The Moral Certainty or Uncertainty of Nurses Regarding End-of-Life Treatment Decisions

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This is to certify that I have examined this bound copy of a doctoral thesis by

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ABSTRACT

THE MORAL CERTAINTY OR UNCERTAINTY OF NURSES REGARDING END-OF-LIFE TREATMENT DECISIONS

Much has been written about the importance of decision-making in nursing ethics, but few research studies have been completed which examine nurses' ethical decision-making. In order to address this absence of research, two concepts that are integral to nurses' ethical decision-making were analyzed: moral certainty and moral uncertainty.

These concepts were studied in the context of the issue of withholding or withdrawing artificial nutrition and hydration. This issue was chosen as an exemplar of issues about which nurses feel morally certain or uncertain.

The research questions addressed by this research were: (a) Are nurses morally certain or uncertain about whether artificial nutrition and hydration may be withdrawn from an elderly person in the end stages of life in long-term care? (b) If nurses are morally certain, what is the experience of this moral certainty? and (c) If nurses are morally uncertain, what is the experience of this moral uncertainty?

A qualitative design was used to describe nurses' experiences of moral certainty or uncertainty. A convenience sample of BSN- and MSN-prepared nurses employed in long-term

care in Northeastern and Southeastern Wisconsin was used. Twenty-five participants completed the Brim Desire for Certainty Scale, a demographic data sheet, and an interview.

Five categories of conviction emerged from the data: Absolute moral conviction (AMC), strong moral conviction (SMC), moderate moral conviction (MMC), moral uncertainty with conviction (MUWC), and moral uncertainty (MU). The majority of participants (80%) believed, with varying degrees of conviction, that it should be permissible to withhold or withdraw artificial nutrition and hydration from elderly persons in the end stages of life in long-term care. The remaining 20% were uncertain about whether it should be permissible.

The experiences of moral certainty and moral uncertainty, described by these nurses, are compared and contrasted. The additional findings supplied by the Brim Scale and the Demographic data sheet are discussed. Finally, the findings are interpreted and suggestions made for future research.

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A dissertation is partly an individual effort, but there are also numerous large and small contributions made by family and colleagues. Without this encouragement and assistance, an undertaking of this scope could not become a reality.

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CHAPTER I

BACKGROUND

Within the past ten years, ethical questions have come to the forefront of nursing practice. Books on the subject of nursing ethics attest to the fact that nursing ethics as a subject distinct from medical ethics is seen as important, not only by nurse scholars, but also by practicing nurses and philosophers of biomedical ethics (Bandman & Bandman, 1985; Curtin & Flaherty, 1982; Fromer, 1981; Jameton, 1984; Murphy & Hunter, 1983; Muyskens, 1982; Thompson & Thompson, 1985). In fact, the nurse is no longer seen as an "intelligent machine", there to carry out doctors' orders, but as belonging to a profession with "an emerging integrity" (Benjamin, 1988).

Originally, many of the articles found in journals on nursing ethics related to support for the teaching of nursing ethics (Aroskar, 1977; Andrews & Hutchinson, 1981; Aroskar & Veatch, 1977; Steinfels, 1977; Stenberg, 1979). Gradually, emphasis in nursing ethics changed to the use of decision-making frameworks, and to defining nursing's role in bioethics. This led to discussions of the primary ethical issues nurses deal with -- autonomy, truth-telling informed consent, rights, nurse-patient relationships, and euthanasia (Aroskar, 1980; Bandman & Bandman, 1977;1979; Bell, 1981; Churchill, 1977; Creighton, 1978; Crisham, 1985; Curtin, 1978a;1978b;1982; Davis & Aroskar, 1978; Fagin, 1975;

Fletcher, 1973; Levine, 1977; Lumpp, 1979; Murphy & Murphy, 1976; Thompson & Thompson, 1981).

More recently, the ethical issues nurses face as well as the teaching of nursing ethics, have received renewed attention. The role of the nurse on hospital ethics committees, international nursing ethics, the development of nursing ethics theory, and philosophical nursing ethics are also being discussed in the literature (Bishop & Scudder, 1990; Cassells & Redman, 1989; Chinn, 1989; Davis, 1989; Fry, 1989a; 1989b; 1989c; 1989d; Gaul, 1989; Murphy, 1989).

Thus, much has been written about teaching nursing ethics, decision-making frameworks, nursing ethical issues, and, more recently, nursing ethics theory and philosophy. But little research has been performed to clarify the underlying concepts of nursing ethics. Crisham (1980) has measured moral judgment in nursing dilemmas, and Ketefian (1981) has studied critical thinking, educational preparation, and the development of moral judgment. Gortner et al.(1984) have studied values in the choice of treatment, and Cassells and Redman (1989) the sources in baccalaureate education which contribute to ethical decision-making skills.

In addition, Silva and Sorrell (1991) recently published an integrative review and critique of research on ethics in nursing education. They critiqued 39 studies of nursing faculty and student moral development and attitudes toward particular moral issues, but none of these studies related

directly to this study. Two of the studies critiqued dealt with nursing student ethical decision-making and contained numerous flaws, which limited their usefulness for this study (Pinch, 1985; Swider, McElmurry & Yarling, 1985).

The author concluded that much has been written about decision-making in nursing ethics, but few systematic research studies have been completed which examine nurses' ethical decision-making. In order to address this absence of research, the author analyzed two concepts that are integral to nurses' ethical decision-making: moral certainty and moral uncertainty. The author chose to study these concepts in the context of the issue of withholding or withdrawing artificial nutrition and hydration from elders in the end stages of life in long-term care. This issue was chosen as a context because, in the author's experience, nurses tend to be certain that artificial nutrition and hydration should be provided, certain it should not be provided, or tend to be uncertain about whether or not artificial nutrition and hydration should be provided. This diversity of belief makes this issue an ideal exemplar of nurses' experiences with moral certainty and moral uncertainty.

Research Questions

The questions this research addressed are three: (a) Are nurses morally certain or uncertain about whether artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care?

(b) If nurses are morally certain that artificial nutrition and hydration may or may not be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral certainty? and (c) If nurses are morally uncertain that artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral uncertainty? The questions are descriptive questions which seek to clarify the meaning moral certainty and uncertainty have for nurses.

Operational Definitions

For this study, moral certainty is defined as having absolute moral conviction. Moral certainty is evidenced in the experiences of nurses by the motivation to act on their beliefs. Moral uncertainty is defined as a state of mental indecision. Moral uncertainty is evidenced in the experiences of nurses by the inability to decide whether a contemplated moral action is "right". This results in a questioning attitude toward an ethical issue.

Artificial nutrition and hydration is defined as nutrition and hydration provided through a feeding tube. The term "feeding tube" includes either a nasogastric tube or a gastrostomy tube, an intravenous infusion, or hyperalimentation. Withholding artificial nutrition and hydration is defined as never inserting a gastrostomy or nasogastric tube, an intravenous, or hyperalimentation tubing.

Withdrawing artificial nutrition and hydration is defined as removing a feeding tube, intravenous line, or hyperalimentation after artificial feeding and hydration is in progress. Artificial refers to the use of mechanical means to provide nutrition and hydration. Providing oral food and fluids is not considered artificial.

The term "elderly person" refers to persons between the ages of 65 and 100. Long-term care refers to care provided in the nursing home. The end stages of life means that the elder has a condition which is irreversible and predisposes the elder to death within months to a few years.

Significance for Nursing

Nurses are confronted with some moral certainty and moral uncertainty on a daily basis, whether it is their own or anothers'. Moral certainty and/or moral uncertainty impact every ethical decision confronted by the nurse. These concepts profoundly affect how an ethical decision is viewed, the decision made, and the outcome of the decision. Furthermore, they impact on the mental health and well-being of nurses, colleagues, and clients, as well as on social policy decisions nurses make. Responses to an ethical decision may range from total uncertainty -- a true dilemma -- to absolute moral conviction, with seemingly absolute knowledge of the appropriate choice. This author hopes to clarify the impact of moral certainty and moral uncertainty on nurses' ethical decisions.

The experience of moral certainty and uncertainty is a relatively new phenomenon for study. In the past, many health care decisions were made by the physician. However, with the rising responsibility and autonomy of nurses and clients, this unilateral decision-making is becoming an artifact of the past. Nurses and clients are becoming more and more involved in ongoing and recurrent issues.

Numerous conditions have made nurses' ethical choices necessary and immediate, including expanded technology and the rising status of nurses as actors in the health care system, and ethical arena. Improved communication, more highly educated practitioners who recognize a dilemma when confronted with one, and an expanded consciousness of nursing's responsibility and impact on society have also had an effect. This study will expand nursing's knowledge base and impact nursing practice in long-term care, by clarifying nurses' responses to the issue of withholding or withdrawing artificial nutrition and hydration from elders in the end stages of life in long-term care.

Assumptions

The assumptions of the proposed study are that:

(a) Ethical decision-making is accompanied by moral conviction or moral uncertainty in the nurse.

(b) Moral certainty and moral uncertainty have antecedent environmental, psychological, and social factors.

(c) Moral certainty and moral uncertainty have psychological and social consequences.

(d) Moral certainty and moral uncertainty can be described.

(e) The findings of this study will help clarify nurses' responses to ethical decision-making.

Limitations

The following aspects could be considered limitations of the study:

(a) Moral certainty and moral uncertainty cannot always be isolated from other psychological or social mechanisms and accurately measured (validity).

(b) This researcher's interpretations of interview content may not be consistent (reliability).

(c) A precise tool to measure moral certainty and moral uncertainty is lacking.

(d) Participants are not always able to accurately access their own mental processes.

(e) The study of retrospective moral situations, as opposed to current moral situations, can result in less reliable data because participants may have inaccurate recall.

In summary, the author addressed three questions in this study: (a) Are nurses morally certain or uncertain about the issue of withholding or withdrawing artificial nutrition and hydration from elders in the end stages of life in long-term care; (b) if certain, what is the experience of moral

certainty; and (c) if uncertain, what is the experience of moral uncertainty. Neither moral certainty nor moral uncertainty have been previously studied or extensively discussed in the literature.

CHAPTER II

REVIEW OF THE LITERATURE
The Phenomena

Numerous ethical concepts have been analyzed in the nursing ethics literature (rights, competency, responsibility, informed consent, justice). Application of these concepts, which is one of the primary roles of nurses in nursing practice and health care, requires conviction (Gaul, 1989). Yet, most situations in which ethical concepts might be applied have been considered dilemmas, suggesting uncertainty about action to pursue, or priority of values. This tension between the search for moral certainty and moral uncertainty in nursing ethics has been present in the nursing literature on ethics that will be reviewed in this chapter.

The issue of withholding or withdrawing artificial nutrition and hydration from the elderly in the end stages of life in long-term care was chosen to be studied as an example of an issue which prompts moral certainty in some nurses and moral uncertainty in others. It provides the context within which the phenomena of moral certainty and uncertainty are studied. For this reason, the literature related to this issue is also reviewed.

Finally, this chapter will include a discussion of a conceptual framework of moral certainty and moral uncertainty. This conceptual framework is based on the available nursing ethics literature.

Moral Uncertainty and Moral Certainty

Little has been written about the moral certainty or uncertainty experienced by nurses while making ethical decisions. Davis and Smith (1980) described the conflicts produced by moral uncertainty. Quinn and Smith (1987) described "living with uncertainty" and the sources of nurses' ethical uncertainty. Jameton (1984) suggested that moral uncertainty arises when one is unsure of which values or principles to apply to a dilemma, or even what the moral problem is. The literature generally suggested that moral uncertainty is found not only in the ethical dilemma, but also in communications, relationships, reasoning, and the situations involved in dilemma resolution (Benjamin & Curtis, 1981; Curtin & Flaherty, 1982; Murphy & Hunter, 1983).

The consequences of moral uncertainty have also been rarely discussed in the nursing ethics literature. Quinn and Smith (1987) believed nurses feel a loss of control when faced with ethical ambiguity, one aspect of moral uncertainty. Crisham (1980) found that moral uncertainty leads to indecision accompanied by the inability to make ethical decisions. Much of the available anecdotal literature conveyed an impression of frustration, anger, depression, stress, and anxiety as a result of moral uncertainty.

In fact, uncertainties in nursing ethics have abounded. Some of these related to the issues, the choice of principles, relationships, ethical dilemmas, and conflicts of values. Most

related to conflicts among rights, duties, and obligations (Davis & Smith, 1980).

Ethical conflicts, with their accompanying moral uncertainty have been the topic of most textbooks on nursing ethics and numerous articles. Jameton (1984) sorted moral and ethical problems which nurses face into three categories: moral uncertainty, moral dilemmas, and moral distress. Moral uncertainty arises when one is unsure what moral principles or values apply to a moral problem or even what the moral problem is. Moral dilemmas arise when two or more clear moral principles apply, but they support mutually inconsistent courses of action. Finally, moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.

Because uncertainty in dealing with moral questions is so ubiquitous, a recent book on nursing ethics discussed "living with uncertainty" (Quinn & Smith, 1987). The authors acknowledged the feeling of loss of control felt by the nurse when faced with ambiguity, one aspect of uncertainty, but also saw positive value in its impetus to a search for further knowledge. They saw the source of ethical uncertainty as lack of factual knowledge, situational uniqueness, lack of certainty about basic principles and values, or uncertainty about how to apply principles to a specific situation. Caution was advised to prevent excessive acceptance of uncertainty and

to avoid indifference to new and developing knowledge. Yet, some acceptance was also advised, so as to avoid paralysis of action. Moral dialogue with colleagues was seen as the remedy for ethical uncertainty.

Quinn and Smith (1987) suggested that a rule of thumb is that one must consider outcomes that should always be sought or always be avoided. The suggestion was that we may be morally certain about the desirability or undesirability of some outcomes.

Davis and Smith (1980) pointed out that certain, rule-based ethics dominated in nursing until the past quarter century. Obedience and loyalty were the primary rules in nursing ethics. Even today, nurses are expected and expect themselves to resolve the dilemmas they confront. Even the term "dilemma resolution" suggests an ultimate, finite, certain outcome to an ethical issue.

Yet, what the literature suggested was that uncertainty is the norm. Davis and Smith (1980) have found that uncertainty in nursing ethics usually involved (a) a conflict between two ethical principles; (b) a conflict between two possible actions in which there are some, not conclusive, reasons favoring a particular course of action and some, not conclusive, reasons against the same course of action; (c) a conflict between a demand for an action and the need for reflection in a situation for which present ethical training gives insufficient precedents or preparation; (d) a conflict

between two equally unsatisfactory alternatives; and (e) a conflict between one's ethical principles and one's role obligations.

Still nurses persisted in a search for a certain moral grounding for nursing ethics. Nurses in search of autonomous decision-making capacity, and striving for a degree of moral certainty have studied ethics, clarified their values, acquired ethical reasoning skills, and learned to justify their decisions by using ethical decision-making frameworks (Payton, 1978; Curtin, 1978a; Crisham, 1985). Today nurses are seen as key figures in developing a moral climate for health consumers and providers (Bandman & Bandman, 1985).

As in the past, moral certainty is still the goal for which many nursing authors and nurses strive. Yet, contemporary authors have also recognized uncertainty and moral distress among nurses (Jameton, 1984). The hope of nurse ethicists seems to be in educating practicing nurses to the principles which may be followed, values clarification, resolution of conflict, and to the arguments surrounding specific ethical dilemmas (Jameton, 1984; Bandman & Bandman, 1985; Steele & Harmon, 1983; Meux, 1986; Fromer, 1981).

Most recently, Silva and Sorrell (1991) summarized their recommendations for nursing education after having critiqued 39 research studies in nursing ethics. They found numerous methodological errors, a lack of theoretical grounding, and content areas which were premature when related to the

developmental stage of the nursing ethics research literature. They recommended concentrating on the conceptualization and study of values in order to assist with the resolution of ethical conflicts. They also suggested continuation of research into attitudes toward ethical issues such as the aggressiveness of care for the terminally ill.

Although this author's study did not directly examine values, the participants' values were expressed and are reported in the findings. In their critique, Silva and Sorrell (1991) concluded that the study of values would be accomplished by examining nurses' ethical decision-making at some essential level. This author believes that the present study is studying nurses' ethical decision-making at an essential level, despite the fact that values are not the primary focus.

In summary, although moral uncertainty has seemed to be very prevalent in nursing practice, as a concept it has seldom been studied by nurses. Similarly, the concept of moral certainty has seldom been studied, although a search for moral certainty seems to be implied in many of the nursing ethics articles. In addition, most of the nursing ethics research literature has dealt with the moral development of nurses or students, and their attitudes toward current ethical issues (Silva & Sorrell, 1991). Few have dealt with the concepts of nursing ethics. Silva and Sorrell (1991) suggest that the essences of nursing ethical decision-making be explored. This

author attempted to look at what is essential in nursing ethical decision-making. As a preliminary step the phenomena of moral certainty and moral uncertainty were analyzed.

