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Jones, Maxine Blackmon

A CASE ANALYSIS OF THE LEGAL, PROFESSIONAL, AND ETHICAL RESPONSIBILITIES OF REGISTERED NURSES FOR DISCLOSURE OF PROGNOSTIC INFORMATION TO DYING ADULTS

The University of Alabama in Birmingham

D.S.N. 1983

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A CASE ANALYSIS OF THE LEGAL, PROFESSIONAL, AND ETHICAL RESPONSIBILITIES OF REGISTERED NURSES FOR DISCLOSURE OF PROGNOSTIC INFORMATION TO DYING ADULTS

by
MAXINE BLACKMON JONES

A DISSERTATION

Submitted in partial fulfillment of the requirements for the degree of Doctor of Science in Nursing, in the School of Nursing in The Graduate School, University of Alabama in Birmingham

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Maxine Blackmon Jones

ABSTRACT OF DISSERTATION GRADUATE SCHOOL, UNIVERSITY OF ALABAMA IN BIRMINGHAM

Degree _	DSN	Major Subject Nursing		
Name of	Candidate _	Maxine Blackmon Jones		
Title _	A Case An	alysis of the Legal, Professional, and Ethical Responsibilities		
_	of Registered Nurses for Disclosure of Prognostic Information to Dying			
	Adults			

Information is desirable on factors affecting the decisions registered nurses must make as they attempt to respond to a patient's perplexing question, "Nurse, am I dying?" If a physician and family wish to spare the patient from the distress associated with learning about a fatal illness, what can the nurse do to assure that the patient's request for information will be met? The purpose of this study was to determine the legal, professional, and ethical responsibilities of registered nurses as they make decisions about disclosure of prognostic information to dying adults.

A case study design utilizing content analysis to examine issues and sub-issues was used to investigate three research questions. Data for analysis were selected from nursing, medical, legal, and philosophic literature. Two case studies were chosen for analysis. The <u>Tuma</u> case, an actual occurrence, involved an Idaho nurse who disclosed alternative treatment information to a dying adult who was suffering from leukemia. The <u>Yarling</u> case, a hypothetical situation, involved a nurse who faced a decision about disclosing a prognosis to a dying adult. Issues included due process, unprofessional conduct, professional nursing, health care provider-consumer relationships, informed consent, and disclosure. Sub-issues involved rights, responsibilities, conflict, confidentiality, and

deception in terminal illness. Kantianism and utilitarianism were the two ethical theories used to analyze the selected cases.

Major findings included that ambiguity in the definitions of unprofessional conduct and professional nursing created unclear consequences for nurses regarding the disclosure of prognostic information to dying adults. Some nurse practice acts have been interpreted to permit nurses to discuss alternative therapy or prognosis as one aspect of the nurse's duty to teach patients. Kantianism and utilitarianism supported nurses for not deceiving patients and for communicating relevant information to both patients and appropriate health care professionals. Implications for nursing practice and nursing education were discussed and recommendations for further study were enumerated.

Abstract Approved by: Committee Chairman fant S. Autry

Program Director School School

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CHAPTER I

INTRODUCTION

Introduction and Statement of the Problem

A literature review has led to the conclusion that nurses generally fulfill those responsibilities dealing with preservation of life or promotion of the quality of life. When confronted by terminally ill patients, decisions and actions by nurses were sometimes hampered by a secretiveness associated with terminal illness. In situations where diagnostic and prognostic information was kept secret from the patient, the nurse was faced with a conflict between a desire to meet the patient's request for information and an obligation to abide by the physician's plan of care.

In a study reported in <u>Dealing with Death and Dying</u> (1977), 15,000 nurses responded to the following question: "When a patient who has a terminal illness bluntly asks you if he is dying and his physician does not want the patient to know this information, what do you usually do?" (p. 141). Most nurses responded with the supposedly "correct answer": they would try to get the patient to talk about his feelings. This answer avoided open disclosure. Only one percent of the 15,000 responding nurses would tell the patient that he had a terminal illness.

A majority (85%) of nurses who responded to the <u>Dealing with Death and Dying</u> questionnaire stated that it was more difficult to care for a terminally ill person who had not been told his prognosis than to care for one who knew the facts of his illness. One nurse responded by saying, "I'm always afraid that I'll

say the wrong thing or act too sympathetically" (<u>Dealing with Death and Dying</u>, 1977, p. 158). When asked how many patients knew and referred to their impending death when physicians had refused to tell them, the nurses speculated that at least 58 percent of the patients knew that they were dying (<u>Dealing with Death and Dying</u>, 1977).

When Elizabeth Kubler-Ross (1969) was asked how many of the terminally ill persons with whom she worked knew their diagnosis even when the physician had not told them, she responded, "All of them" (p. 38). Thus, registered nurses who care for persons who are terminally ill may be placed in a conflict between meeting the patient's request for information and adhering to the physician's plan of care.

Additional information is desirable on factors affecting the decisions registered nurses must make as they attempt to respond to a patient's perplexing question, "Nurse, am I dying?" If a physician wishes to spare the patient from pain, trauma, and distress associated with learning that he has a fatal illness, what can the nurse do to assure that the patient's request for information will be met? This question becomes more significant when one considers the fact that therapeutic privilege is legally acceptable in situations in which the provider fears that disclosure may have negative effects on a patient (Rosoff, 1981).

