveness of nursing care for older patients and those with

- do-not-resuscitate orders. Nursing Research, 36(3), 157-162.
- Sherlock, R. & Dingus, C.M. (1985). Families of the gravely ill: Roles, rules, and rights. Journal of the American Geriatrics Society, 33, 121-124.
- Smith, K.F., & Bengtson, V.L. (1979). Positive consequences of institutionalization: Solidarity between elderly parents and their middle-aged children. The Gerontologist, 19, 438-447.
- Task Force on Supportive Care. (1984). The supportive care plan--its meaning and application: Recommendations and guidelines. Law, Medicine, and Health Care, 12, 97-102.
- Thompson, J., Pender, K.K., & Hoffman-Schmitt, J. (1987). Retaining rights of impaired elderly. Journal of Gerontological Nursing, 13(3), 20-25.
- Thompson, J.E., & Thompson, H.O. (1985). Bioethical decision making for nurses. Norwalk, CT.: Appleton-Century-Crofts.
- Uhlmann, R.F., Clark, H., Pearlman, R.A., Downs, J.C.M., Addison, J.H., & Haining, R.G. (1987). Medical management decisions in nursing home patients. Annals of Internal Medicine, 106, 879-885.
- Uhlmann, R.F., Pearlman, R.A., & Cain, K.C. (1988). Physicians' and spouses' predictions of elderly patients' resuscitation preferences. Journal of Gerontology, 43(5), 115-121.
- Veatch, R.M. (1981). A theory of medical ethics. New York: Basic Books.

- Veatch, R.M. (1984). An ethical framework for terminal care decisions: A new classification of patients. Journal of the American Geriatrics Society, 32, 665-669.
- Volicer, L., Rheaume, Y., Brown, J., Fabiszewski, K., & Brady, R. (1986). Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. Journal of the American Medical Association, 256, 2210-2213.
- Watts, D.T., Cassel, C.K., & Hickam, D.H. (1986). Nurses' and physicians' attitudes toward tube-feeding decisions in long-term care. Journal of the American Geriatrics Society, 34, 607-611.
- Youngner, S.J. (1987). Do-not-resuscitate orders: No longer secret, but still a problem. The Hastings Center Report, 17(1), 24-33.
- Zerwekh, J. (1983). The dehydration question. Nursing, 13(1), 47-5.

Appendix A
Ethical Systems, Religious Traditions,
and Western Liberal Political Philosophy

Decision-making involving the use of ethical principles is not an exact science. This is because the decision that is made will depend, in part, on the ethical framework which is used. According to Veatch, the frameworks used in the United States may include the major ethical theories of teleology and deontology, the major religious traditions of Judaism, Catholicism, and Protestantism, and Western liberal political philosophy.

Major Ethical Theories: Teleology and Deontology

Teleology, also referred to as utilitarianism, is derived from a Greek word meaning consequences. It considers the end result of an action to determine the morality of the action and also considers what will do the greatest good for the greatest number of those concerned. This, however, leaves the question of how to determine what constitutes the good, and the problem of computing the net result when an action may result in both benefit and harm (J. Thompson & H. Thompson, 1985). The Hippocratic corpus, on which much of medical ethics has been considered to be based, is a utilitarian ethic (Veatch, 1981).

Deontology is derived from a Greek root meaning binding duty. A deontological ethical system is based on a set of rules or principles. Many different principles may be used within a deontological framework; they are often grouped under headings such as beneficence, autonomy, nonmaleficence, or justice. Religious traditions are another source of principles used in a deontological system. One of the problems with this system is that a decision promoting one principle, such as beneficence, may violate another, such as autonomy. To make the issue more confusing, it is also possible to consider utilitarianism a

principle (Thompson & Thompson, 1985).

Religious Traditions

Three major religious traditions which may have an effect on medical decision-making in the United States are the Judaic tradition, the Catholic tradition, and the Protestant tradition. The Judaic tradition is a deontologic system derived from the laws in the Talmud. It emphasizes the importance of preserving health and the sanctity and dignity of human life. Life is to be preserved at all costs and preservation of life supercedes even the other ritual laws. Withdrawal of treatment is considered to be the same as killing in the Judaic tradition. The only exception is the recognition of a moribund state, when death is imminent, called gesisah. During gesisah it is permissible to withdraw an impediment to dying. However, interpretations of the tradition disagree on whether medical therapies that prolong dying are considered impediments to dying (Veatch, 1981).