The Context

Withholding or Withdrawing Nutrition and Hydration

In order to study the experience of moral certainty and moral uncertainty, an issue was chosen which would elicit these phenomena in nurses' responses to the issue. The issue which was examined in this study is that of when to withdraw or withhold artificial nutrition and hydration from elderly persons in the end stages of life in long-term care facilities. In this portion of the review of literature, the many facets of this issue will be discussed as a context for the study. In addition, the literature related to nurse caretaker's experiences with this issue will be reviewed.

Background

Since the turn of the century there have been numerous changes in the death experience -- changes in the causes of death, location of death, and interventions to prevent death (President's Commission, 1983). Between 1900 and the present, the cause of death changed from communicable diseases to chronic, degenerative diseases. The places where people die changed from home to hospital or nursing home. At the same time, medical technology advanced dramatically (President's Commission, 1983).

As medicine and nursing have been able to do more for the elderly, institutionalization has become necessary in some cases. This institutionalization of care has created changes in the dying process which are of immediate concern to residents of nursing homes, families of residents, health care professionals, and society in general. The concerns arising from residents, and on behalf of residents, center around the artificial prolongation of the dying process. As such, life extension is not always viewed as humanitarian and tension has developed between the wish to prolong life and the wish to reduce suffering (Hastings Center Guidelines, 1987).

Recently, some of the technologies used to prolong life have been receiving widespread attention. Among these are the equipment and measures taken to provide artificial nutrition and hydration. Artificial nutrition and hydration have been seen as humanitarian measures necessary to the comfort of the dying person. Debate has arisen, however, about whether even these basic life support measures are not merely prolonging dying. This, then, is the context in which moral certainty and moral uncertainty were studied.

The Debate

Numerous articles have outlined the competing ethical factors and positions taken on this issue. Some authors have come to certain conclusions while others have discussed the issue as a dilemma fraught with uncertainty (Annas, 1986; Annas, 1985; Green, 1984; Meilaender, 1984; Annas, 1983). In

many articles there has been a mixed message -- support for the self-determination of the resident, but concern that a slippery slope is being created (Editorial Hospital Ethics, 1988). Furthermore, in contrast to termination of treatment decisions in general, there is no consensus on withholding or withdrawing artificial nutrition and hydration (Priester, 1988).

The decision of whether to withhold or withdraw nutrition and hydration from an elderly person in the end stages of life is of special importance to elderly residents of nursing homes. This critical decision raises many issues for the resident, family members, and professionals. Among these concerns are protection of the resident's autonomy, competence and choice, dementia occurring in the end stages of life, conflicts of interest, the quality of life, age as a standard for nontreatment, and suffering.

Autonomy

The majority of authors on the subject believe that the elderly resident's autonomy ought to be protected in this decision as in other decisions. Distinctions are made between coercion and choice (Dubler, 1988), and paternalism versus self-determination (Perry & Applegate, 1985). Many authors discuss programs to enhance resident autonomy (Ambrogi & Leonard, 1988; Dubler, 1988; Hegeman & Tobin, 1988; & Hofland, 1988). All would agree that resident autonomy is the ideal.

Competence and Choice

Yet, within the area of protecting the autonomy of elderly residents, there arises the issue of constraints on autonomy in the form of dementia, disabilities, and depression. All three of these conditions predispose the elder to having diminished capacity for decision-making. All three may raise the issue of whether artificial feeding and hydration might be appropriate. At a point in the elder's life when decision-making is the most difficult, this very complex decision may require the elder's competent consideration.

Elders at risk of having their autonomy usurped include those in the terminal stages of amyotrophic lateral sclerosis, Alzheimer's disease, Huntington's chorea, multi-infarct states, multiple sclerosis, dementias, Parkinson's disease, those who are noncommunicative, those who are recumbent, and those who have aspirated (Campbell - Taylor & Fisher, 1987).

Dementia

By far the largest group of elderly at risk for having their autonomy limited is those with dementia. According to a recent study by Harvard Medical School researchers, 47.2% of persons over age 85 and 10.3% of those over 65 years of age suffer from probable Alzheimer's disease (Evans & Funkenstein, 1989). These figures suggest that there are approximately 4 million cases of Alzheimer's disease nationwide and that as many as 14 million cases will exist by the middle of the next century (Leary, 1989). At least one-half million nursing home

residents in the United States are incapacitated to varying degrees by dementia (Leary, 1989).

Dementia is frequently described as death of the self. Personality, memory, vocabulary, capacity for abstract thought and most cognitive functions are lost. Death usually occurs in five to ten years from complications such as pneumonia or feeding problems (Post, 1990). Agitation, wandering, impaired sleep-wake cycles, depression, and hallucinations are common. Arras (1988) describes these residents as having biological life but having lost biographical life.

Generally, most demented residents survive to a stage where the swallowing reflex is affected. This results in choking and aspiration pneumonia. Choking and pneumonia can be prevented by inserting a nasogastric tube, however this prolongs a difficult situation, with the resident surviving in a vegetative state (Walshe & Leonard, 1985).

Even tube feedings have certain associated complications. These may include psychological intolerance, trauma to the nasal mucosa, malpositioning of the tube, mechanical obstruction, gastric erosion and bleeding, gastric distention, aspiration pneumonia, diarrhea, and wound infection if a gastrostomy is inserted (Morley et al., 1986). Hazards of tube feeding are further exacerbated by physiologic factors. These include recumbency, noncommunication of resident, reduced oral/hypopharyngeal sensation, dysphagia, reduced competence of upper and lower esophageal sphincters, reduced esophageal

peristalsis, delayed gastric emptying and reflux brought about by the supine position (Campbell - Taylor & Fisher, 1987). Thus, it may be seen that the conditions for a real dilemma exist in the end stages of the demented person's life.

Volicer (1986) suggested that this dilemma can be prevented by instituting a hospice approach in which residents are kept comfortable with analgesics and antipyretics, but not treated for infections. High (1987) suggested planning for decisional incapacity by providing the necessary advance directives. Stanley, Stanley, Guido, and Garvin (1988) suggested special aids such as modified consent procedures or proxy consents may be necessary for the cognitively impaired.

Kloezen, Fitten, and Steinberg (1988) emphasized that not all elderly residents who have cognitive deficits are demented nor are all cognitively impaired or demented residents necessarily incompetent to make treatment decisions. They suggested using the "least restrictive alternative" principle, developing more objective and effective means of assessing decision-making capacity, and modification of information to maximize the use of preserved resident abilities. Post (1990) believes one ought to view the demented experience as different, but containing redeeming experiences. He believes that protection of these, the most vulnerable, is essential, because purposeful destruction erodes symbolically and concretely the prohibition against killing. It endangers healthy elderly (the slippery slope) as well as the demented.

Thus, one can see that although constraints on decision-making exist in the elderly with cognitive impairments, it cannot be assumed that incompetence exists. Planning ahead is essential if the ultimate feeding dilemma is to be avoided.

Other issues also impact on the decision to withhold or withdraw nutrition and hydration from an elderly nursing home resident. Among these are issues of quality of life, conflict of interests, age as a standard for nontreatment decisions, and suffering.

Quality of Life

Studies suggested that, when confronted with a resident who cannot feed him or herself, but who refuses to be fed by others, nurses are most strongly influenced by the happiness of the resident. If the resident was happy, or younger, nurses more often opted for a feeding tube (Watts, Cassel, & Hickam, 1986). Mental status did not affect these nurses' preferences (Watts, Cassel, & Hickam, 1986). Generally, nurses had a higher preference for tube feeding than physicians (Watts, Cassel, & Hickam, 1986). The physician's intervention was based upon prognosis and functional status, that is, the ability to care for self, the ability to interact, communicate, be independent and lucid. With an abnormal or deteriorating mental state, immobility, and pain, the person was more likely to be treated with comfort measures (Gillick, 1988).

This reliance on the state of happiness as a barometer for feeding and nonfeeding decisions raises the question of the quality of life of some elderly residents of nursing homes. The quality of life is difficult to predict and frequently the diagnosis and prognosis may be uncertain. There is lack of communication between caregivers and resident and also lack of measurability of quality of life. There is inherent ambiguity. Similar evaluations of a resident's quality of life may lead to different treatment decisions (Pearlman & Jonsen, 1985).

Jonsen et al. (1982) proposed three definitions of the "quality of life": (a) subjective satisfaction with the physical, mental, or social situation; (b) congruent evaluations of a situation by competent patients of the same age and condition (Thomasma, 1984); and (c) the achievement of certain attributes highly valued in our society.

According to Jonsen et al. (1982), the ideal would be for the clinician to respect the client's autonomy and evaluation of their own quality of life. But, when a patient is unable to communicate his or her feelings about life-sustaining procedures, a minimal threshold for quality of life may be considered a decisive factor.

One recommendation for a minimal threshold of quality of life was extreme physical debilitation and a complete loss of sensory and intellectual activity. According to Jonsen et al. (1982), only when the qualities common to human interaction

have been irreversibly lost should the clinician's assessment of the resident's quality of life affect the decision to withhold life-supporting therapy. This minimum standard reflects respect for the personhood, cerebration, and essential human qualities of the resident. One might consider withholding or withdrawing food and fluids if: (a) human interaction is lacking; (b) the resident is unable to express his or her preferences; or (c) technology is prolonging a life that is only biologically functional.

Conflicts of Interest

The ambiguity of decisions based upon quality of life criteria emphasizes the inherent conflicts of interest in this dilemma. According to Wikler (1988), theories of interest have been divided into two broad categories: subjective and objective. A subjective view of interest encompasses that which a resident enjoys, values, or wants. An objective view suggests that some things are good for people even though they may not enjoy, value, or want them.

To bridge subjective and objective views of what is in the resident's best interest, a third view considers the resident's own rational choices. In effect, this view asks what the resident would want or prefer, if rational.

Thus, "best interests" may be experiences, wants, objectively-determined benefits, or rational preferences. A few interests are common to all individuals: well-being of the

person, control of one's own life, and the well-being of one's loved ones (Lynn, 1988).

Yet, because the idea of "interest" is so complex, there may be no single standard (Wikler, 1988). What residents want may differ from what is "best" for them. Choices made on behalf of an incompetent resident may not be in his or her best interests. Finally, there may not be one best interest. Therefore, according to Wikler (1988), the question is not what is in the resident's "best interest", but who decides?".

This question of who decides leads to a plethora of conflicts. As Lynn (1988) pointed out, there may be conflicts within patients, conflicts within practitioners, conflicts between the patient and the system, and conflicts involving surrogates.

Age As a Standard for Nontreatment Decisions

Another issue arises when discussing the withholding or withdrawal of artificially administered food and fluid from the elderly -- age as a standard for nontreatment decisions. Although Callahan (1987) would not support withholding or withdrawing artificial nutrition and hydration even from residents who request it, he has a very different view of nontreatment generally. He believes that because a rising share of the gross national product (GNP) is devoted to health care, eventually other vital areas of national life will be shortchanged. His view of rationing is based upon a concept of a natural life span. He believes the government should be

required to help persons live out a natural life span and provide a better quality of life for the aged. After the natural life span (80) there should be no obligation to use expensive medical technology at public expense. The elderly should be encouraged to think of death as an intimate part of life and dying as a sort of service to the younger generation. He believes that prudence about the goals of medicine would lead to the achievement of a natural life span and then the relief of suffering. Deliberate life extending health care such as mechanical ventilation or CPR (cardiopulmonary resuscitation) after a natural life span would not be offered. He believes that this withholding of technological assistance would be better for the elderly and that the elderly ought to prefer it. As far as the elderly are concerned, Callahan (1987) believes, the meaning and significance of life for themselves is best founded on a sense of medicine's limits. Presently, the elderly are held captive to technology. Their true social needs are neglected. The elderly's true needs, what they want, and what we should provide, according to Callahan (1987) are: (a) as much independence as possible; (b) freedom from fear of impoverishment and other burdens of health care; and, (c) assistance to find meaning and significance in old age.

Daniels (1985) has another viewpoint, based upon Rawls' theory of justice. He believes that citizens would decide ahead of time that certain technologies would be eliminated

for everyone at a certain age. Each person could plan ahead and would know what to expect. The plan would be administered by "prudent deliberators" who would operate behind a veil of ignorance as to the current age of the person for whom they were allocating care. All would be treated equally, but care would decrease with age.

Thomasma (1989) further developed the theme of age as a standard for nontreatment decisions. He suggested: (a) one has the right to refuse treatment to prolong life even if one is not terminally ill; (b) that the physician acts as surrogate against the family if inappropriate care is requested by them; (c) functional care categories should be established which define a range of medically indicated treatments for categories of function (if there is decreased function, less intervention would be provided); and (d) within functional ranges, individual treatment could be provided.

Churchill (1988) believes all current proposals are untenable and that rationing on any basis divides us. What is needed is an overall policy of prudence which would make refusal of excessive treatment the norm.

Suffering

Suffering is yet another aspect of the issue of withholding or withdrawing artificial nutrition and hydration that nurses and long-term care residents experience. Battenfield (1984), a nurse author, began an analysis of the experience of suffering. Both she and later nurse authors

related suffering to a desire to find meaning in life through aesthetic experience. Steeves and Kahn (1987) emphasized that the act of experiencing meaning in life, health and illness, and suffering, entails engagement of the mind, body, emotions, and spirit.

In the nursing research literature, nurses' responses to patient suffering was originally studied by Davitz and Davitz (1980). They found that nurses differentially respond to client's suffering based upon social class, age, and ethnic background. Persons who are poorer and considered to be in the lower class are perceived to experience more suffering. Persons who are younger are perceived to experience more suffering: Oriental, Anglo-Saxon, and Germanic peoples are perceived to experience less suffering. In all of these studies suffering was equated with pain and psychological distress. Nurses who had experienced suffering in their own lives were found to be more likely to empathize with their clients distress (Davitz & Davitz, 1980).

In addition, one group of nurses stood out as being very sensitive and empathetic to their clients. These nurses had a variety of motivations for entering nursing including a search for meaning in life and a sense of responsibility to others. They evidenced a strong commitment to nursing, a rigorous and demanding educational experience, strong role models early in practice, high self-esteem, and confidence of colleague respect. They found caring for others to be the most

important source of professional satisfaction, and found the nurse-patient relationship to be the "core of nursing". Davitz and Davitz call these nurses "the empathetic nurses".

Findings from nursing research also demonstrates that nurses tend to be especially sympathetic to certain kinds of patients. For some it is the young, for others the old, and for still others those who remind them of parents or friends (Davitz & Davitz, 1980; 1981).

As Steeves, Kahn and Benoliel (1990) pointed out, there is little descriptive research about how nurses experience and react to a patient's suffering. The researchers performed a qualitative study of nurses' interpretation of client suffering. They found that suffering was seen as an experience of the patient that the nurse could not share. After socialization into the work culture of nursing, the nurse perceived suffering differently. The nurse originally believed suffering to be a condition of the patient, but this interpretation was modified as the nurse gained more experience, to later be seen as a personal experience of both the patient and the nurse (personalized suffering). For some this personalized suffering was the reason for withdrawing from clinical nursing.

Cassell (1991) developed a comprehensive analysis of suffering. His definition of suffering is that of an impending threat (actual or potential) to the integrity or continued existence of the whole person. Kahn and Steeves (1987) define

it as a threat to the self. Cassell (1991) believes that those who are suffering cannot be adequately cared for until their suffering is recognized. Recognition of suffering entails "feeling with" the sufferer and knowing the sufferer well enough to know how and why they suffer. It entails aesthetic, factual, and value knowledge.

Despite this "recognition" of suffering Cassell (1991) does not believe one can truly have knowledge of another's suffering because total knowledge of another is impossible and suffering is ultimately an individual experience.

Experiences of Nurse Caretakers of the Impaired Elderly

Generally, it has been found that institutional caregivers provide less aggressive care to the aged than to younger persons (Shelley, Zahorchak & Gambril, 1987). Despite this lack of aggressive treatment, Volicer, et al., (1987) found that there is little difference in the mortality rates of terminal stage dementia patients who are tube fed and those who are encouraged to eat by mouth, suggesting that aggressive care does not improve longevity. Michaelsson et al. (1987) found that most end-stage patients were able to be spoon-fed and did not need tube feeding. In addition, Fabiszewski, Volicer, and Volicer (1990) found that there was no difference in survival rates of Alzheimer's patients with fevers who were treated with antibiotics and those who were not. Michelson (1991) studied the preferences of nursing home residents. She

found that they were opposed to aggressive treatment except when the treatment would relieve pain or promote comfort.