Significance of the Problem

Registered nurses encounter dying patients in a variety of settings. These settings include hospitals, nursing homes, hospices, clinics, physicians' offices, nurses' offices, and patients' homes. In some rare instances the nurse may be the key decision maker, as when a nurse in private practice agrees to provide care to a dying patient and consults with a physician only to provide medical care. In

other more frequently occurring instances, the nurse is one member of a team of professionals who provide health care to dying patients in a variety of settings. In most of these traditional settings, the physician is considered the key decision maker for the entire health team. Thus, other team members assume a position in which they are expected to carry out the decisions of the physician. The position of registered nurses in the health care hierarchy often places them in a situation of great responsibility with little decision-making power (Jameton, 1977).

Research indicates that some physicians are reluctant to discuss openly with patients information about fatal illnesses (Cappon, 1962; and Caldwell & Mishara, 1972). The responsibility for obtaining informed consent for treatment rests with physicians, but they can invoke therapeutic privilege to withhold from the patient what they consider to be harmful information (Rosoff, 1981). What should nurses do when patients ask questions that place them in a conflict situation between withholding information because of physicians' directives and honoring patients' requests for information?

Statement two in the <u>Patient's Bill of Rights</u> gives credence to the patient's right to information concerning his own well-being.

The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in his behalf. (Thompson & Thompson, 1981, p. 212)

Furthermore, the International Council of Nursing's <u>Code for Nurses</u> indicates that "the nurse's primary responsibility is to those people who require nursing care" (Thompson & Thompson, 1981, p. 12). When a physician willingly or unwillingly withholds information from the patient, is the nurse responsible for

providing more complete disclosure? Do patients' terminal prognoses increase or decrease the nurses' responsibilities for providing them with information?

To withhold prognostic information from dying persons could deprive them of achieving some of their major life goals. For example, they may desire to give special attention to financial and spiritual affairs. Also, they may wish to make their own decisions about how they will live out their remaining, limited lives. The nurse receives guidance in decision making about disclosure from Section One of the American Nurses' Association's Code for Nurses with Interpretive Statements that includes the following statement:

When caring for a terminally ill or dying person, the nurse should use all the measures at her command to enable the patient to live out his days with as much comfort, dignity, and freedom from anxiety and pain as possible. His nursing care will determine, to a great degree, how he lives this final human experience and the peace and dignity with which he approaches death. (1976, p. 2).

Curtin (1978a) contended that it was a major task of health care professionals to refrain, as much as possible, from making decisions for patients. Health care professionals need to increase their skills in the analysis of ethical problems in order to help patients and families as they make difficult health care decisions. Jameton (1977) stated that a careful analysis of autonomy and role conflict could assist in explaining and perhaps in changing decision-making patterns in health care. Analysis of the current legal, professional, and ethical responsibilities of registered nurses as they make decisions about disclosing prognostic information to dying adults can guide nurses in a common and crucial area of nursing.

Purpose of the Study

Recent attention has been devoted to such areas as informed consent, patient rights, expanded nurse practice acts, and professional codes of ethics. Therefore, legal, professional, and ethical responsibilities of registered nurses may be changing in the area of disclosing prognostic information to dying adults. The purpose of this study was to determine through case analysis (Fromer, 1980) the responsibilities of registered nurses as they make decisions about disclosure of prognostic information to dying adults.

Research Questions

To address the purpose of this study the following three research questions were explored:

- 1. What are the legal responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults?
- 2. What are the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults?
- 3. Based upon Kantianism and utilitarianism, what are the ethical responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults?

Assumptions

This study was based on the following assumptions:

- 1. Law can provide valid direction for nursing practice.
- 2. Ethical theories can clarify relevant options for decision-making choices.

- 3. Specific professional codes and practice acts can provide valid direction for nursing practice.
 - 4. Case analysis can provide guidance for decision making in nursing.
 - Professional nurses are decision makers.

Definition of Terms

The following terms were identified for use in the study:

Case analysis -- in-depth investigation of an individual, group, institution, or other social unit (Polit & Hungler, 1978).

Content analysis — a method for the objective and systematic description of communications and documentary evidence which may be applied to such materials as letters, diaries, speeches, dialogues, reports, books, articles, and other linguistic expressions (Polit & Hungler, 1978).

Legal responsibilities -- those duties that must be performed as a result of the standards of human conduct established and enforced by the authority of an organized society through its government (Creighton, 1975).

Ethical responsibilities -- those duties, other than legal, that can be identified by a reasoning process about right and wrong human actions (New Oxford English, 1971).

Professional responsibilities -- duties that require one to behave toward others in certain ways as specified by occupational guidelines (Murchison, Nichols, & Hanson, 1982).

Registered nurses -- persons who are licensed to practice professional nursing as defined by the state nurse practice act (Bullough, 1980).

Decisions -- judgments based upon assessments of data and/or behavior (Bullough, 1980).