The Catholic tradition of medical ethics evolved from general principles of the Christian religion and from a special set of principles called casuistry, developed for solving specific problems in ethics. Veatch (1981) identified five principles of Catholic medical ethics; those pertinent to this discussion are stewardship, inviolability of human life, and the principle of double effect. The principle of stewardship holds that the body belongs not to the individual, but to God, and thus the individual is obligated to take proper care of the body entrusted to his care. Since life belongs to God, it is sacred, and man does not have the authority to take life. When the proper conditions are met, the principle of double effect

allows actions that produce harm indirectly. These conditions require that: the act is not inherently evil, the evil effect is not the intended effect, the evil effect is not a means to the good effect, and there is a good reason for the action. An example of double effect is the administration of a narcotic to relieve the pain of a terminal illness, but which also depresses respiration and hastens death (Veatch, 1981).

The Catholic tradition has also made a distinction between ordinary and extraordinary measures for the prolongation of life. In 1957 Pope Pius XII interpreted the tradition to mean that only ordinary treatment, that which did not constitute a grave burden on the patient or others, need be given (President's Commission, 1983). The benefits may be weighed against such burdens as cost, pain, and inconvenience (Merritt, 1987).

The Protestant tradition is derived from two very broad principles based on the scriptural teachings of the Bible. The first is the notion of covenant, or fidelity. The second is agape, or Christian love of neighbor. Because these principles are very broad, they are subject to interpretation and may not be useful in making a specific ethical decision. Knowing what is the most loving thing to do can be difficult (Veatch, 1981).

Western Liberal Political Philosophy

Veatch (1981) described the principles of Western liberal political philosophy as self-determination, tolerance, equality, and liberty. The principle of self-determination allows each individual to make decisions about what happens to his body. The informed consent

doctrines, including the right to refuse treatment, are a result of this passion for autonomy and self-determination. This is in sharp contrast to the Judeo-Christian notion of stewardship.

Because decision-making involving ethical dilemmas may use any one or a combination of these frameworks, a first step in decision-making may be determining what framework will be used by the parties to the decision. Then the issues can be examined within the chosen framework in order to reach a decision.

Appendix B
Facility Characteristics Questionnaire

Facility Characteristics

Code number _____

Bed capacity _____

Please indicate actual number of patients (not beds) at the following levels of care:

Medicare/Skilled _____

ICF/Skilled _____

ICF _____

RCF _____

Is your facility For profit Non-profit ?

What is the sponsorship of your facility? (Please check any that apply.)

Hospital

Religious

Community group

Teaching Institution

Fraternal organization

Private corporation

Multi-facility chain

County

State

Federal

Is your facility used as a clinical practice site for nursing students?

Yes

No

Does your facility have an ethics committee?

Yes

No

Appendix C
Interview Schedules

Code: _____

DNS Interview Schedule

As a long-term care nurse, I have been involved in discussions about whether certain kinds of treatments involved more burden than benefit for residents with multiple, chronic problems. These discussions sometimes led to a decision to limit treatment, for example, deciding not to hospitalize a resident, but to provide comfort-based, supportive care within the nursing home. I would like to know more about how nurses are involved in decision-making about limiting treatment and what helps to make the best possible decisions. I would like to ask some questions about your experiences with decision-making about limiting treatment.

1. Nursing homes are often limited in what services they can provide to residents. For example, most can provide only basic CPR and some cannot take residents who require I.V. therapy. What information is given to residents or their families about what can and cannot be provided in this facility?

(Who discusses this with residents or families? (Is the information written? Yes/No)

If YES, may I have a copy? (Identifying information will be "whited out" or cut off.)