Norberg, in association with other authors, has conducted a series of studies on the issue of feeding the elderly in the end stages of life. Ackerlund and Norberg (1985) have found that health care workers in Sweden experience distress and anxiety when residents with incurable dementia no longer take food or fluid voluntarily. Secondly, as the disease progresses and it becomes difficult to feed residents, feeding is perceived by nurses to be forced feeding. The nurse was caught in a conflict of perpetuating suffering versus prolonging life. The nurse received conflicting messages which contradicted each other and created a double bind. Anxiety increased as the ability of the client to communicate decreased because the nurse had a more and more difficult time interpreting the resident's feeding behavior. In addition, the nurse's anxiety increased with increased forced feeding.

Forced feeding may be defined in many ways. In the Ackerlund and Norberg (1985) study the definition varied from persuasion to physical violence. Ethical limits were described differently. Some nurses continued feeding, coaxing and prying with a spoon until the resident was able to swallow. Others gave up if the client kept his or her lips compressed. With few exceptions, forcing the client's mouth open with violence was considered disgusting.

In the Ackerlund and Norberg (1985) study, there were four ethical rules followed by each of four groups of nurses: (a) keep the resident alive because feeding is right and starving wrong; (b) keeping the resident alive is right; (c) don't cause suffering, but keep the resident alive; and (d) don't cause the resident suffering.

The first group believed that keeping the person alive was very important, and that starvation was wrong. Achievement of feeding the difficult resident was experienced as gratifying. This group had no anxiety, believed their actions to be correct, did not perceive even "fairly harsh methods" as violent, and attributed the resident's inability to eat to brain dysfunction rather than a wish to die.

The second group, although wishing to keep the resident alive, felt anxiety at having to force feed because they believed that they were causing suffering. This, the largest group, complained about stress and anxiety. They believed that the refusal to eat was related to brain dysfunction, and provided the researchers with vivid descriptions of the feeding experience. They used no force for fear of hurting the resident, questioned whether keeping the person alive was correct, complained about not knowing the resident's feelings, and were concerned if the resident felt pain or distress. This group seemed, according to Ackerlund and Norberg (1985), to project their own wish to survive onto their residents. They were anxious about the resident choking, had overwhelming

feelings of guilt, and expressed a need to discuss the ethics of feeding, because they felt so ambivalent about feeding these people.

The third group of nurses wanted to keep residents alive but not cause suffering. They had less anxiety than group two, could share their thoughts and feelings about feeding, were concerned about the resident's quality of life, and explained the refusal to eat as brain dysfunction, a wish to die, or depression. This group of nurses were generally teleologists concerned about the consequences of feeding, based on their impressions of the resident's wishes and desires. They attributed their beliefs to personal and professional growth and maturation.

The fourth group of nurses who believed that one ought not cause the resident suffering did not express their feelings freely. They experienced decreased close contact with the resident, lacked pleasure in their work, and generally avoided any intimacy with the resident.

Two other subsidiary groups emerged from Ackerlund and Norberg's (1985) study. One group pleaded for euthanasia based upon a quality of life deontologic argument. The other was a group who believed in situational ethics with a quality of life framework. Many in this study feared situational ethics, believing that no human being is competent to make the ultimate decisions about life and death.

Finally, in this study all of the respondents faced a conflict of the precedence of principles (i.e. autonomy, beneficence, non-maleficence, and justice), brought about by an inability to determine what the resident's refusal of food meant. Because they did not "know" what the resident wanted, they had to imagine the resident's discomfort and wishes.

In a continuation of this series of research studies Norberg, Asplund, and Waxman (1987) found that the choice for nurses between intrusive tube feeding and withdrawing feeding was very difficult. Bexell, Norberg, and Norberg (1980) found that some of the difficulty was in assessing the prognosis, interpreting the prognosis, and assigning value priorities. The prognosis was found to be difficult because a resident could have serious eating problems, but neither be dying nor in a persistent vegetative state.

Despite an uncertain prognosis, Norberg and Hirschfeld (1987) found that, in contrast to Swedish caregivers, Israeli caregivers fed residents artificially without hesitation or anxiety, because their overriding cultural principle was the sanctity of life. Therefore, there was little acknowledged uncertainty or anxiety, because it was believed that demented residents should be fed.

As a continuation of this series of studies, Norberg, Asplund and Waxman (1987) found that at a Swedish nursing home five categories of caregiver beliefs emerged: 14 caregivers (24%) believed that food and fluids should certainly be given

by some means, 11 caregivers (19%) were uncertain about whether residents should be kept alive or whether food and fluids ought to be withheld or withdrawn, 14 caregivers (24%) believed with certainty that food and fluids ought to be withdrawn or withheld, 8 caregivers (14%) believed with certainty that nutrients and fluids should be withdrawn or withheld, but had uncertainty about active euthanasia, and 2 caregivers (3%) believed with certainty that withholding and withdrawing nutrition and hydration is permissible to the point of active euthanasia.

Nurses in the first group were certain that feeding ought to continue by some means, because they believed that the resident wished to live, and that they couldn't be sure the resident wished to die. In addition, they believed that life is sacred and that, as a rule, one keeps the resident alive. They also believed that other residents would not feel safe if some residents were not kept alive.

The second group of nurses were uncertain about keeping residents alive with tube feeding because they had a conflict of personal feelings and professional demands, lack of knowledge of whether withholding or withdrawing artificial nutrition and hydration increases or decreases suffering, and a lack of knowledge of the wishes of the relatives of the resident.

The third group of nurses was divided into two categories. There were those nurses who believed in

withholding or withdrawing artificial nutrition and hydration, because the resident was believed to be suffering, because life for the resident was believed to be meaningless, and because dying from starvation and dehydration believed to be painless. The second category were nurses who believed in withholding or withdrawing artificial nutrition and hydration because the resident was believed to have a right to a high quality of life and a natural death. Both of these categories of practitioner were opposed to active euthanasia.

The fourth group of nurses agreed certainly with withholding or withdrawing artificial nutrition and hydration, but were uncertain about active euthanasia. Their views were based upon the belief that the resident's suffering was intense and incurable, and the fact that the resident had made out a living will.

The fifth group of nurses believed in active euthanasia in order to allow the resident to die with dignity and to relieve the relatives' suffering.

According to Norberg, Asplund, and Waxman (1987) the findings suggest that persons can be morally certain or morally uncertain and call upon the same principles; that much of the uncertainty is about the resident's suffering and wishes; and that many of the problems are problems of fact, not value, and, therefore, resolvable through empirical research. Some of the factual disagreements involved lack of

certainty about the meaning of eating behavior, and the acceptability of forced feeding.

In a series of related studies, these authors continued to assess how nurses make their decisions related to this issue. Michaelsson, Norberg, and Norberg (1987) found that the criteria for a diagnosis of the end stage of life included change in appearance, change in respiration, eating difficulties, diminished psychic contact with the caregiver, change in pulse and blood pressure, decreased urine volume and a special body odor.

Athlin and Norberg (1987) described the development of the interaction between severely demented patients and their caregivers during feeding. The study included four caregivers and six spoon-fed severely demented residents. Each caregiver fed her resident 14 meals. The residents exhibited many feeding problems including primitive reflexes and lack of purposeful behavior. The caretakers were uncertain of the resident's understanding and were unable to interpret the resident's feeding behavior. After 14 meals the caretakers felt more certain of how to interpret the resident's behavior and felt that the residents understood them. This resolved many problems and also enabled the caregivers to handle many of the feeding problems. It also allowed feeding to focus more on relationship than task, increased the caregiver's positive image of the resident, and increased the caregiver's satisfaction with being one of those feeding the residents.

Michaelsson, Norberg, and Samuelsson (1987) studied the criteria by which Swedish nurses assess the experience of thirst in severely demented residents in the terminal phase of life. These criteria included a priori opinion, intuition, identification with the resident (empathy), amounts of fluids received, resident behavior, and state of hydration. Resident behaviors included sucking eagerly, accepting oral fluids, and becoming calm after being offered fluids. The state of hydration was measured by determining the dryness of the mouth, lips, and skin turgor.

Norberg, Backstrom, Athlin, and Norberg (1988) studied forced feeding. They found that most of the nurses in their sample were opposed to forced feeding, but that forced feeding was still carried out. The force used varied from a command to eat, to opening the mouth with the spoon or fingers and compressing the chin, or pushing the spoon into the mouth and holding it there until the resident swallowed. Some believed that holding the resident's nose more humane than forcing a spoon into the mouth. Generally the person feeding the resident could not distinguish between lack of desire to eat versus an inability to eat. The interpretations of the resident's behavior varied from a belief that the behavior was existential withdrawal and a wish to die, to reflexive withdrawal associated with dementia, a dislike of food, or a reaction against certain caregivers.

In a final study Norberg and Asplund (1990) found that, of 60 nurse participants in their study, the majority believed that the severely demented experience life as meaningless. Despite this belief, only a few believed the care of the severely demented to be meaningless.

Nursing, Health Care, and Societal Implications

For the resident, his or her family's and caretaker's decisions about withdrawing food and fluids have profound consequences. Death may be forestalled or accelerated. The resident's remaining moments of life may be peaceful or painful. The family's and caretaker's leave-taking of the resident may be peaceful or plagued with doubts.

These decisions also have inevitable social consequences; consequences which will affect our society as a whole. These include changes in perceptions of the value of life, the worth of the individual, and the role of society in protecting those who cannot care for themselves. The social consequences compel us to examine our beliefs about respect for life, death with dignity, respect for the autonomy and dignity of the individual, and our understanding of professional responsibility. They force us to confront issues of justice, beneficence, and non-maleficence. Our decisions will help determine institutional and public policy, law, and the care of future residents.

In order to meet these responsibilities, nurses need to carefully consider this dilemma in light of professional

goals, societal and resident values, and personal integrity. Nurses need to be able to base their decisions on ethical principles and moral knowledge.

As fewer people experience a quick and unexpected death, and more undergo a long and protracted dying experience, often with invasive treatment, death becomes burdensome, painful, and expensive. Many residents will be unable to make decisions or will have a difficult time making choices about their own care. This poses difficulties for nurses because they may be expected to assist with decision-making and provide ongoing supportive care. It poses difficulties for health care in general because the outcomes of these decisions will determine standards for humane care. It poses difficulties for society because society as a whole must balance protection of the most vulnerable against changing attitudes toward death and dying.

The consequences for nurses, health care, and society are profound if the question is ignored. Preserving life is an admirable goal of health care, but may be incompatible with another objective of health care, relief of suffering. Nurses need to clarify the meaning of death for themselves, their residents, and their families, and jointly determine the measures which support their values and goals. Ultimately, nurses' choices will promote or compromise their own and their clients' values.

CONCEPTUAL FRAMEWORK

In this final portion of the review of the literature, the conceptual framework for this study is developed. The framework is based upon nursing ethics, nursing research, and philosophical literature.

Moral uncertainty and moral certainty are seldom discussed in the nursing ethics or nursing research literature. Moral uncertainty is most often discussed in reference to an ethical dilemma. Most nursing ethics textbooks begin with a discussion of the dilemmas found in nursing practice (Benjamin & Curtis, 1982; Fromer, 1981; Jameton, 1984; Quinn & Smith, 1987; Muyskens, 1982; Thompson, Melia, & Boyd, 1983; Thompson & Thompson, 1985). The classic definition of a moral dilemma is the uncertainty of choice between two equally unsatisfactory alternatives (Curtin & Flaherty, 1982; Thompson, Melia, & Boyd, 1983).

The issue or dilemma confronted by the nurse will be considered the context for the model. In this study, the issue is that of withholding or withdrawing artificial nutrition and hydration from the elderly in the end stages of life in long-term care. The phenomena of the model are moral certainty and moral uncertainty. The antecedents and consequences of the phenomena, are described.

Moral Uncertainty

According to Quinn and Smith (1987), a lack of ethical knowledge, situational uniqueness, insufficient precedents, questions about the applications of principles, and a difference in basic values or principles, lead to moral conflict. Moral conflict is comprised of conflict between principles, conflict between two moral actions, conflict between the demand for action and the need for reflection, conflict of equally unsatisfactory alternatives, conflicts of value, and conflicts of principles and role obligations (Davis & Smith, 1980). These authors present numerous cases of the conflicts of principles, duties, rights and role obligations experienced by nurses (Davis & Smith,1980; Quinn & Smith, 1987). Veatch and Fry (1987) delineate these role obligations as a duty to the profession, the physician, the institution, society, and the client.

This plethora of conflicts when accompanied by a lack of moral knowledge or experience leads to moral uncertainty (see Figure 1). Moral uncertainty in this study is defined as an inability to determine the "right" course of action to pursue. The findings of the study support this definition and will be discussed in the final chapter.

Moral uncertainty results in feelings of loss of control and indecision (Crisham, 1981; Quinn & Smith, 1987). In addition, Parker (1990) suggests that nurses have tried to

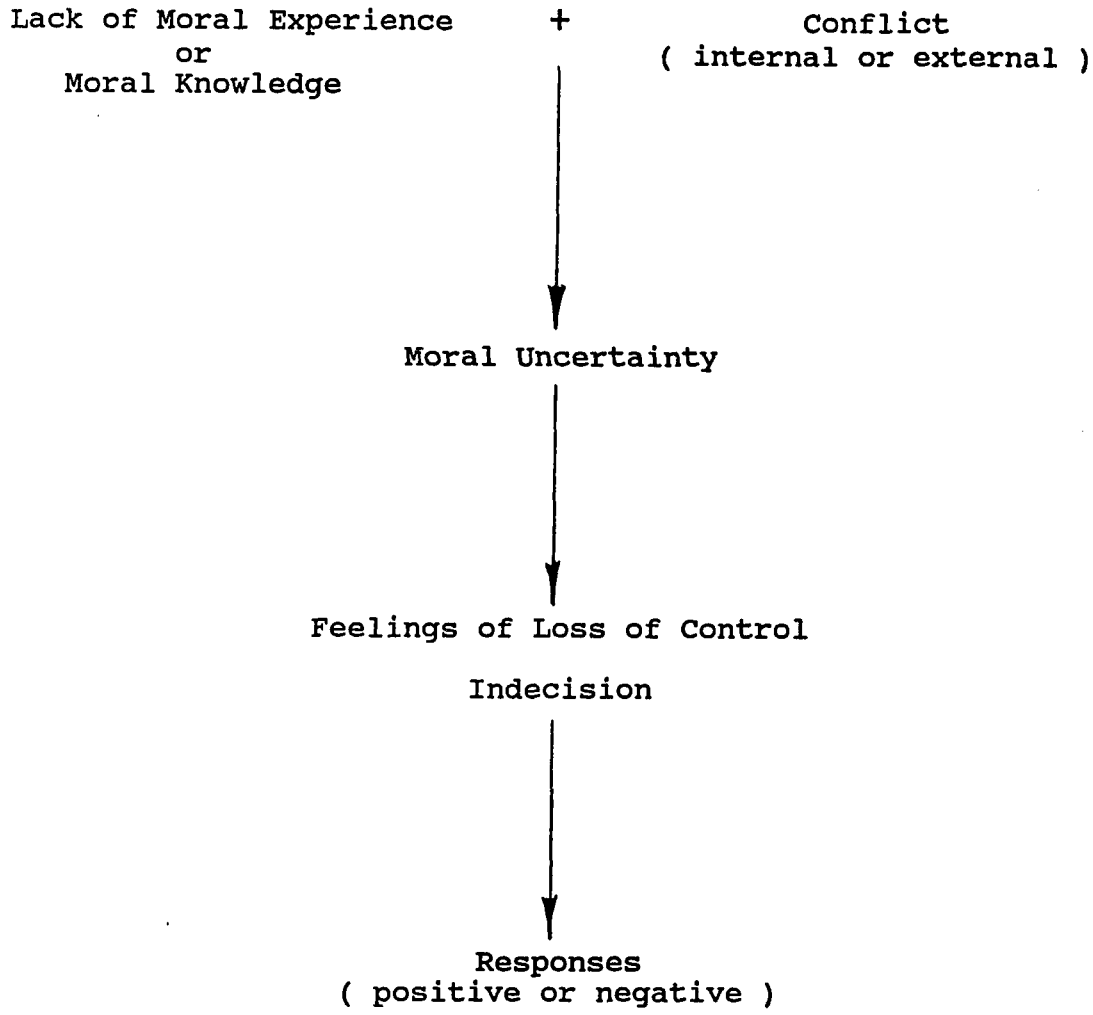


Figure 1. Model of Moral Uncertainty.

"memorize the conventional scripts of biomedical ethics". She believes that when the traditional moral theories fail to provide guidance for moral action, nurses question their own "moral competence". This uncertainty of questioning oneself reinforces the passive, subservient role of nursing according to Parker (1990).

A few authors describe the responses (see Figure 2) that are possible when one is morally uncertain (Corbin, 1980; Quinn & Smith, 1987). Quinn and Smith (1987) suggest acknowledging uncertainty, both for the nurse's sake and for the client's sake. They suggest participating in a dialogue about possible options in an attempt to make moral uncertainty a moral opportunity.

Quinn and Smith (1987) also see detrimental aspects to the typical responses to moral uncertainty. They believe that acceptance or tolerance of moral uncertainty, a common reaction, may lead to indifference to dilemma resolution and new knowledge which may be available.

Another possible reaction to moral uncertainty is described by Corbin (1980). She has found in her studies that there is a "conservative bias in uncertainty": when people are uncertain they choose the status quo because it has less uncertainty and responsibility. If one cannot make a choice, delay makes it possible to inspect further alternatives, and induces a "readiness to decide" (cognitive simplification) (Corbin, 1980). When the choice is not attended to, this

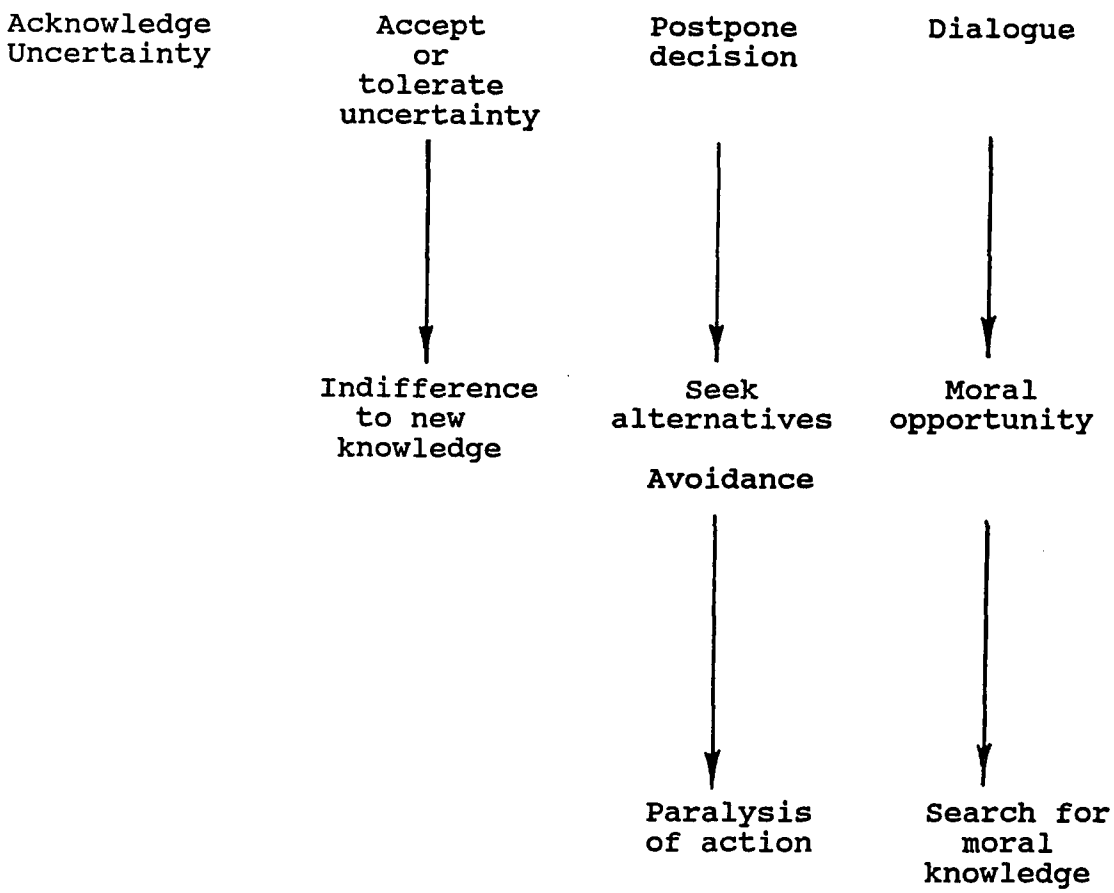


Figure 2. Responses to Moral Uncertainty.

inattention may involve avoidance or failure to perceive an occasion for choice (Corbin, 1980). Under these conditions, reducing the ambiguity of the decision may prompt conscious acknowledgment that a choice exists. Quinn and Smith (1987) caution that postponing an ethical decision due to uncertainty may lead to paralysis of action. However, most authors consider making no choice a viable choice (Quinn & Smith, 1987).

Generally, the consequences of moral uncertainty are perceived as described in the literature as negative by most authors and nurses. However, Quinn and Smith (1987) see moral uncertainty as a positive ethical opportunity whose result may be a search for ethical knowledge.

Moral Certainty

In contrast to moral uncertainty, moral certainty is based upon absolute conviction, psychological commitment, and the absence of doubt (Klein, 1981; Miller, 1978). This absolute conviction is based upon indubitable evidence that the absolute belief is "right". In addition, there can be no strong counter-evidence (Odegaard, 1982). Strong belief, coupled with convincing evidence, leads to moral certainty. In this study moral certainty is defined as the willingness to take action based upon an absolute conviction of the "rightness" of a course of action (see Figure 3).

Moral certainty may have different results, depending upon the nurse's potential to act upon the belief. If there

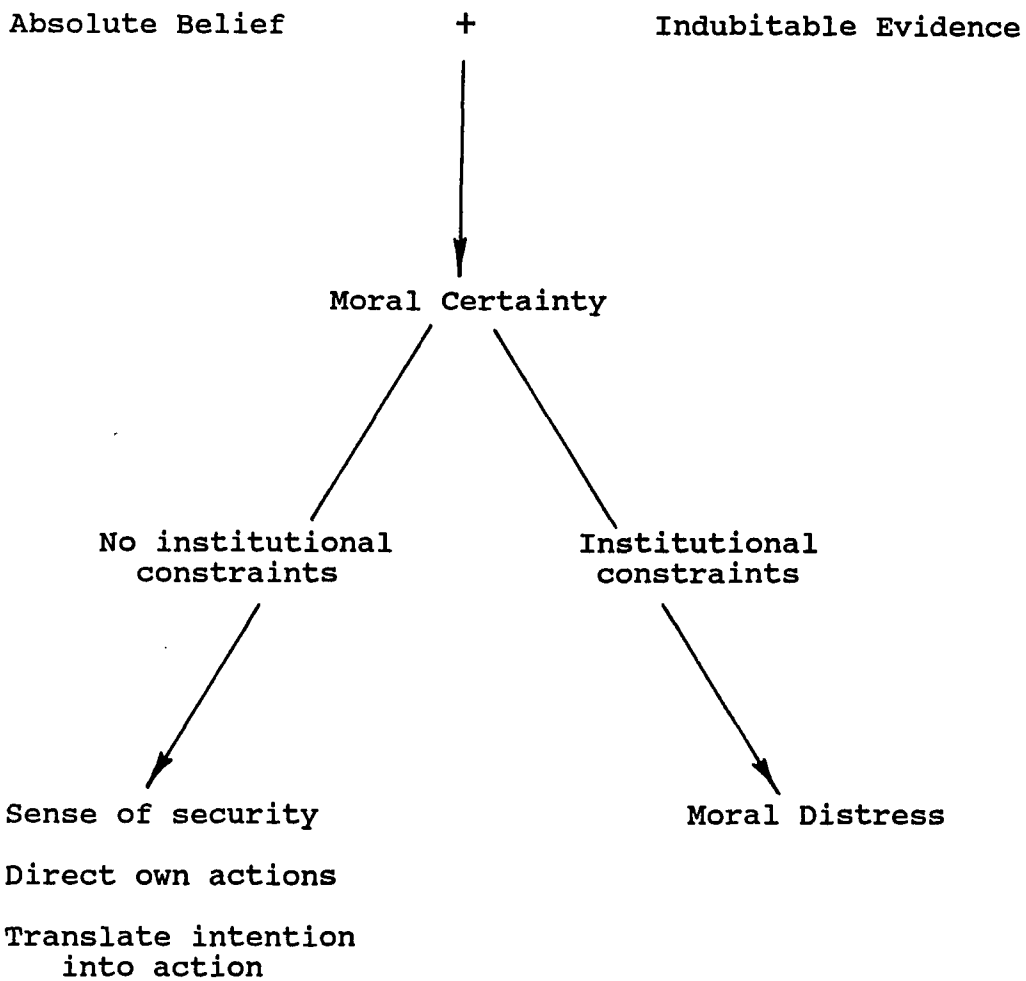


Figure 3. Model of Moral Certainty.

are no institutional constraints, the nurse may experience a feeling of security. In addition, the nurse may be able to direct his or her own course of action, thus translating intention into action (Quinn & Smith, 1987). Conversely, if there are institutional constraints which make action impossible, moral distress may result (Jameton, 1984). McElmurry and Yarling (1986) believe that nurses cannot be moral agents who translate beliefs into moral action, because of institutional constraints.

In summary, moral certainty and moral uncertainty are ubiquitous in the moral worlds of nurses. However, little has been written about the experience of moral certainty and moral uncertainty. The described model was the framework for this study and was based upon the nursing research, nursing ethics, and philosophical ethics literature. The model will be further evaluated in the final chapter of this paper.

CHAPTER III

METHODOLOGY

The study design, sample and setting, data collection instruments, and data collection procedures are presented in this chapter. Data analysis strategies are also discussed.

Study Design

A qualitative design was used to describe the experience of long-term care nurses with the issue of withholding or withdrawing artificial nutrition and hydration. The researcher examined the degrees of certainty experienced by nurses while dealing with this issue. The specific questions answered were: (a) Are nurses morally certain or uncertain about whether artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care? (b) If nurses are morally certain that artificial nutrition and hydration may or may not be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral certainty? and (c) If nurses are morally uncertain that artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral uncertainty? Because of the qualitative nature of the questions and the lack of previous studies in this area, this

exploratory-descriptive design was deemed appropriate (Brinks & Wood, 1988).

Sample and Setting

The target population of this study was baccalaureate-prepared nurses working in long-term care settings in Northeastern and Southeastern Wisconsin. The selection criteria for participants were that the participant be a nurse with a baccalaureate degree, be employed in long-term care, and that they have experience with the issue of withholding or withdrawing artificial nutrition and hydration from elder residents of a nursing home. The sample was restricted to baccalaureate degree-prepared nurses because it was believed that the findings could then be generalized to a specific group of nurses.

A letter requesting participants was sent to the Director of Nursing (see Appendix A) of every nursing home in Northeastern and Southeastern Wisconsin. In this letter, the criteria for selection of participants were stated. The Director was asked to contact each of the agencies' baccalaureate-prepared nurses who met the criteria, requesting their consent to take part in the study. Postcards and letters for each nurse who met the criteria were included with the letter (see Appendix B). A returned postcard from each participant implied consent to participate.

Forty nurses working in long-term care facilities in Northeastern and Southeastern Wisconsin returned postcards.

The Brim Desire for Certainty Scale was then mailed to each of the 40 participants, accompanied by an informed consent form (see Appendix C, D, and E). Of the original 40 participants, one requested to withdraw after receiving the Brim Scale, one person's work address changed and she was unable to be contacted, and nine did not return the Brim Scale. The remaining 29 participants were interviewed. Of those interviewed, one was later found to be an LPN, three were found to be diploma graduates, one interview was unintelligible, and one interview was deemed to be too short. Because these six participants did not meet the study requirements, they were deleted from the analysis. This left 23 applicable interviews. Two more participants who were uncertain about their response to this issue, and who also met the criteria for participation in the study, were known to the author. They were contacted and consented to be interviewed. This brought the total number of interviews to 25.

Data Collection Instruments

Data were collected with three instruments. These included the Brim Desire for Certainty Scale, an interview guide, and a demographic data sheet.

The Brim Desire for Certainty Scale

Originally the Brim Desire for Certainty Scale (see Appendix D and E) was to be sent to all participants and used to divide the sample into two groups, a certain group and an uncertain group (Brim, 1955). The author was going to

interview twelve participants who had a low score (high desire for certainty) on this scale and twelve participants who had a high score (low desire for certainty) on this scale. Research indicates that persons who score low on this measure are more intolerant of ambiguity, have less experience with novel or uncertain situations, and show lower levels of integrative complexity for uncertain situations (Kelman & Barclay, 1963; Kirscht & Dillehay, 1967; Schroder, Driver, & Streufert, 1967).

Another researcher was going to receive the completed Brim Scales, score them, and assign two groups of twelve participants each to this author to interview. The author would not know which participants belonged to which group (the certain or uncertain group).

The Brim Desire for Certainty Test was mailed to the 40 nurses who responded to the original request for research participants. Twenty-nine participants returned the completed scale. After receiving twenty-nine replies (only five more than originally planned) it was decided to interview all of the participants who responded in order to maintain a reasonably sized sample. This appears to have been a wise decision because, despite a specific request for baccalaureate or higher degree nurses, four replies were received from nurses who did not meet the participation criteria. In addition, one interview was very short and another was unintelligible. Twenty-three participants remained and two

more participants were recruited bringing the total participants to 25. These 25 participants were interviewed.

The Brim Desire for Certainty Scale consists of 32 statements related to everyday events. Each participant (40) was asked to decide the percent probability for each event occurring (1-100%) and their own degree of confidence that this event would occur by rating each estimate on a five point "sureness" scale from 1 (very sure) to 5 (not at all sure). (Please see a copy of the Brim Scale in the Appendix).

Scoring of the Brim Scale was based on the assumption that a strong "desire for certainty" would be expressed by two tendencies: (a) to select probability values close to the extremes of 0 and 100; and (b) to express confidence in these extreme choices. Thus, to determine a Brim Desire for Certainty score for a given test, the distance of each probability estimate from its nearest end point (0-100) was calculated and multiplied by its corresponding "sureness" score (very sure = 1, ..., not at all sure = 5). The resultant products were then summed over all 32 statements. By this procedure a low score indicates a high "desire for certainty" and a high score a low "desire for certainty". The test took approximately 20 minutes to complete. A computer program was developed to aid in scoring the questionnaires.

The Brim Desire for Certainty Test has a split-half reliability coefficient of 0.81. Validity studies have shown that in comparing this scale to other scales purported to

measure similar and different constructs, it has strong construct validity. A study by Brim and Hoff (1957) offers more evidence of construct validity for the scale. "Desire for certainty" was found to be significantly ($p<.05$) related to extreme responding on several measures, including a variety of attitude scales.

Interviews

The interview questions consisted of seven open-ended neutral questions (see Appendix F) designed to allow participants to express themselves without being influenced by the researcher. These questions were developed to allow the participants to describe in their own words their experiences with the issue of withholding or withdrawing artificial nutrition and hydration from elders in the end stages of life. It was believed that an orientation toward moral certainty or moral uncertainty would be evidenced in their responses to general, neutral questions about this issue.

Four of the questions were original. The participants were asked to describe a situation in which they had participated in which an elderly person in the end stages of life was having tube feeding withheld or withdrawn. They were then asked how they responded to this situation, why they responded as they did, and if they would have done anything differently.

Three questions were added after the pilot study to maintain logical flow in the interviews. The author asked the

participants for any additional comments, asked participants to discuss their professional background, and asked the participants if there were any consequences of their choice.

Demographic Data Sheet

The third instrument consisted of a demographic data sheet (see Appendix G) designed to determine whether age, education, religion, or professional position were related in any way to the person's degree of conviction about this issue. The demographic data sheet included three written post-interview questions designed to provide additional support for the validity of the analysis of the interviews.

Question 1 sought information about whether the participant considered this issue a dilemma. Question 2 asked, what, in the participant's experience, was the most frequently made decision in their facility (i.e. to withhold artificial nutrition or hydration, or both, to withdraw artificial nutrition or hydration, or both, or to artificially feed and hydrate). Question 3 asked whether or not the participant agreed with the decisions most frequently made in their facility.

A demographic data sheet was completed by each participant after each interview. The sheet was then placed into an envelope and sealed by each participant. The researcher did not see the results of the demographic information and the three additional questions until after all of the interviews had been analyzed.

Pilot Study

The interview questions, demographic data sheet, and the Brim Desire for Certainty were piloted with six nurses presently employed in long-term care. The pilot study was done to test the reliability and validity of the tools. During the pilot study three more, neutral, open-ended questions were added to the interview tool to allow for a smooth flow and logical conclusion to the interviews.

The demographic data sheet was also revised. After the pilot study, the demographic data sheet was changed to indicate that the three additional questions referred to the withdrawal or withholding of artificial nutrition and hydration not oral food and fluids. In addition, more verbal direction was given to participants after the interview and before completing the demographic data sheet because the three additional questions contained so many possible options that some of the pilot participants were confused by all of the options. These questions were retained, however, because they were deemed to be important and answerable with additional instruction from the researcher (see Appendix D).