2. Does this facility routinely schedule meetings or conferences involving residents' family members? Yes/No

IF YES:

- a. Who meets with the family?
- b. When or how often does this take place?
- c. Are families asked if they have thought about
 - resuscitation? I.V. fluids?
 - hospitalization?
 - tube feedings
- d. Who discusses this with families?
- e. Are there any other treatments that are discussed?

(What are they?)

3. Many facilities now ask physicians, residents, and/or families whether or not they want residents to be given CPR.

Is CPR discussed in your facility? Yes/No

If YES:

a. Who talks to residents or families about whether or not the resident should have CPR? (Are you ever the one who talks to them? How else might you be involved?)

b. When a decision about CPR has been made, how is it documented?

c. How is the decision communicated to facility staff?

4. For chronically ill elderly, the burdens of some kinds of treatment may outweigh the benefits. Sometimes there is discussion about whether other treatments, such as hospitalization or nasogastric tube feeding, are appropriate for some residents. Such discussions might lead to decisions about limiting treatment. Within the last year, do you recall any times when the possibility of limiting treatment was considered with respect to residents in your facility? Yes/No

IF YES:

- a. Would you tell me what kind of treatment was being considered?
- b. Were any other kinds of treatment also considered in the discussion? If YES, what were they?
- c. What caused the topic to be raised?
- d. Who raised the topic?
- e. Who was involved in the discussion?
- f. Were you involved? Yes/No

If YES, in what way?

5. Can you recall instances when you have been the one who raised the issue of limiting treatment by asking families if they wanted certain kinds of treatments? Yes/No

If YES:

- a. What has prompted you to raise the issue?
- b. What kinds of treatment have you discussed?

(If not included, prompt: Have you discussed

resuscitation?

tube feedings?

hospitalization?

antibiotics?

I.V. fluids?

6. Have any other kinds of treatments been discussed as possibly being inappropriate for some residents in your facility? Yes/No

If YES:

a. What were they?

b. Although some of these may have been mentioned before, I would like to clarify the times when discussions about limiting treatment might come up. Does discussion of whether some kinds of treatment are appropriate ever come up

at the time of admission?

when there has been a change in a resident's condition?

during quarterly assessment?

during team review?

during a scheduled physician visit?

at the request of nursing staff?

at the request of family members?

at the request of a resident?

Would this be

verbal?

written (e.g. "Living Will")?

7. What factors are considered when trying to reach a decision about limiting treatment?

(Probes: Finances

Benefits vs. burdens

Expressed wishes of the patient in the past

Religious beliefs

Quality of life (What does that mean to you?)

8. If a decision is reached that a treatment is not appropriate

for a resident in your facility,

- a. how is that decision documented?
- b. how is the decision communicated to other staff members?

9. Because residents in nursing homes often have multiple chronic problems, including mental impairment, determination of their ability to participate in decision-making is a special concern. How do you determine if a resident in this facility is able to participate in decision-making?

10. How do you determine who will make decisions for a resident in this facility if the resident is unable to make decisions?

11. Does this facility have written guidelines, standards, or policies that discuss making decisions about limiting treatment?

Yes/No

If YES:

- a. How were they developed? (By whom?)
- b. May I have a copy? (Identifying information will be "whited out" or cut off.)
- c. In what ways are they helpful?
- d. In what ways are they a problem (or might they be a problem)?
- e. What do you think should be changed or added?

If NO, do you think they are needed? Yes/No

12. Some nursing homes are establishing ethics committees to help them develop guidelines and policies for decision-making and assist with difficult decisions. Does your facility have such a committee? Yes/No

If YES, who is included on the committee?

13. Sometimes physicians request that residents who are dying should "just be kept comfortable." This is sometimes called "supportive care" or "comfort-based care." Does your facility have written care plans that help you determine how to best meet the needs of these residents? Yes/No

If YES: May I have a copy? (Identifying information will be "whited out" or cut off.)

If NO: What kinds of things would be done for the patient? What kinds of things would be done for the family?

So far we have discussed your experiences with decision-making about limiting treatment. Because facilities may vary widely in the kind and amount of experience they have had with decision-making, I would also like to discuss a hypothetical example. I am going to give you a description of a hypothetical case to read. When you have finished, I would like to discuss the case with you:

- a. Do you have any questions about the case before I begin?
- b. If Mrs. B were a resident in this facility, who would be notified of the change in her condition? (Would the family be notified? Which family members? Who would notify them? What else would you ask the family?)
- c. As you assess the changes in Mrs. B., are there any issues related to limiting treatment you might

consider? What are they? (Would you pursue an order to withhold CPR if she didn't have one? Would you assume the patient would be hospitalized? Who would you ask? Would you ask about I.V.s? tube feeding? Who would you ask?)

d. What information would you feel you needed to have in order to make the best decisions about what to do for Mrs B.?

e. What philosophy or other guidelines would you use or help others use in making decisions about whether or not to limit treatment for Mrs. B.?

f. If the decision were made to provide comfort-based, supportive care in the nursing home:What would supportive care for Mrs. B. include? (Would it include

Oxygen?

Suctioning?

Antibiotics?)

What would supportive care for Mrs. B. exclude, or not include?

g. Is there anything else you would like to share with me about your responses to this hypothetical case?

14. Is there anything else you would like to share with me concerning decision-making about limiting treatment and your facility?

How long have you worked in long-term care?_____ How long

have you been DNS in this facility?_____ What is your current
level of nursing education? (circle one): Diploma

A.D.N. B.S.N.

Thank you for participating in this study.

Code: _____

Patient Care Manager Interview

As a long-term care nurse, I have been involved in discussions about whether certain kinds of treatments involved more burden than benefit for residents with multiple, chronic problems. These discussions sometimes led to a decision to limit treatment, for example deciding not to hospitalize a resident, but to provide comfort-based, supportive care within the nursing home. I would like to know more about how nurses are involved in decision-making about limiting treatment and what helps to make the best possible decisions. I would like to ask some questions about your experiences with decision-making about limiting treatment.

1. Does this facility routinely schedule meetings or conferences involving residents' family members? Yes/No

IF YES:

- a. Who meets with the family?
- b. When or how often does this take place?
- c. Are families asked if they have thought about
 - resuscitation?
 - I.V. fluids?
 - hospitalization?
 - tube feedings?
- d. Who discusses this with families?
- e. Are there any other treatments that are discussed?

(What are they?)

2. Many facilities now ask physicians, residents, and/or families whether or not they want residents to be given CPR. Is CPR discussed in your facility? Yes/No

If YES:

- a. Who talks to residents or families about whether or not the resident should have CPR? (Are you ever the one who talks to them? How else might you be involved?)
- b. When a decision about CPR has been made, how is it documented?
- c. How is the decision communicated to facility staff?

3. For chronically ill elderly, the burdens of some kinds of treatment may outweigh the benefits. Sometimes there is discussion about whether other treatments, such as hospitalization or nasogastric tube feeding, are appropriate for some residents. Such discussions might lead to decisions about limiting treatment. Within the last year, do you recall any times when the possibility of limiting treatment was considered with respect to residents in your facility? Yes/No

IF YES:

- a. Would you tell me what kind of treatment was being considered?
- b. Were any other kinds of treatment also considered in the discussion? If YES, what were they?
- c. What caused the topic to be raised?
- d. Who raised the topic?

e. Who was involved in the discussion?

f. Were you involved? Yes/No

If YES, in what way?

4. Can you recall instances when you have been the one who raised the issue of limiting treatment by asking families if they wanted certain kinds of treatments? Yes/No

If YES:

a. What has prompted you to raise the issue?

b. What kinds of treatment have you discussed?

(If not included, prompt: Have you discussed

resuscitation?

tube feedings?

hospitalization?

antibiotics?

I.V. fluids?

5. Have any other kinds of treatments been discussed as possibly being inappropriate for some residents in your facility? Yes/No

If YES:

a. What were they?

b. Although some of these may have been mentioned before, I would like to clarify the times when discussions about limiting treatment might come up. Does discussion of whether some kinds of treatment are appropriate ever come up

at the time of admission?

when there has been a change in a

resident's condition?