Informed Consent

Rights of the participants in this study were protected by several methods. Written permission to begin the study was provided by both the University of Minnesota and the University of Wisconsin - Oshkosh Human Subjects Committees after review of the research proposal. An informed consent

form was signed by each participant and returned to the researcher (see Appendix C).

Participants were informed of the goals of the study and given the opportunity to withdraw at any time. They were assured that their identities would be confidential and that the gathered information would be recorded in anonymous form. In addition, participants were given assurance that no release of information would identify a specific individual or setting.

Data Collection Procedure

The author mailed 173 requests to all Directors of Nursing in Long-Term Care facilities in Southeastern and Northeastern Wisconsin. Included with the request were a letter to the Director of Nursing of the facility, informed consent forms for each potential participant, and a post card for each interested participant to return to the author. Forty replies were received for a return rate of 23%. Ten responses were received from persons saying they would like to participate, but that their facility did not deal with this issue or that in some other way they did not meet the criteria. Although the return rate may seem low, several explanations are possible. It may be that few baccalaureate-prepared nurses practice in long-term care in Wisconsin, that the facilities contacted may not have dealt with this issue, or that the request was sent to persons who did not meet the criteria. That is, they lacked experience with this issue.

Upon receipt of the post cards from those willing to participate, the Brim Desire for Certainty Scale was mailed to the 40 participants. Twenty-nine participants returned the Brim Scale to the Research Coordinator for the College of Nursing at the University of Wisconsin - Oshkosh. He received the replies and kept them confidential, scored the Brim Scale with a computer program developed for this purpose, and maintained this information until the analysis of the interviews was complete. The replies and Brim scores were purposely kept from the author in order to avoid any bias in the analysis of the interviews. The author did not want to know how participants scored prior to analyzing the interviews.

Twenty-five participants were contacted by telephone by the author, using the information provided on the returned postcard. Times, places, and dates for the interviews were arranged. Each interview lasted approximately 45 minutes and took place at a location chosen by the participant. Most of the interviews took place in the participant's place of employment or their home. The locations of the interviews varied. They occurred in offices, meeting rooms, chapels, homes, and one in a restaurant parking lot. The geographic locations varied from rural to inner city urban areas. The interviews were performed between the dates of August 1, 1991 and December 1, 1991.

Each interview was tape recorded after obtaining verbal permission from the participant. Each participant had also given prior written permission to tape recording the interviews on the informed consent form. After each interview the demographic data sheet with the three additional questions was given to each participant to complete. The completed sheet was sealed in a numbered envelope and returned to the author.

During the interviews, it became evident that the majority of the participants had convictions about the issue of withholding or withdrawing artificial nutrition and hydration. Because only two of the original sample were categorized as uncertain, and this author felt that a category of two was not large enough to make generalizations, another nurse researcher was consulted about the possibility of developing a nominated sample of "uncertain participants" to supplement the original sample. Two more "uncertain" participants meeting the criteria for the study were found and interviewed. This brought the number of participants identified as morally uncertain to four. Although this is not a large sample, it was deemed sufficient for a qualitative study.

During Fall 1991 (August - December 1991) the interviews were transcribed. Analysis of the interview tapes and transcripts was ongoing during the collection of data.

Data Analysis Procedure

The data analysis followed an adaptation of the seven - step method for qualitative analysis developed by Colaizzi (1978). First, the author listened to each of the interview tapes in their entirety to get a "feel" for them. From each interview, significant statements were extracted by the author while again listening to the taped interview.

The interviews were next divided into five categories based upon these significant statements. The five categories indicated the degree of conviction expressed by the twenty - five interviewees.

Various qualitative validity tests as suggested by Sandelowski (1986) were then performed to determine the validity of the interpretation of the interview data. These included methods to demonstrate credibility and confirmability -- going back to the participants and seeking recognition of the findings, and auditability -- the ability of another researcher to follow the "decision trail" used by the investigator in order to come to comparable conclusions. This researcher went back to one participant from each category (five degree of conviction categories) and determined with the participant that the category description correctly identified their strength of belief about withholding or withdrawing artificial nutrition and hydration. The author then presented five interview transcripts to another doctorally-prepared nurse researcher. The researcher was asked to place each of

the five interview transcripts into a category of conviction based upon the content of the transcript and a list of definitions of each category of conviction provided to the researcher with the transcripts. The categories of conviction included absolute moral conviction, strong moral conviction, moderate moral conviction, moral uncertainty with conviction, or moral uncertainty.

The above-mentioned researcher was able to associate four of the five transcripts with a category of conviction. The transcript which this author believed to indicate absolute moral conviction the other researcher found easiest to identify. The transcripts which indicated strong moral conviction and moderate moral conviction were somewhat more difficult to identify, but there was interrater agreement. It was the transcripts indicating moral uncertainty that were the most difficult to identify. Both transcripts were identified as moral uncertainty with conviction by the other researcher. This author had identified one as being morally uncertain and the other as having moral uncertainty with conviction.

All of the transcripts of the participants who were morally uncertain and morally uncertain with conviction were then reanalyzed by this author in an attempt to determine the basis for this disagreement. After the reanalysis, one of the transcripts was changed from the category of moral uncertainty to moral uncertainty with conviction. This resulted in a total of three participants who this author believes were uncertain

with conviction, and only one participant who was totally uncertain. The transcript about which there was disagreement is still considered by this author to contain a description of complete uncertainty. Both the auxiliary researcher and this author believe that repeatedly listening to the interviews on tape, as opposed to simply reading a transcript of the interviews would have improved the interrater reliability and made it easier to identify a particular tape with a category of conviction.

Next, each of the categories was again analyzed to determine the meanings of the significant statements (formulated meanings). Finally, the predominant themes in each interview were examined. Common themes appeared in all interviews of a category and in two cases appeared across categories in all 25 interviews.

The decision tree of this author was then examined by another researcher and found to be appropriate. The other researcher could agree with the themes that the author believed to be present in each transcript. There were no suggested revisions.

Finally, the Brim Desire for Certainty Scale and the demographic data sheet were analyzed after the entire qualitative analysis was complete. The Brim Scores were computed by the Research Coordinator at the University of Wisconsin-Oshkosh using a computer program developed for this purpose. He presented the author with a list of the

participant identification numbers corresponding to a Brim score for each participant. The author rearranged the list to order the scores from lowest (high desire for certainty) to highest (low desire for certainty). The author then compared the category of conviction into which each participant had been placed with their Brim Score. The results of this comparison will be presented in the next chapter.

The demographic data sheet was then analyzed. The participant's age, education, religion, and position in the organization were compared to their conviction category and answers to the three additional questions. A spreadsheet was developed with columns of information which made the pattern of the data emerge more clearly. In addition, the descriptive statistical characteristics (i.e. frequencies, mean, median, etc.) of the data were computed by the author. The findings from this data will be presented in the next chapter.

Summary

In summary, a qualitative design was used to describe the experiences of baccalaureate-prepared nurses in long-term care with the issue of withholding or withdrawing artificial nutrition and hydration from elderly persons in the end stages of life. Twenty-five baccalaureate-prepared nurses employed in long-term care were interviewed to determine their degree of certainty about this issue. In addition these 25 nurses completed the Brim Desire for Certainty Scale and a demographic data sheet. The results of the interviews as well

as the results of the Brim Desire for Certainty Scale, and the demographic data sheet will be presented in the next chapter.

CHAPTER IV

FINDINGS

The purpose of this study was to describe the experience of moral certainty and uncertainty as interpreted by nurses involved with the issue of whether to withhold or withdraw artificial nutrition and hydration from elders in the end stages of life in long-term care. This chapter describes the research sample and findings related to the phenomena (moral certainty and moral uncertainty). The participants in this study expressed five degrees of moral conviction about this issue. Each of these five degrees of moral conviction, including moral certainty and moral uncertainty, will be compared and contrasted. The data gathered from the demographic data sheet and the Brim Desire for Certainty Scale related to these five categories of conviction will also be described.

Description of the Sample

The sample consisted of 25 baccalaureate and masters-prepared nurses practicing in long-term care in Northeastern and Southeastern, Wisconsin. The sample was obtained by contacting all Directors of Nursing of Long-Term Care facilities in these two areas of Wisconsin and asking them to distribute requests to participate to all baccalaureate and master-prepared nurses on their staffs. Forty replies were received for a return rate of 23%. The Brim Desire for

Certainty Scale was then mailed to these 40 participants. Of these, 29 participants returned the Brim Scale. Six interviews did not qualify for the study. The interviewees were either not BSN or MSN graduates, the interviews were too short, or in one case an interview was garbled. Twenty-three of the 29 interviews were usable for the study. In addition, two more participants were obtained and interviewed through a nominated sample process. The additional two participants were obtained to enhance the number of uncertain participants. The findings from the sample, as described throughout the remainder of this chapter, refers to data collected from these 25 participants.

Table 1 presents frequency data concerning the demographic characteristics of the sample.

Table 1

Demographic Characteristics of the Sample

	N	%
Sex		
Female	24	96
Male	1	4
Age		
20-29	2	8
30-39	9	36
40-49	10	40
50-59	2	8
60-69	2	8
Religion		
Catholic	14	56
Lutheran	8	32
Presbyterian	1	4
Jewish	1	4
Christian	1	4

All except one of the respondents were female. The age range of the sample was from 28 years to 61 years. The mean age was 41 and the median age was 40. The majority of respondents (36%) were between the ages of 30 and 39 years. The majority of the sample (56%) were Catholic. The second most represented religion (32%) was Lutheran. The remaining religions represented were Presbyterian, Jewish, and Christian; each represented by four percent of participants.

Table 2 presents frequency data concerning the professional characteristics of the sample.

Table 2

Professional Characteristics of the Sample

	N	%
Educational Preparation		
BSN	21	84
MSN	4	16
Position in Organization		
Director of Nurses	8	32
Assistant Director	4	16
Staff Development Coordinator	3	12
Staff Nurse	3	12
Unit Manager	6	24
Administrator	1	4

Educational preparation at the baccalaureate or higher degree level was a prerequisite for participation in the study. Eighty-four percent of the sample were baccalaureate-prepared and 16% were master-prepared. Of the total participants, 32% were Directors of Nursing, 24% were unit managers, 16% were Assistant or Associate Directors of

Nursing, 12% were Staff Development Coordinators, 12% staff nurses, and 4% (one person) was an Administrator.

The sample generally represented a homogeneous group of long-term care nurses. All except one were female, many were in their thirties (36%), Catholic or Lutheran (88%), educated with a BSN or MSN (100%), and in management positions in their organizations (88%).

Findings Related to the Research Questions

Question 1: Are nurses morally certain or uncertain about whether artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care?

Five categories of moral conviction emerged from the data. The descriptions of these categories are summaries of the predominant themes in the participant's statements found in the interviews. Table 3 presents the five category descriptions.

Table 3

Degrees of Moral Conviction

Absolute Moral Conviction	-	Will act upon choices both personally and professionally, sometimes assuming risk to self personally or professionally.
Strong Moral Conviction	-	Will act upon beliefs personally, and most of the time professionally, but this depends on circumstance and who is more powerful.

Table 3 (continued)

Moderate Moral Conviction	- Will express views and act upon personal choices, but professional actions follow agency policies or MD orders.
Moral Uncertainty with Conviction	- Will express views and feel strongly about desired outcome, but uncertain which choice will lead to desired outcome. Desire to take the "right" action. Is not certain of what is "right".
Moral Uncertainty	- Unsure of what the desired outcome ought to be because is unsure of what is "meant to be". Is not certain of what is "right".

Each of the participants in this study fell into one of these five categories of conviction. Twenty percent (5 participants) were absolutely convinced (morally certain) that artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care. Another 16% (4 participants) had strong conviction that artificial nutrition and hydration may be withheld or withdrawn. Forty-eight percent (12 participants were moderately convinced. Twelve percent (3 participants) were morally uncertain about whether nutrition and hydration may be withheld or withdrawn, but convinced that residents should not suffer. Finally, four percent (1 participant) was totally uncertain about this issue. Table 4 contains the frequency data related to these degrees of conviction.

Table 4
Frequency Data by Conviction Category

N	%	Category
5	20	Absolute Conviction
4	16	Strong Conviction
12	48	Moderate Conviction
3	12	Moral Uncertainty with Conviction
1	4	Moral Uncertainty

Question 2: If nurses are morally certain that artificial nutrition and hydration may or may not be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral certainty?

The most distinctive feature of absolute moral conviction (moral certainty) found in this study was the willingness to act both personally and professionally on strong beliefs, sometimes assuming risk to oneself personally or professionally. The decisions made by these morally certain nurses were frequently irrevocable. They recognized this irrevocability, but were still willing to take whatever action was required. An example of this willingness to take action follows:

> Even with my grandparents, I strongly believe in following whatever their wishes are. I cry every time after I leave from seeing them because they don't want treatment when it's things that could even be treated and wouldn't take much to treat they don't want treatment. And I have to accept that. You know, I get upset when I leave because I don't want to ever lose them, but I realize I will and if that's their decision, that's how

> they want to go, I have to respect it. Other family members have called me and I have told them that you shouldn't make them do anything they don't want to do.

Another example is:

> Both of my folks were at the point where I either tube feed them or not so guess what, I said "no tube feeding". Okay, and in two days my Dad died. My mother - no way. She was 78. She laid there for 4 months with no tube feeding. When she finally died her bedsore was, what the doctor said he had never in his 20 years of experience seen, a bedsore where it was not only down to the back bone, but as wide as a volleyball. Now, I know that that does not seem humanly possible, but they would take a box of 8 x 10's and stuff it, that's how big this was and I wasn't tube feeding her. I do not believe that I had the strength not to tube feed and then she lived anyway. Okay. Finally, after four months she did die of infection. But the thing is, I was lucky that the doctor in charge of the facility was willing to go along with "no, no tube feeding, no antibiotics, no, no aspirin". Nobody could understand how you could live four months, but she did. It just shows you.

The basis for this absolute moral conviction was very negative experiences with tube feeding and the prolonged dying of elders in their care. They expressed these experiences in the interviews as horrifying images and stories about the tube feeding of elders who could not respond or defend themselves. Their descriptions of the suffering they had witnessed in long-term care related to tube feeding invariably conveyed their beliefs that tube feeding is inhumane, degrading, and cruel. The basic reaction expressed in the interviews was repugnance at the inhumanity of forced feeding. Frequently, they stated that they "could never do that" or "imagine living like that". In addition, this group of nurses also had very positive experiences with "natural death".

> I've worked the home for 33 years, but I've also worked in other places. I've worked in places where they've done everything with elderly people, and I've seen these people suffer so much, and they die in such a traumatic way, whereas our residents die very peacefully, very comfortably. Over my 33 years I have seen just about 100% of our residents die very peacefully without tube feedings. They have died such a natural death.

Generally in this study, the decision to withhold, withdraw or feed and hydrate was made by the person with the most influence. This might be the doctor, a family member, or a friend. If a morally certain nurse was present, he or she acted as a moral agent in the situation by trying to influence and intervene with the family of the elder. The morally certain nurses seemed compelled to influence the process and experienced cognitive dissonance when confronted with elders being tube fed.

As one nurse put it:

> Why do we tie people down to beds and drug them so that they're in a comatose state to keep a feeding tube in to keep them alive? I could not put this together with living naturally.

In addition, the morally certain nurses tended to be impervious to the influence of others. They had strongly held beliefs and tended to maintain them despite evidence which might have gone contrary to their views. For example, the strongly held belief that tube feeding causes suffering and that withholding and withdrawing nutrition and hydration leads to a quick, painless death might be contradicted by particular experiences, but maintained by the moral certainty that in the

long run and generally the strongly held belief was valid. This maintenance of the strongly held belief that tube feeding causes suffering seemed to be based on past negative experiences with tube feeding.

> I really believe these families do not realize what is going to happen down the road, meaning that the person will become just a piece of flesh in the bed. They're contractured and you are feeding them to keep them going. But, do you want them to have those terrible bed sores? Do you want them contractured? Do you want them to lie like that? I think tube feeding is so, so inhuman.

Question 3: If nurses are morally uncertain that artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral uncertainty?

In contrast to the plethora of experiences both positive and negative of the morally certain nurses, the morally uncertain nurses had relatively little experience with tube feeding elders. Because of this limited personal and professional experience they had very limited evidence either of the negative aspects of tube feeding or the positive aspects of "natural death". Their descriptions of tube feeding elders were more abstract and less emotional. One nurse described her experience with this issue as follows:

> I have never participated in any situation where they have had to withhold or withdraw tube feeding, but I have been aware of them. In one case the patient was deteriorating, there was not hope for her, she was comatose, the EEG's were unequivocal, there was very little brain activity. I didn't see very much, for like I said she wasn't on my patient load, but I remember going in the room, just out of curiosity mainly. She just kind of faded away.

In addition, the morally uncertain nurses took very little or no direct action to influence the process of decision-making. They sought permission, consensus, and agreement among the persons involved in the decision and were capable of being influenced by others or the situation.