- during quarterly assessment?
- during team review?
- during a scheduled physician visit?
- at the request of nursing staff?
- at the request of family members?
- at the request of a resident?

Would this be

- verbal?
- written (e.g. "Living Will")?

6. What factors are considered when trying to reach a decision about limiting treatment?

- (Probes: Finances
- Expressed wishes of the patient in the past
 - Benefits vs. burdens
 - Religious beliefs
 - Quality of life (What does that mean to you?)

7. If a decision is reached that a treatment is not appropriate for a resident in your facility,

- a. how is that decision documented?
- b. how is the decision communicated to other staff members?

8. Because residents in nursing homes often have multiple chronic problems, including mental impairment, determination of their ability to participate in decision-making is a special

concern. How do you determine if a resident in this facility is able to participate in decision-making?

9. How do you determine who will make decisions for a resident in this facility if the resident is unable to make decisions?

10. Does this facility have written guidelines, standards, or policies that discuss making decisions about limiting treatment?

Yes/No

If YES:

- a. Please tell me about them.
- b. In what ways they helpful?
- c. In what ways are they a problem?
- d. What do you think should be changed or added?

If NO:

- a. Do you think they are needed? Yes/No

11. Some nursing homes are establishing ethics committees to help them develop guidelines and policies for decision-making and assist with difficult decisions. Does your facility have such a committee? Yes/No

If YES, have you had any experience in which the committee was involved? (What was it?)

12. Sometimes physicians request that residents who are dying should "just be kept comfortable." This is sometimes called "supportive care" or "comfort-based care." Does your facility have written care plans that help you determine how to best meet the needs of these residents? Yes/No

If YES: May I have a copy? (Identifying information will be "whited out" or cut off.)

If NO: What kinds of things would be done for the patient?

What kinds of things would be done for the family?

13. So far we have discussed your experiences with decision-making about limiting treatment. Because facilities may vary widely in the kind and amount of experience they have had with decision-making, I would also like to discuss a hypothetical example.

I am going to give you a description of a hypothetical case to read. When you have finished, I would like to discuss the case with you:

- a. Do you have any questions about the case before I begin?
- b. If Mrs. B were a resident in this facility, who would be notified of the change in her condition? (Would the family be notified? Which family members? Who would notify them? What else would you ask the family?)
- c. As you assess the changes in Mrs. B., are there any issues related to limiting treatment you might consider? What are they? (Would you pursue an order to withhold CPR if she didn't have one? Would you assume the patient would be hospitalized? Who would you ask? Would you ask about I.V.s? tube feeding? Who would you ask?)
- d. What information would you feel you needed to have

in order to make the best decisions about what to do for Mrs B.?

e. What philosophy or other guidelines would you use or help others use in making decisions about whether or not to limit treatment for Mrs. B.?

f. If the decision were made to provide comfort-based, supportive care in the nursing home:

What would supportive care for Mrs. B. include?

(Would it include

Oxygen?

Suctioning?

Antibiotics?)

What would supportive care for Mrs. B. exclude, or not include?

g. Is there anything else you would like to share with me about your responses to this hypothetical case?

14. Is there anything else you would like to share with me concerning decision-making about limiting treatment and your facility?

How long have you worked in long-term care?_____ How long have you worked as Patient Care Manager at this facility?_____

—
The unit you usually work on is best described as (circle one):

Medicare/Skilled

ICF/Some skilled

ICF/Non-skilled

Your basic nursing education was (circle one):

L.P.N. Diploma A.D.N. B.S.N.

Thank you for participating in this study.

Hypothetical Case

Mrs. B. is an 87 year old, widowed woman. She was a home-maker and an active member of her Presbyterian church. She is slightly hard of hearing, her vision is poor, and she has full dentures. She was diagnosed as having Alzheimer's disease 4 years ago. She also has mild congestive heart failure and degenerative arthritis. A year and a half ago, her daughter placed her in your nursing home. At that time, she walked with supervision, talked in a nonsensical way, and could answer "yes" or "no" appropriately. Now she is non-ambulatory, incontinent, and totally dependent for all ADLs. She is fed a pureed diet and is up in the recliner for about 3 hours daily. She attends activities twice a week, but it is difficult to tell if she is aware of what is going on. She takes Lanoxin 0.125 mg daily, and has orders for a Tylenol suppository for pain or elevated temperature and a phosphate enema for constipation. She has two daughters and one son, living nearby. One daughter visits weekly, the other children about once a month. Her siblings are all deceased except for one sister who lives in the Midwest.

For the past six months, she has been losing weight and has shown progressively less interest in her surroundings. A ten week trial of anti-depressants was not helpful. Her daughter has expressed concern that "mother is failing". Her vital signs are stable, her digoxin level is within therapeutic limits, and her last CBC and chemistry panel were within normal limits except for a slightly low hemoglobin/hematocrit and slightly low total protein. This morning, she was discovered to

be non-responsive, her left arm is flaccid, her respirations are stertorous, and she is apparently unable to swallow.

Appendix D
Letters to Research Subjects

Letter to Director of Nursing Service

Dear

Thank you for agreeing to participate in a study about nursing in nursing homes. I have been a long-term care nurse for 6 years and I am also a graduate nursing student at Oregon Health Sciences University. I am conducting a study of decision-making about limiting treatment in long-term care facilities. Examples of such decision-making are decisions not to perform CPR, not to hospitalize the client, or not to give a specific form of treatment, such as IV fluids, tube feedings, or antibiotics. I am interested in exploring how decisions about limiting treatment are being made and who is involved in making them. Participation in this study may help you and your staff think about how these decisions are made in your facility.

I realize that this topic is very sensitive and wish to assure you that all information will be recorded so that confidentiality of individuals and the facility will be maintained. A copy of the results of the study will be available to your facility if you wish to have one.

I am enclosing a consent form for you to read and a short questionnaire for you to fill out that will describe your facility. If you have any questions, please call me at home, 649-8655, or leave a message with the Department of Mental Health Nursing, Oregon Health Sciences University, 279-7827.

I am looking forward to meeting you on _____
_____ to obtain written consent and to conduct the interview. I will also be happy to discuss any questions or concerns you might have at that time.

Sincerely,

Rose Soriano, R.N.

Letter to Patient Care Manager

Dear

Thank you for agreeing to participate in a study about nursing in nursing homes. I have been a long-term care nurse for 6 years and I am also a graduate nursing student at Oregon Health Sciences University. I am conducting a study of decision-making about limiting treatment in long-term care facilities. Examples of such decision-making are decisions not to perform CPR, not to hospitalize the client, or not to give a specific form of treatment, such as IV fluids, tube feedings, or antibiotics. I am interested in exploring how decisions about limiting treatment are being made and who is involved in making them. Participation in this study may help you think about how these decisions are made in your facility.

I realize that this topic is very sensitive and wish to assure you that all information will be recorded so that confidentiality of individuals and the facility will be maintained. A copy of the results of the study will be available to you if you wish to have one.

I am enclosing a consent form for you to read. If you have any questions, please call me at home, 649-8655, or leave a message with the Department of Mental Health Nursing, Oregon Health Sciences University, 279-7827.

I am looking forward to meeting you on _____
to obtain written consent and to conduct the interview. I will also be happy to discuss any questions or concerns you might have at that time.

Sincerely,

Rose Soriano, R.N.

Appendix E
Consent Form

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form

TITLE An Exploratory Study of Decision-making About Limiting Treatment in Long-term Care.

PRINCIPAL INVESTIGATOR Rose Soriano, R.N., under the supervision of Dr. Beverly Hoeffler, D.N.Sc.

PURPOSE The purpose of the study is to explore the nature of policies about limiting treatment in long-term care facilities and the role of nurses in decision-making about limiting treatment.

PROCEDURES I understand that I will be asked to answer questions about policies and practices in the long-term care facility where I work and to relate experiences that I may have had involving decision-making about limiting treatment. Participation will require about 45 minutes of my time. I understand that I may be asked to give my permission to have the interview tape recorded.

RISKS AND DISCOMFORTS I understand that it may be difficult to discuss issues relating to the physical decline and possible death of patients in my care.