> It is up to the doctor to talk to the resident. I need to talk to the doctor to see what measures are going to be taken. Generally there must be a consensus among family, doctor, and staff before tube feedings are withheld. As far as I am concerned, we will do whatever the family, resident, and doctor give us permission to do.

The morally uncertain participants in this study had specific uncertainties, along with the uncertainty of whether or not to withhold or withdraw tube feedings. One was uncertain of what the resident feels. For example, she wondered what it felt like to starve and dehydrate. Another wondered what the resident wanted. This nurse was a staunch advocate of advance directives which would tell her the resident's wishes. A third participant was uncertain about whether it is right to support the family's decision no matter what that decision. This nurse was in a situation in which a family was having treatment withheld from a resident who was not terminally ill. These three participants, although uncertain about aspects of the issue, also held the conviction that residents should not suffer.

The final uncertain participant and the only participant who was totally uncertain, was uncertain about what is "meant to be" or "supposed to be". Her uncertainty arose from the contradiction between what her religious acquaintances were

telling her and her experiences as a nurse. The following are her words.

> You get that ambiguousness, you know, and in certain circumstances it seems right and in certain circumstances not so right to do certain things. Like when I listen to the religious stations and people are very fired up over certain things, then it seems like I'm on the side of the pro-life people or the people who want to continue giving this person the food and fluid, but then sometimes when you are directly involved, then it's harder to be so cut and dried, sometimes, for those decisions. Uh, I think probably, like I say, I'd be real ambiguous with each of these circumstances that came. Um, you know, not knowing.

An again, in her words:

> Your morals and religious beliefs, I think that that one part says that, yes, you should do this, that's the right thing to do, but then in reality when you see different things, then it doesn't seem like it's wrong at the time, perhaps. You know, your upbringing or what has been indoctrinated or what you're hearing and you think you should believe dominates one side but then the reality of the situation kind of contradicts that sometimes, I think. I'm always in the middle of the road. If you could look to the future and know how that person would be, you know, you'd have the answer, but, it's, it's just tough to know and then, you know, sometimes to live with that decision. You know, to know what is the right thing to do.

Moral Certainty and Moral Uncertainty - Comparison and Contrast

Generally, the morally certain nurses were capable of expressing their viewpoint. In contrast, the uncertain nurses seemed to have had many questions that at least initially in the interview were inexpressible. These inexpressible questions seemed to result in mild to severe discomfort. For example, one nurse described the feeling of being uncertain as a feeling of being "all churned up inside". She expressed this internal conflict as a feeling of being "torn" -- seeing

both sides of the question, but being uncertain about which side was "right".

The morally uncertain nurses experienced the issue mentally rather than through an actual physical experience. Many had not actually witnessed other's suffering. They were experiencing this issue, as one nurse described it, "more in my mind". None of the morally uncertain nurses believed they "knew" the answer, in contrast to the certain nurses who, based upon experience, believed they "knew" the appropriate action to take.

In addition, the morally uncertain nurses saw tube feeding as non-invasive and easy to take care of and empathized as much with the person making the decision to withhold or withdraw as with the dying person. Conversely, the morally certain nurses empathized with the elder and saw the tube feeding as a violation of the person. In fact, the morally certain nurses saw the elder as having severely diminished personhood while being tube fed. One nurse described the resident being tube fed as "nothing - absolutely nothing".

For both morally certain and morally uncertain nurses the decisions made, beliefs expressed, and actions taken or not taken were based on "gut feeling" rather than analytic reasoning. For the morally certain nurses beliefs were based on mental visualization of the physical torment of their residents and for the morally uncertain nurses mental

visualization of the imagined torment of starvation and dehydration. The following is one certain nurse's mental image of the torment of her residents:

> I am willing to take family members in to show them a tube feeder person because lots of times they do not know what they are getting themselves into. They watch this person deteriorate by the quarter of an inch. They look like they are dead, only they are living and they are staring at you. They get bed sores as big as your hand and you think to yourself "I just can't do this to my family". And they just stare up at you and they are all contractured and the families, they just stop coming. They can't believe what's happening and when they started it, it was the "right" thing to do.

In contrast, the following is an example of imagined starvation and dehydration and the almost inexpressible questions of an uncertain nurse:

> Even though I know they are in a vegetative state and that they probably aren't aware of it, I still feel like, well how do we, how much do we know they are aware of? Don't they feel the pain and hunger? I am respecting their wish, but am I really doing what, am I really, am I letting them, you know am I, is what I have done making them die an agonizing death?

The primary action of the morally certain nurses was to intervene with the family to influence the process. For many of the other nurses on all areas of the conviction continuum part of their conviction was that the family and process ought not be influenced by the nurse. This one belief seemed to be a moral certainty for many of the nurses not convinced of other appropriate actions in this situation.

> Sometimes other nurses upset me. I think "why do you tell them?" "why don't you let them make up their own mind?" I try not to let the family know my feelings, so that I do not influence them. I try to be an advocate, but try not to let the family know my true feelings. I try to give information, not sway the family and then carry out their wishes.

In summary, morally certain nurses evidenced very strong beliefs and a willingness to act upon their beliefs. They described their depth of experience with this issue through very graphic mental imagery. Their personal experience was the basis for their moral conviction. Their personal experience involved both positive experiences with natural death and negative experiences with death prolonged through tube feeding. Their negative mental images of prolonged dying were interpreted as inhumane, degrading, and cruel, while the positive mental images of natural death were seen as peaceful. For these nurses, emotion or feelings were the basis for their conclusions rather than analytic reasoning. They strongly believed in maintaining the integrity of personhood in the elders for whom they cared.

In contrast, the morally uncertain nurses had limited experience with this issue, and limited evidence of the elder's suffering. The descriptions of their experiences were more abstract and unemotional. They also tended to see the situation differently. For example, they saw the feeding tube as noninvasive and tended to empathize with the family or other decision-maker rather than the elder. In some cases the lack of experience and different interpretation of the

experiences they had had, led them to conclude that withholding or withdrawing tube feeding causes suffering, but they were unsure of whether even this was true.

The morally uncertain nurse felt a great deal of ambivalence about this issue and did not take any action. In fact, not only did this nurse not take action, but in many cases had so much internal conflict about it that she/he was very uncomfortable with the question of what was the "right" course of action to follow. The primary physical result of this ambivalence was having difficulty asking their inexpressible questions.

Other Degrees of Moral Conviction

In addition to nurses who were morally uncertain or morally certain, this author found that the majority of nurses (48%) had a moderate degree of conviction and that another 16% had strong conviction about this issue. In fact, only 20% demonstrated absolute moral conviction (moral certainty) and of the 16% of morally uncertain nurses (four participants), two of them (8%) demonstrated strong conviction that suffering of elders was intolerable despite their uncertainty about whether tube feeding causes suffering. Overall, the author found that a majority of these nurses had moral convictions about this issue (92%). The difference between the categories of conviction seems to be the willingness to take moral action based upon one's beliefs.

The morally certain nurse acted both personally, and professionally. This action took the form of trying to influence her own family or the family of the resident respectively. The nurse with strong moral conviction (SMC) followed his or her convictions personally, but in some cases did or did not professionally. In the strongly convinced nurse, the beginnings of the taboo against influencing the family of the resident began to appear. As the degree of conviction decreased, the "influence taboo" seemed to become stronger. Moderately convinced nurses frequently mentioned not wanting to influence the family decision-maker. In fact, this "influence taboo" took on the characteristics of a moral rule that many felt must be followed and hoped other nurses would follow as well.

In addition, the moderately morally convinced nurse (MMC) acted upon personal choices and beliefs, but professionally followed agency policy or physician orders. This following of agency protocol, or the physician's orders, was combined with a belief that the issue needed thorough documentation. They frequently expressed the need for structured preplanning, often referring to documents such as the durable power of attorney for health care or the living will. These nurses respected the resident's wishes generally, but needed documentation that, in fact, these actually were the resident's wishes. In a few cases, the adherence to agency

policy went beyond expectations of what a nurse would do in order to follow agency policy.

> If a regulation came out and said I had to do this or that, I could go along with that if it were justified. I can't see anything changing right now, but I could always go with the flow. I'm okay with that; it doesn't bother me one way or the other. But then, I'm a person who could resuscitate someone who's 95 years old where somebody else couldn't do it.

In addition, one case of forced feeding was described.

> If a doctor orders an NG tube and they fight you and you tie them down -- you know, those are the only times I figure that you're fighting with a person and that does bother you. But, I still push -- I still push the fluids to her mouth myself even though I know she doesn't want them. I'll persist to that point. I will syringe-feed people. Sometimes that's tough to do. They are turning their head; they are disagreeing with you. But, I'm not putting that tube in their nose.

Following agency policy demanded much of some nurses because they disagreed with an agency policy, but was not a problem or concern for nurses who agreed with their agency's policies. Of all of these nurses, 76% agreed with their agency policies and only 24% disagreed.

One nurse described her concerns about the policies in the agency where she works and her moral concerns.

> Last week we had a Parkinson's patient. He is a severe Parkinsons and he spiked a temp at night. He keeps saying he wants to die and he has for years not wanted to live with Parkinsons anymore. Very unhappy, and so the family decided "Why treat this pneumonia, and the next one, and the next one, and just prolong it?" I felt really bad. I almost felt like this was a passive euthanasia type thing. You know, a decision was made about the quality of his life - that he doesn't have quality, so let's let him die of something that normally is not fatal. So, I didn't feel real good about it. In the past, you know, you had to have a cancer, you know, inoperable and not treatable, non-responsive or whatever. Now it seems to be that as

> long as the family delineates what it is they want and sign it and get the doctor to agree, that we are supportive to them, despite our personal feelings.

In summary, nurses with strong moral conviction (SMC) in contrast to nurses with absolute moral conviction (AMC) were willing to act upon their beliefs personally, but professionally they believed the decisions related to dying belonged to the individual resident or family. Those nurses with moderate moral conviction (MMC) expressed their views and also acted upon personal choices, but professionally followed agency policies or physician orders. Morally uncertain nurses with conviction (MUWC) expressed their views and felt strongly about the desired outcome (to reduce suffering) but were uncertain about what choice would lead to the desired outcome. In contrast to the morally uncertain nurse with conviction, the totally morally uncertain nurse was uncertain about what the desired outcome might be. She was uncertain about "what was meant to be". For both the nurses who were uncertain with conviction and the nurse who was totally uncertain there was a desire to take the "right" action, but uncertainty about what the "right" action might be.

In addition to the findings from the interviews, the demographic data also provided insights into this issue.

Demographic Data

The nurse's age did not seem to have a relationship to the nurse's beliefs about this issue. In fact, there were

nurses of all ages who believed in withholding artificial nutrition and hydration.

Secondly, education did not seem to have a relationship to beliefs, primarily because all of the nurses chosen for the study had to have a BSN or MSN. Religion also seemed to make no difference in beliefs. The majority of participants were Catholic or Lutheran and had many diverse views, both pro and con. In addition, the nurses' positions in the organization did not seem to be related to beliefs. Most of the participants were managers who had many different views. For all of these demographic variables there did not seem to be a pattern or relationship between them and the expressed beliefs of these nurses.

Responses to the Three Additional Questions

The first question asked was whether withholding or withdrawing artificial nutrition and hydration from the elderly in the end stages of life was a dilemma. Sixty-four percent of the sample believed that it was a dilemma, although 12% believed it to be a dilemma for others, but not for themselves. Thirty-six percent did not believe this issue was a dilemma.

The second question asked was: In your experience, what decision is most frequently made - (a) to withhold artificial nutrition, hydration or both; (b) to withdraw artificial nutrition, hydration, or both; or (c) to feed and hydrate artificially? Eleven participants (44%) had experience

primarily with artificial feeding and hydrating. Eight participants (32%) had the most experience with withholding artificial nutrition and hydration. Five participants (20%) had the most experience with withholding or withdrawing artificial nutrition and hydration. One person was familiar with providing nutrition orally only (4%) and one person (4%) was familiar both with withholding artificial nutrition and hydration and with providing artificial nutrition and hydration.

The third question asked whether the participants agreed with the decision most frequently made in their setting. Sixteen participants (64%) did agree, six participants (24%) disagreed, and three participants (12%) said that "it depended" but that they agreed "most of the time".

Table 5 represents the answers to the three additional questions asked after the completion of the interviews and included with the demographic data sheet.

Table 5

Three Additional Questions

Question	Frequency of Response					
	Yes	%	No	%	Depends	%
1. Is withholding or withdrawing artificial nutrition and hydration from the elderly in the end stages of life a dilemma?	16	64	9	36	-	-
2. In your experience, what decision was most frequently made?						
To withhold artificial	-	-	-	-	-	-
Nutrition?	-	-	-	-	-	-
Hydration?	-	-	-	-	-	-
Both?	8	32	-	-	-	-
To withdraw artificial	-	-	-	-	-	-
Nutrition?	-	-	-	-	-	-
Hydration?	-	-	-	-	-	-
Both?	-	-	-	-	-	-
To withhold and withdraw?	5	20	-	-	-	-
To artificially feed and hydrate?	11	44	-	-	-	-
To feed orally only?	1	4	-	-	-	-
3. Did you agree with the decision?	16	64	6	24	3	12

Note: Dash (-) indicates no response

These three questions were utilized in this study as a validity tool. The author wanted to determine if there was a pattern of moral conviction which would show up as a pattern in the interviews as well as in the answers to these three questions. A pattern did emerge (see Table 6).

Table 6

Pattern of Experience

Category	Age	ED.	Religion	Position	Dilemma	Decision	Agree
MU[a]							
	34	BSN	C	Manager	Yes	N&H	Yes
	41	BSN	L	DON	Yes	N&H	Yes
	42	BSN	C	DON	Yes	N&H	Yes
MUWC[b]							
	37	MSN	C	DON	Yes	N&H	Yes
MMC[c]							
	39	BSN	L	Staff Dev Coord	No	N&H	No
	42	BSN	L	DON	No	Feed orally No TF	Yes
	30	BSN	C	Asst DON	Yes	Withhold N&H	Yes
	36	BSN	C	Head Nurse	No	N&H	No
	41	MSN	C	AsstDON	Yes	Withhold N&H	Yes
	61	BSN	L	QMRP	Yes	N&H	No
	60	BSN	C	Staff	No	Withhold N&H	Yes
	50	BSN	L	DON	Yes	Withhold N&H	Yes
	41	BSN	L	AsstDON	Yes	Withhold N&H	Yes
	38	MSN	C	Staff Dev. Coord.	No	Withhold N&H	Yes
	28	BSN	L	DON	Yes	N&H	No
	42	BSN	C	Supervisor	No	Withhold N&H	Yes
SMC[d]							
	32	BSN	P	Staff	Yes	N&H	No
	42	BSN	J	Staff Dev. Coord.	No	N&H	No
	41	MSN	C	DON	Yes	W/W	Yes
	58	BSN	C	Health Service Coord.	No	Withhold N&H	Yes

Table 6 (continued)

Category	Age	ED.	Religion	Position	Dilemma	Decision	Agree
AMC[e]							
	47	BSN	C	Admin	No	Withhold Food	Yes
	47	BSN	C	Staff	Yes for others	W/W	Yes
	37	BSN	C	AsstDON	Yes	W/W	Yes
	35	BSN	C	DON	Yes for others	W/W	Yes
	29	BSN	L	Manager	No	W/W	Yes

Note:
[a] Moral Uncertainty (MU)
[b] Moral Uncertainty with Conviction (MUWC)
[c] Moderate Moral Conviction (MMC)
[d] Strong Moral Conviction (SMC)
[e] Absolute Moral Conviction (AMC)
N&H Nutrition and Hydration (Artificial)
W/W Withhold or Withdraw N&H
TF Tube Feeding

The pattern which emerged supports the qualitative findings of the study. The qualitative analyses of the interviews were performed before the demographic data sheet was examined by the author. The pattern that appeared was based upon the conviction categories already developed by the author prior to looking at the three additional questions.

The categories -- absolute moral conviction, strong moral conviction, moderate moral conviction, moral uncertainty with conviction, and moral uncertainty were to be correlated with specific belief about this issue. Those who were uncertain or uncertain with conviction only had experience with feeding and hydrating residents and agreed

with feeding and hydrating residents artificially. Those nurses with moderate moral conviction had experience with feeding and hydrating residents, and with withholding artificial nutrition and hydration. This group of nurses all disagreed with feeding and hydrating residents artificially and agreed with withholding artificial nutrition and hydration. The nurses who had strong moral conviction were also opposed to tube feeding and agreed with withholding tube feeding. Finally, those nurses with absolute moral conviction had the most experience with this issue which included both withholding and withdrawing tube feedings and they agreed with both withholding and with withdrawing tube feedings.