BENEFITS I understand that I may benefit from participating in this project because consideration of the decision-making process may assist me in evaluating my practice concerning decision-making. I understand that this information may help health care professionals to better understand the process of decision-making about limiting treatment.

CONFIDENTIALITY I understand that all information obtained from me will be kept confidential and that anonymity will be maintained for myself and the facility where I am employed by the use of code numbers to identify all documents including interview sheets and audio tapes. Neither my name nor my identity will be used for publication or publicity purposes. I have been assured that the audio tapes will be destroyed after the information from the interviews has been analyzed.

LIABILITY The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If I suffer injury from the research project, compensation would be available to me only if I establish that the injury occurred through the fault of the University, its' officers or employees. If I have further questions, I may call Dr. Michael Baird, M.D., at (503) 279-8014.

Rose Soriano, R.N. and Dr. Beverly Hoeffler, D.N.Sc. have offered to answer any questions I may have about this study and

it's uses. I can contact them through the Oregon Health Sciences University, School of Nursing, Department of Mental Health, telephone number 279-7827.

I understand that participation in this study is voluntary. I may refuse to participate, or withdraw from this study at any time without affecting my relationship with or medical treatment at the Oregon Health Sciences University.

I understand that I will receive a copy of this consent form.

My signature below indicates that I have read the foregoing and agree to participate in this study.

Signature: _____ Date: _____

I approve tape recording: _____
(Initial)

Witness: _____
Date: _____

AN ABSTRACT OF THE THESIS OF

ROSANNE SORIANO

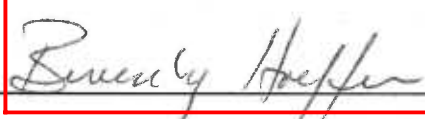
FOR THE MASTER OF SCIENCE DEGREE IN NURSING

Date of receiving this Degree: June 8, 1990

TITLE: AN EXPLORATORY STUDY OF DECISION-MAKING

ABOUT LIMITING TREATMENT IN LONG-TERM CARE

Approved: _____

A handwritten signature in cursive script, enclosed in a red rectangular box. The signature appears to read "Beverly Hoeffler".

Beverly Hoeffler, RN, DNSc, Thesis Advisor

An exploratory, descriptive survey of policies and nursing practices concerning decision-making about limiting treatment was conducted in nine of the 20 skilled nursing homes in three Oregon counties. An interview guide developed by the investigator was used to conduct face-to-face interviews with the director of nursing service and one nurse who was a patient care manager in each facility.

Guidelines suggested by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research were used as a standard for examining policies and practices related to decision-making about limiting treatment. Only one facility (11%) was found to have a written policy about limiting treatment; another was developing a policy. Nursing roles, identified by qualitative analysis of the taped interviews, included facilitator, liaison, team member, documentor, and patient advocate.

The findings of this study are consistent with existing literature concerning the characteristics of nursing homes that had policies about

limiting treatment. Decision-making practices are also consistent with existing recommendations for decision-making about cardio-pulmonary resuscitation. Congruence with recommendations of the President's Commission was found in the areas of joint decision-making and care plans for dying residents. Current practice does not reflect the President's Commission recommendations on determining decision-making capacity of residents or designating a surrogate decision-maker.

The roles of the nurse identified in this study are more numerous and complex than the suggested role of advocate found in the literature. This study seems to indicate that nurses rely on families knowledge about residents rather than the nurse's knowledge of resident's goals and values. Results of this study seem to confirm that families rely on nurses because nurses are more available than physicians in long-term care facilities, but also suggests that nurses may be more willing to discuss the consequences of the options that are being discussed. These factors contribute to nursing roles as facilitator, member of the decision-making team, liaison, and advocate.

The study was limited by its small size, cross-sectional design, and possible social desirability response bias. The findings suggest the need for policies to guide decision-making about limiting treatment in long-term care facilities. Further research on roles of the nurse in decision-making about limiting treatment are needed. Nurses need to examine their practice related to decision-making about limiting treatment to ensure that nursing home residents have maximal opportunity for self-determination.