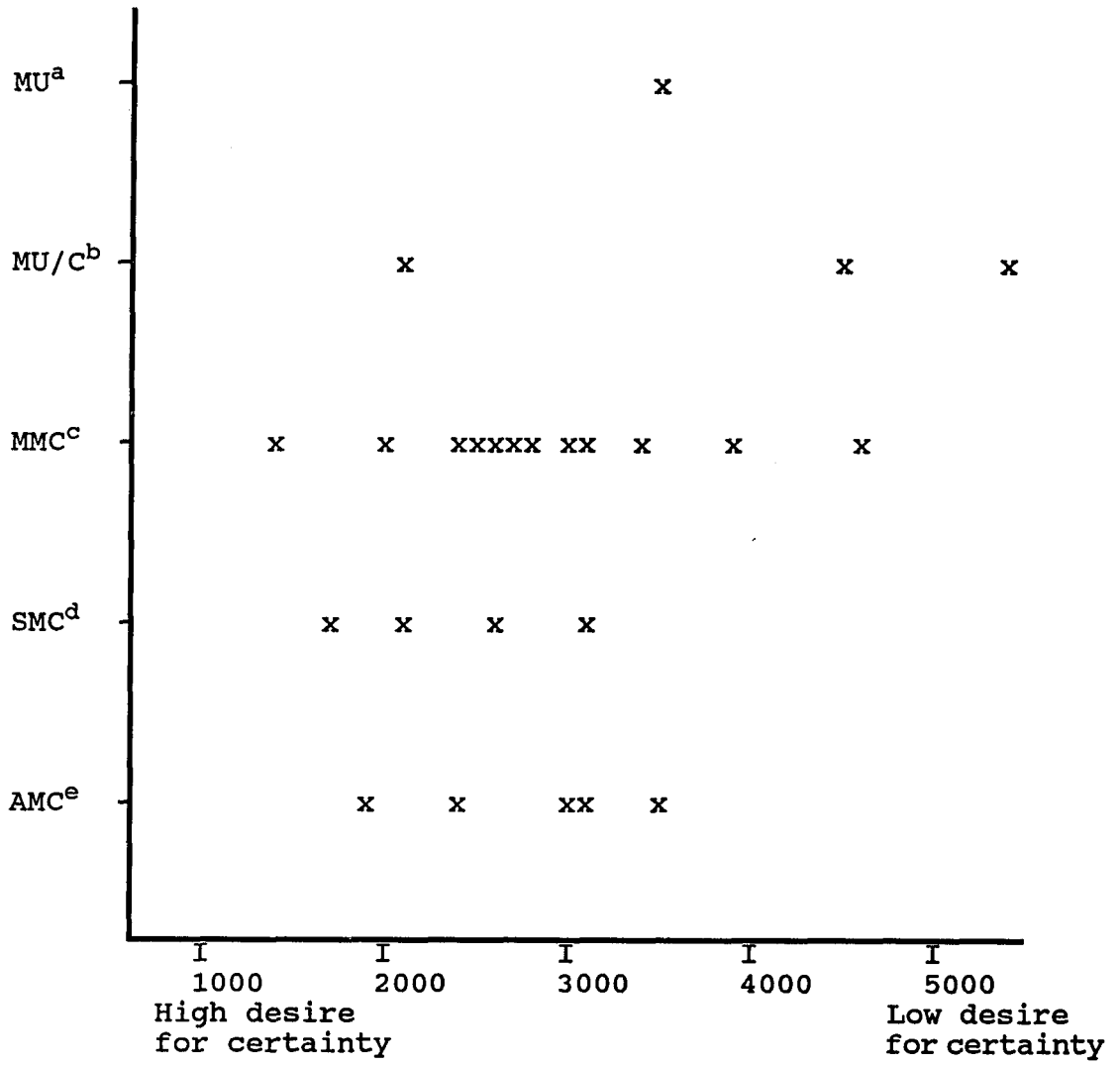
From the pattern displayed, nurses with the least experience with withholding or withdrawing tube feedings and with the most experience with feeding and hydrating residents, agreed with artificially feeding and hydrating residents. As experience increased, with the addition of the experience of withholding nutrition and hydration, nurses agreed with withholding tube feedings. Then, as nurses had even more experience and became more convinced, withdrawing nutrition and hydration was also viewed as appropriate. This apparent pattern will be discussed in the final chapter.

Brim Desire for Certainty Scale

The Brim Desire for Certainty Scale was originally included in this study as a mechanism for separating the participants into two groups, those with a high desire for certainty and those with a low desire for certainty. This would have given the author a method for validating that, in fact, the participants were being appropriately divided into two groups (certain and uncertain) during the qualitative analysis of the interviews. This separation into two groups using this scale was going to take place prior to the interviews. However, after the interviews (pilot study) were begun, it became evident that the majority of participants had convictions about this issue. In fact, it was not until nearing the completion of all of the interviews that uncertain participants were finally found. In addition, because there were so few willing participants, the author decided after the pilot study that all of those willing to participate were necessary for the study. For these reasons, although the Brim Desire for Certainty Scale was mailed to all participants, it was not used to divide the sample into two groups -- morally certain and morally uncertain participants -- and no participant was excluded on the basis of this scale.

Upon completion of the study the Brim Scale was considered another possible source of information. The author received a list of the participant numbers matched

with a Brim Score from the researcher who kept this information for the author. He had calculated the Brim Scores using a computer program developed for this purpose. The author took the list and ordered the Brim Scores from lowest to highest (most certain to least certain). The author then determined into which category of conviction each participant fell and compared this to the Brim Score (see Figure 4). Three of the four uncertain participants did have high Brim Scores (3000-5000) indicating a low desire for certainty. In addition, nine of the twelve moderately convinced participants had scores in the middle range (1500-3000), and all of the lowest Brim scores (1000-3000, indicating a high desire for certainty) belonged to persons with some degree of conviction. Two-thirds of these were participants who were categorized by this author as having strong or absolute conviction about the studied issue. The author used this information as supplemental data which showed some support for the qualitative findings, but did not assign great import to it, because the objective of using the tool was to divide the sample into <u>two</u> categories (moral certainty and moral uncertainty), not into <u>five</u> categories. The author did not know until the study was complete that five categories of conviction would emerge from the qualitative data, nor was the tool ever purported to reliably divide the group into five categories.



Note:

[a] Moral Uncertainty (MU)
[b] Moral Uncertainty with Conviction (MU/C)
[c] Moderate Moral Conviction (MMC)
[d] Strong Moral Conviction (SMC)
[e] Absolute Moral Conviction (AMC)

Figure 4. Brim Scores and Degree of Certainty Categories

Summary

In summary, twenty-five baccalaureate and masters-prepared nurses employed in long-term care in Northeastern and Southeastern Wisconsin were interviewed, completed a demographic data sheet, and the Brim Desire for Certainty Scale. Five categories of moral conviction were described by this sample of nurses related to the issue of whether to withhold or withdraw artificial nutrition and hydration from elderly persons in the end stages of life in long-term care. The characteristics of these five categories of conviction were compared and contrasted. In addition, the findings from the demographic data sheet were described. The Brim Desire for Certainty Scale was also briefly discussed.

CHAPTER V

DISCUSSION

In this chapter the conclusions, derived from the study, the discussion of the findings, and recommendations for future research will be discussed.

Conclusions

The primary conclusion drawn from this study is that, long-term care nurses have strong convictions about the issue of withholding or withdrawing artificial nutrition and hydration from elders in the end stages of life in long-term care. The majority of the nurses in this study (80%) were convinced that providing artificial nutrition and hydration was frequently not in the resident's best interests. These morally convinced nurses based their judgments on past negative experiences with tube feeding and past positive experiences with natural death. They expressed their conviction in graphic depictions of perceived inhumanity, cruelty, and degradation of tube-fed residents. The author considered that "certain" nurses may have been more willing to "volunteer" and "uncertain" nurses less willing because perhaps they did not want to talk about or expose their uncertainty, resulting in a sample that had strong conviction about this issue.

The degrees of conviction about this issue expressed by the participants varied, but fell into five categories of

conviction that emerged from the data. Of the total, 20% were absolutely morally convinced (AMC), 16% were strongly morally convinced (SMC), 48% were moderately morally convinced (MMC), 12% were morally uncertain with conviction (MUWC), and 4% were totally morally uncertain (MU) of the appropriate choice.

Those nurses who were absolutely convinced of their beliefs were willing to act upon their beliefs, both personally and professionally. Those with strong moral conviction acted upon their beliefs personally, and sometimes professionally. Those with moderate conviction acted upon personal choices, but generally followed agency policy within their professional role. Those nurses who were morally uncertain with a conviction that suffering is wrong, would express their views, but take no action. Finally, the totally morally uncertain nurse had difficulty expressing an opinion, and did not act upon beliefs about this issue.

Discussion of the Findings

Research Questions

Question 1: Are nurses morally certain or uncertain about whether artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care?

Eighty percent of these nurses were convinced that elders in the end stages of life in long-term care should not be tube fed. The beliefs of these nurses seemed to be based upon feelings that somehow tube feeding diminishes the person. They

expressed the belief that tube feeding was not only aesthetically repugnant, but also futile. They believed strongly that age is a factor in making nontreatment decisions and that these residents would be more humanely treated if not tube fed. The desired end for these residents was a "comfortable" and peaceful death.

Few called upon ethical principles to guide their conduct. Two mentioned the "rights of residents", and one the autonomy of the resident, but the majority seemed to base their ethical decisions on their own or the resident's level of comfort. Comfort seemed to be the criterion for judging the "rightness or wrongness" of any moral action taken.

Comfort is seldom mentioned in the literature except as it applies to "comfort measures" for the dying (during the course of this study a request was made to the Kennedy Institute of Ethics for a literature review of the concept of comfort, but no references were found).

Yet, every one of these nurses mentioned comfort level as the determinant of their moral actions, of the family's final choice, and as the outcome sought when educating the family. Comfort with an action determined for these nurses whether or not their beliefs were translated into moral action. This author questions whether there might not be times when moral action is appropriate despite a nurse's discomfort at taking the action. In fact, a Kantian ethic would suggest that duty

or obligation, although not always comfortable, be the basis for moral action.

Question 2 and 3: If nurses are morally certain or morally uncertain that artificial nutrition and hydration may or may not be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral certainty or moral uncertainty?

Five categories of conviction emerged from the data. These included absolute moral conviction (moral certainty) and total moral uncertainty. The most striking finding was that morally certain nurses were willing to act upon their beliefs and that morally uncertain nurses were unlikely to act upon their beliefs.

The more convinced a nurse was the more likely she was to intervene in the decision-making process. The primary nursing intervention of the absolutely morally convinced nurses was to "educate" the family. This education involved presenting options, showing the relatives a "tube feeder", and trying to support the family in making a "comfortable" decision. There was a great emphasis on the family accurately "seeing" the "true" predicament of the resident. In contrast, the less convinced nurses, those who were strongly convinced, moderately convinced, uncertain with conviction, and totally morally uncertain, tried not to influence the family's

decision. The taboo against influencing the family was almost a moral imperative.

Both morally certain and morally uncertain nurses based their judgments on images: the morally certain nurses on images of tube feeding and the morally uncertain nurses on mental images of what starving and dehydration must be like. There was great emphasis placed on this sensory evidence and little analytical reasoning expressed. One nurse mentioned ethical principles as a background for her decisions. She was concerned about ethical issues she had experienced in her life and career, and went back to school to study these issues in her Masters Program. Two other nurses tried to explain the scientific basis for withholding or withdrawing artificial nutrition and hydration, and several nurses believed they had read that overhydration could be deleterious to the dying resident. But generally, these nurses based their decisions on mental images of negative experiences with tube feeding or positive experiences with residents "sleeping away".

The major difference found between the literature and the findings of this study is that of assuming that nurses base their decisions on ethical principles rather than common professional values. This study supports a belief that nurses have "principles" that are specific to the nursing arena. These principles are not always those that nurse educators teach (i.e. autonomy, beneficence, nonmaleficence, justice). Only one of these nurses mentioned autonomy as a principle.

Two indirectly referred to justice in a discussion of resident "rights". But overall, traditional principles were not a part of these nurses' stories.

Recently, two nurse authors have emphasized developing the ethical principles specific to nursing from the experiences of nurses, as expressed in their stories (Benner, 1991; Parker, 1990). Given the findings of this study this would seem to be a very appropriate suggestion.

The extent to which moderately convinced nurses follow agency policy was also of interest. Yarling and McElmurry (1986) contend that institutional constraints make it impossible for nurses to be moral agents. Of the participants in this author's study, 64% were likely to follow agency policy despite their own opposing beliefs. Eighty percent of the participants had real concerns about trying to influence the family's decision. These nurses would not take any action that would oppose the resident's or family's wishes. The author concluded that although institutional constraints do not impede the decision-making of all nurses, many nurses do follow institutional policy or the resident's and family's wishes. Only 20% of nurses in this study would take a moral action based upon an independently held belief.

The percentage of nurses favoring inaction may be even higher, however, because those 20% who were morally certain and action-oriented were also employed in institutions where their beliefs corresponded with agency policy. In two cases

the nurses actually set the policy for the institution. In another case a nurse had moved from a previous place of employment where she had had difficulties because she disagreed with the doctors at the institution. In two other cases the nurses took action, but the actions were not actions that directly opposed the institution's policies. In this instance, the nurses tried to indirectly influence the process by influencing the family. The author questions to what extent agreement or congruence between nurse belief and agency policy affected the findings of this study.

This congruence between nurse belief and agency policy might explain the almost total lack of moral distress displayed by these nurses. According to Jameton (1984), moral distress occurs when institutional constraints make it difficult for nurses to base their moral actions on their strongly held beliefs. However, 19 of the 25 participants in this study (76%) agreed with their agency policies. The remaining 24% did not evidence moral distress despite a lack of congruence between their beliefs and their agency's policies. In fact, the only truly distressed nurses were the morally uncertain nurses with or without other convictions (16%).

The question must be raised as to whether the nurses with absolute conviction may not have been distressed because they were taking action based upon their beliefs, and therefore felt some sense of personal control, whereas, the nurses with

strong or moderate moral conviction felt no distress because their beliefs were not strong enough for them to experience a sense of violation of belief.

Serendipitous Findings

There were several serendipitous findings related to the context of this study. Changes in the way health care views this issue abounded in the nurses' descriptions. At one time the doctor made the decision, with or without the resident's and family's consent. Today, families and residents, and some nurses, influence the choice made. The decision to withdraw or withhold artificial nutrition and hydration was based, in these nurses' experiences, on the judgment of the person with the most influence: the doctor, family member, or resident. But, the institution in which the resident finds him or herself still makes, in many cases, the final decision.

The author was interested to find also that the resident almost never made the choice to forego treatment. In fact, few nurses even mentioned the resident having anything to do with the decision. The decision was most frequently made after the resident was cognitively impaired or in a vegetative state.

The author also found that the precipitants of the decision to withhold or withdraw artificial nutrition and hydration were most often dementia and strokes, both accompanied by communication and mentation difficulties. A persistent vegetative state was seldom diagnosed in these institutions because, the author hypothesizes, (a) there was

no reason to be that specific, (b) the staff (doctors and nurses) did not have the expertise to make this judgment, and (c) the question of a specific diagnosis seldom arose.

In addition to the above precipitants, in at least two cases a resident's continued expressed wish to die was acknowledged and acted upon by family and staff. The staff accepted the family's wishes to not have these residents treated for pneumonia or artificially fed and hydrated despite their belief that the residents were not terminal.

Demographic Data

Because all of these nurses were from a homogeneous sample, it was difficult to tell whether age, sex, religion, or education influenced these nurses' beliefs about the issue. None of these characteristics seemed to have an influence. Position in the organization, however, may have. The author was unable to determine this because almost all participants held management positions. The views expressed may be those of nurse managers, but not those of staff nurses. Staff nurses may have different beliefs, but did not respond to the request for participants, and so were not available for study.

Three Additional Questions

For the majority of these nurses (64%) the issue is not a dilemma, but for 36% it is a dilemma for themselves, or others. The majority of these nurses (44%) have experience with feeding and hydrating. Thirty-two percent have experienced withholding artificial nutrition and hydration,

and 20% have experienced withdrawing artificial nutrition and hydration. Seventy-six per cent of the participants agreed with the decisions made in their agency and 24% disagreed with the decisions made.

The pattern that emerged suggested that the more experience a nurse has with nontreatment (withholding or withdrawing) the more likely the nurse is to perceive this as an appropriate choice. When the nurse had experience with withholding alone, withholding was seen as an appropriate choice, but withdrawing was seen as inappropriate and impermissible. When the nurse had experience with feeding and hydrating only, providing artificial nutrition and hydration were seen as the only appropriate choices. When the nurse had experience with both withholding and withdrawing this was seen as permissible.

The question this raises is -- which comes first? Nurses with absolute moral conviction may have chosen agencies or professional situations which allowed for withholding and withdrawing tube feedings because these policies agreed with their own convictions. Or, the experience with a variety of action options may have increased their conviction that both withholding and withdrawing tube feeding was an appropriate and an acceptable action. It does seem, though, that as experience with more options occurs, nurses are able to accept more definitive measures.

Brim Desire for Certainty Scale

The Brim Desire for Certainty Scale was not used as initially anticipated. It was examined after the interviews were analyzed and was not used to separate the sample into two groups, a morally certain group and a morally uncertain group. It was not used because most of the sample displayed conviction of a degree and the tool was not intended to divide the group into five categories of conviction. In addition, because the sample was small all of the willing participants were interviewed.

Although the tool did seem to pick out 75% of the uncertain participants, 75% of the moderately certain participants, and two-thirds of the participants with conviction, it was not reliable enough to be used confidently. Because the most morally certain person in the entire study had a very high score (uncertainty) on the scale and one of the most uncertain participants scored low (certainty) on the scale, the author questions whether moral certainty the trait is different from moral certainty the state and the same might be true of moral uncertainty.

The author also questions, based upon the Brim Scale, whether moral certainty and moral uncertainty are issue-specific. It is possible to score high or low on this scale and still hold the opposite view of this issue. One might have the personality trait moral uncertainty and yet believe strongly or absolutely that elderly residents of nursing homes

not be provided with artificial nutrition and hydration. Conversely, one might have a personality trait for moral certainty and yet be uncertain about this issue.

Conceptual Framework

Finally, the conceptual framework for this study was evaluated. The conceptual framework, based upon the available literature, seems to describe moral certainty and moral uncertainty accurately.

The morally certain nurses in this study did base their judgments on a strong belief and they did have absolute conviction, psychological commitment to their choice, and no doubt about the rightness of their beliefs. In addition, they based their beliefs on compelling sensory evidence and, in fact, did not believe there was any strong counter-evidence, often despite considerable counter-evidence which was apparent to an "objective" observer. Without institutional constraints, these nurses directed their own course of action and were able to translate their intentions into actions. Although institutional constraints may have caused these morally certain nurses to feel moral distress, the author could not determine this effect because these nurses did not seem to be experiencing constraints. One of these nurses, the only male participant, did express mild frustration at the constraints of the organization. Two participants mentioned leaving

organizations where there were constraints, but did not seem morally distressed by the change of employment setting.

The theoretical model for moral uncertainty was somewhat more difficult to analyze. The morally uncertain nurses believed they lacked knowledge of the "right" course of action. Situational uniqueness and a lack of experience with this issue were major antecedents to their moral uncertainty. These morally uncertain nurses, however, did not appear to be struggling with questions about the application of ethical principles to the situation. In fact, only three participants ever mentioned principle as having a role in their ethical decision-making.

There did not seem to be a difference in basic values between the morally certain and morally uncertain nurses. Both believed strongly in preventing suffering. While their basic values seemed to be the same, they disagreed on how to achieve this relief of suffering. This disagreement may have occurred because the morally uncertain nurses lacked experience with nontreatment.

Norberg, Asplund, and Waxman (1987) suggest that persons may be able to be morally certain or morally uncertain and call upon the same principles; that much of the concern is about resident's suffering and that many of the problems are problems of fact not value, and, therefore, they are resolvable through empirical research.

The conflicts experienced by the morally uncertain nurses did not seem to be conflicts of principles or basic values. They did seem to be related in one case to a conflict between principle and role obligation, in one case a to conflict between equally unsatisfactory alternatives, and in one case to a demand for action while the nurse felt a need for reflection.

The consequences of, and response to, moral uncertainty did seem to be feelings of loss of control, although this was not expressed as such, and indecision. All acknowledged their uncertainty. All had come to tolerate, if not accept, their uncertainty. None of these participants was indifferent to new knowledge about this subject. All were postponing decisions, not to avoid the decision, but to delay it while looking for alternatives. In addition, although expressing a degree of mental paralysis or paralysis of action they were all actively seeking answers to their moral questions.

In fact, all of these morally uncertain participants were seeking the moral opportunity for dialogue about this issue by becoming participants in this study. They seemed to be actively searching for new facts which would sway them, one way or another.

The author believes that there are consequences of moral conviction and moral uncertainty which lead to social behavior and possibly social consequences. For example, what are the consequences for nurses of taking action based upon moral

certainty or not taking action based upon moral uncertainty? This conceptual framework makes suggestions about what some of these consequences might be. The author concluded that the conceptual framework for this study, although brief, does seem to accurately describe the phenomena of moral certainty and moral uncertainty.

Recommendations for Future Studies

The author has some suggestions for future studies:

1) Replicating this study with a larger sample, regionally, or in another area of the country would be beneficial in order to see whether the categories of conviction are supported. In addition, a second study might be completed with research questions that apply to acute care. Many of the nurses in this study believed the issue of withholding or withdrawing artificial nutrition and hydration to be more of a dilemma for nurses in hospitals than for nurses in long-term care.

2) The Swedish studies of Astrid Norberg et al. cited in the literature review could suggest many possibilities for replication and development of research surrounding the issue of withholding or withdrawing nutrition and hydration. The setting could be varied (hospital, nursing home, or home care) and the sample could be varied (young, elderly, or persons in a true persistent vegetative state). In addition, studies might more thoroughly explore the meaning of feeding behavior.

3) The phenomena, moral certainty and moral uncertainty, also suggest future research studies. What are the antecedents and consequences of moral certainty and moral uncertainty?

4) The conceptual framework of moral certainty and moral uncertainty used in this study might be further tested.

5) The idea that nurses have professional values which supersede moral principles taught in schools of nursing also requires investigation. Parker (1990) describes this as the search for a relational ethic of care. Silva and Sorrell (1991) also suggest examining nursing values. In the present study, preventing suffering was one of the underlying values expressed by these nurses. Are there other values upon which nurses base their judgments that affect their moral certainty or uncertainty?

6) The relationship between institutional constraints and following one's beliefs might be considered for study. In this study nurses with moderate conviction were likely to follow agency policy. Recently, two authors have discussed integrity and compromise. How does not taking a moral action and following agency policy effect nurses' views of their own integrity? Is compromise a legitimate form of moral behavior (Fry, 1989e; Benjamin, 1990)?

7) On what do nurses base their judgments and how do they justify their decisions? The nurses in this study were not using analytical reasoning, problem-solving, or nursing

ethical decision-making frameworks. They were responding to visual images translated into mental images.

8) Finally, the author questions why and how comfort relates to nurses' ethical decision-making. Do all nurses, in fact, use comfort as an intrinsic criterion for the judgment of right and wrong or is it a learned response to practice with its plethora of ethical issues? Do all health professionals use comfort as a criterion for judging right and wrong or is it a criterion specific to nursing? And, if it is a primary criterion for judging right and wrong, how does the level of comfort level relate to the fulfillment of obligations?

Summary

This author sought to answer three questions: (a) Are nurses morally certain or morally uncertain about whether artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care? (b) If nurses are certain that artificial nutrition and hydration may or may not be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral certainty?, and (c) If nurses are morally uncertain about whether artificial nutrition and hydration may be withheld or withdrawn from an elderly person in the end stages of life in long-term care, what is the experience of this moral uncertainty?

Thirty-one interviews were completed with BSN- or MSN-prepared nurses practicing in long-term care in Northeastern and Southeastern Wisconsin. Twenty-five of the interviews were usable. These twenty-five interviews were transcribed and a qualitative data analysis performed. In addition, a demographic data sheet with three additional questions was completed by each participant and analyzed by the author.

The findings of this study demonstrate that there are five categories of conviction into which the participants fell. These categories were absolute moral conviction (AMC), strong moral conviction (SMC), moderate moral conviction (MMC), moral uncertainty with conviction (MUWC), and moral uncertainty (MU). The majority of participants (80%) believed, with varying degrees of conviction, that it should be permissible to withhold or withdraw artificial nutrition and hydration from elderly persons in the end stages of life in long-term care. The remaining 20% were uncertain about whether it should be permissible.

The experiences of moral certainty and moral uncertainty, described by these nurses, were compared and contrasted by this author. Three other degrees of conviction were also compared and contrasted. The additional findings supplied by the demographic data sheet with three additional questions and the Brim Desire for Certainty Scale were discussed. Finally, the findings were interpreted and suggestions made for future research.

APPENDIX A

DIRECTOR OF NURSING COVER LETER

Dear Director of Nursing:

I am a Doctoral Candidate at the University of Minnesota completing my dissertation research. I am interested in knowing what the Baccalaureate and Masters prepared nurses in your agency have experienced when caring for residents whose relatives refuse tube feedings or who request withdrawal of a feeding tube from residents in the end stages of life.

If the nurses in your institution wish to participate in my research, I will be asking them to fill out a short questionnaire and participate in a short interview. The total commitment of time is approximately one hour.

Would you please distribute the enclosed packets to your BSN and MSN staff? If they would like to participate they may return the enclosed card to me and I will send them the questionnaire and make arrangements with them for an interview.

Thank you for your cooperation. I believe this study will develop knowledge which will benefit long-term care nurses and the residents of long-term care institutions.

Sincerely,

Mary Ellen Wurzbach, R.N., M.S.N.
Doctoral Candidate
University of Minnesota
[redacted]

APPENDIX B

RN COVER LETTER I

Dear Long-Term Care RN:

I am a Doctoral Candidate at the University of Minnesota completing my dissertation research. I am interested in knowing what you have experienced when caring for residents whose relatives refuse tube feedings or who request withdrawal of a feeding tube from the residents who are in the end stages of life.

Would you be willing to fill out a short questionnaire and to participate in an interview with me? The entire process will take approximately one hour. If you would be willing to participate, please mail this stamped self-addressed card back to me. I will then mail you the questionnaire and set up a convenient time and place for the interview.

Your responses are confidential. You can ask questions, refuse to respond to a statement, or withdraw from the study at anytime.

I believe your participation in this study will contribute to knowledge which will help you and your elderly residents. I hope you will consider participating and let me know this by returning the enclosed card.

Thank you for your cooperation.

Sincerely,

Mary Ellen Wurzbach, R.N., M.S.N.
Doctoral Candidate
University of Minnesota
[redacted]

APPENDIX C

CONSENT FORM

The Phenomenology of Moral Certainty and Moral Uncertainty

I, Mary Ellen Wurzbach, am an Assistant Professor at the University of Wisconsin - Oshkosh and Doctoral Candidate at the University of Minnesota. I am conducting a research study for the completion of my Ph.D in Nursing. The research is a study of the meaning of moral certainty and moral uncertainty for nurses.

I would appreciate your participation in this study. It will help clarify one of the ethical situations in which long-term care nurses find themselves -- that of withholding or withdrawing nutrition and hydration from nursing home residents in the end stages of life.

As a part of this study, I will ask you to answer a short questionnaire and participate in an interview with me. The interview consists of four questions and its length will depend on your wish to discuss this subject. The questionnaire will take approximately fifteen minutes to complete.

Although I could study this question by sending you a survey form, I am interested in hearing your actual experiences. An interview will allow me to speak directly with you.

I do not anticipate that this study will present any employment or social risk to you, other than the inconvenience of the time required to answer the questionnaire and to talk with me. In fact, participation in this research may benefit you by allowing you to discuss this topic. Hopefully the study will benefit long-term care nurses and residents of nursing homes generally, in that the experience of this situation will be clarified.

The information I gather through the interview and questionnaires will be recorded in anonymous form. I will not release information about you to your employer or to anyone else in a way which could identify you. If you want to withdraw from the study at any time, you may do so. The information collected from you up to that point would be destroyed if you wish.

Once the study is completed, I would be glad to share the results with you. In the meantime if you have any questions, please ask me or contact me:

Mary Ellen Wurzbach, R.N., M.S.N.
[redacted]

If you have any complaints about your treatment as a participant in this study, please call or write:

Chair
Use of Human Subjects Committee
C/O Grants Office
UW Oshkosh
Oshkosh, WI 54901
[redacted]

Although the chairperson may ask your name, all complaints are kept in confidence.

I have received an explanation of the study and agree to participate. I understand that my participation in this study is strictly voluntary.

Participant's Name _____ Date _____

Principal Investigator _____ Date _____

Audiotaping Yes _____ No _____

This research project has been approved by the University of Wisconsin-Oshkosh UHSC for the Protection of Human Subjects for a 1 - year period, valid until

_____

APPENDIX D

BRIM SCALE COVER LETTER

Dear Research Participant:

Thank you for returning the post card indicating your willingness to participate in my doctoral dissertation study. I hope that this experience will be beneficial for both of us.

The enclosed questionnaire will allow me to determine your beliefs about certain aspects of life. To fill out the questionnaire, please put to the left of the statement what you estimate to be the percent probability of that statement occurring. Enter a number from 0 to 100. Then, at the end of each statement tell me on a scale from 1 to 5 how sure you are of your answer, where 1 means you are very sure of your answer, 5 means that you are not at all sure of your answer, and 2, 3, and 4 are varying intermediate degrees of certainty or uncertainty.

For example,

40% Every time you wash the car it rains the next day. 1

means that you believe that, on the average, forty percent of the time after washing your car, it rains, and that you are very sure of your answer.

After you have completed this questionnaire, please put it in the stamped self-addressed envelope and mail it back to Merritt Knox, Research Coordinator in the College of Nursing at the University of Wisconsin - Oshkosh. After analysis, I will contact you to set up an appointment for a future interview time that is convenient for you.

Thank you for the time you are spending on this project.

Sincerely,

Mary Ellen Wurzbach
Doctoral Candidate
University of Minnesota
[redacted]

APPENDIX E

BRIM DESIRE FOR CERTAINTY SCALE

Percent probability of occurring (1 - 100)		How sure ? 1 = very sure - 5 = not sure
----	1. The chances that an adult male will earn at least $20,000 a year are about ... in 100.	----
----	2. The chances that a student entering law school will quit before getting his law degree are about ... in 100.	----
----	3. Frequent thumbsucking during childhood will make teeth stick out (cause buck teeth).	----
----	4. The President of the United States will be a man without a college education.	----
----	5. A major league baseball team will win the pennant if it is in first place July 4th.	----
----	6. A high school graduate will go on to a freshman year in college.	----
----	7. A couple getting married this year will later get a divorce.	----
----	8. An American male now at the age of 40 will live beyond the age of 65.	----
----	9. An American family will live in a place without a telephone.	----
----	10. An American family will own its own home.	----
----	11. The telephone number you call will be busy.	----
----	12. An American citizen will believe in God.	----
----	13. A varsity football player in an American university will be subsidized (given money for his football ability).	----
----	14. An American city of 50,000 people will have a chapter of the League of Women Voters.	----
----	15. The governor of a state will be elected for a second term in office.	----

---- 16. A son will go into the same kind of work as his father. ----

---- 17. A man 70 years old will need financial help from someone to support himself. ----

---- 18. Spanking a child will make him tell the truth the next time. ----

---- 19. An American-born baby will get a poor and inadequate diet during its first year of life. ----

---- 20. An adult male will stay home instead of going to church on Sunday. ----

---- 21. A sixth grade teacher in the public schools will be a man. ----

---- 22. A child whose parents are divorced will have emotional problems. ----

---- 23. In the United States a girl will be married before the age of seventeen. ----

---- 24. A world's champion boxer comes from a poor family. ----

---- 25. An American citizen will be bilingual. ----

---- 26. A five card deal will have two cards of the same kind (one pair). ----

---- 27. A man with a broken neck will die. ----

---- 28. A sexual deviant will have low intelligence. ----

---- 29. A given crime in the United States will be solved (someone arrested and convicted for it). ----

---- 30. The number of auto accidents in a year will be higher than for the previous year. ----

---- 31. A small business will fail within two years after starting. ----

---- 32. The person one marries will have the same religion. ----

APPENDIX F

INTERVIEW QUESTIONS

1. Describe a situation in which you participated in which an elderly person in the end stages of life was having tube feeding withheld or withdrawn.
2. How did you respond to this situation?
3. Why did you respond as you did?
4. Describe any consequences of your response.
5. Would you have done anything differently?
6. Is there anything else you would like to add?
7. Tell me a little about your background.

APPENDIX G

DEMOGRAPHIC DATA SHEET

Name _____

Age _____

Education _____

Religion _____

1. In your experience, is withholding or withdrawing artificial nutrition and hydration from a person in the end stages of life a dilemma?

Yes _____ No _____

2. In your experience, what decision was made?

To Withhold:
Artificial Nutrition ____ Hydration _____ Both _____

To Withdraw:
Artificial Nutrition ____ Hydration _____ Both _____

To feed and hydrate: _____

3. Did you agree with the decision? Yes ____ No ____

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