Disclosure — the release of information or the giving of knowledge in order to achieve a desired therapeutic result (Murchison et al., 1982).

Prognostic information -- facts and opinions about the prospect for survival and recovery from a disease, injury, or infirmity (Gove, 1963).

Dying adults — persons older than 21 years whose recovery from disease, injury, or infirmity is beyond reasonable expectation (Blackmon, Note 1).

Limitations

The following limitations to this study were recognized:

- 1. Professional codes do not have legal status and may vary widely in the interpretation of their statements as well as the extent of their influence in actual cases.
- 2. The case analysis method of study makes generalization of the results more difficult.
- 3. Conclusions pertinent to the care of adults may not be applicable to the care of children.
- 4. There are many ethical theories; no single one is espoused by all nurses.
- 5. Analysis of ethical responsibilities of nurses was limited to those based upon Kantian and utilitarian ethical theories.

Procedures

A case study design was used to investigate the three research questions. Content analysis was used as the research method. Issues were the specific units of content analysis employed in this study. In this context, issues were defined

as "questions of law, fact, or controversial matters which are not yet finally settled" (Gove, 1963, p. 1201).

The first step in the process involved deriving a classification scheme from the research questions. Thus, the three major divisions of classification were legal, professional, and ethical. The second step involved establishment of categories (major issues) and sub-categories (lesser issues); thus, categories and issues were used interchangeably. The issues and sub-issues were then submitted for review and establishment of face validity to two doctorally prepared nurse experts with extensive education and experience in nursing, nursing education, and nursing research. Based on the input of these experts, some structural alteration was made of the issues and sub-issues. Agreement was reached on the face validity of these issues by consensus among the nurse experts and the investigator.

The fourth and final step involved analysis of two case studies according to the content issues. Data for analysis were selected from nursing, medical, legal, and philosophic (including ethics) literature. Attorney briefs as well as selected personal correspondence were used as data sources. The content issues were chosen after review of a minimum of 300 selected articles and 50 books in the above areas of literature. The choice of issues was based upon their relevance to the selected cases and the frequency of their occurrence in the literature.

Two case studies were selected for analysis in this study because they most clearly illustrated the issues and sub-issues. The first case study, <u>Tuma v. Idaho</u>

<u>Board of Nursing</u> (1979), involved a nurse who discussed alternative treatment information, such as Laetrile and reflexology, with a terminally ill adult who questioned her about alternatives to chemotherapy in the treatment of leukemia.

Tuma was charged with unprofessional conduct by the Idaho State Board of

Nursing. Her nursing license was suspended for six months. A district court upheld the State Board of Nursing's decision to suspend her license. Tuma appealed to the Idaho Supreme Court which three years later reversed the lower court decision. The Idaho Supreme Court declared that the Board of Nursing had not adequately defined unprofessional conduct. In the higher court's opinion, Tuma had not been adequately forewarned; therefore, her conduct could not be judged as unprofessional.

The <u>Tuma</u> case was analyzed in the three broad areas designated by the research questions on legal, professional, and ethical responsibilities of nurses. Issues in the legal area were due process, unprofessional conduct, and professional nursing. The 1974 <u>Idaho Nurse Practice Act</u>, which was in effect when Tuma's nursing license was suspended, was examined for data on those three issues. Two legal consultants, practicing attorneys, were utilized to provide further information on the major legal issues involved in the <u>Tuma</u> case. Data were also obtained from the literature in which attorneys such as Gargaro (1978a) and Regan (1979b) discussed issues in the case.

Analysis of the legal issues proceeded by exploring alternatives derived from the data sources, and by posing relevant questions and responses, and determining, when possible, the consequences of selected alternatives. Examples of relevant questions which were considered in the legal area included:

- 1. Would a nurse be liable for an unprofessional conduct charge if she revealed alternative treatment information or a fatal prognosis to a questioning adult patient against the wishes of the patient's physician?
- 2. Would such a disclosure by the nurse exceed the scope of practice according to the definition of professional nursing?

3. What steps would be necessary to insure legal due process for the nurse if the nurse were to be charged with unprofessional conduct because she answered a patient's question for information about his condition?

The professional area of the <u>Tuma</u> case was reviewed according to the issues of health care provider-consumer relationships with sub-issues of rights, responsibilities, and conflict. The American Nurses' Association's <u>Code for Nurses with Interpretive Statements</u>, as well as the American Hospital Association's <u>Patient's Bill of Rights</u> (1970), provided data for these areas. Informed consent and disclosure were two additional major issues in the professional area. Disclosure included sub-issues of confidentiality and deception in terminal illness. Principles derived from <u>Tarasoff v. Regents of University of California</u> (Annas, 1976) were included. This case has been discussed in both ethics and legal literature because of its influence upon confidential patient-therapist relationships and the duties of therapists to warn others when a serious threat to life exists. Principles from <u>Canterbury v. Spence</u> were included because of its precedent-setting influence upon informed consent (Rosoff, 1981).

The second case analysis involved a theoretical incident found in the nursing literature and hereafter referred to as the <u>Yarling</u> case (1978a). This hypothetical case involved issues similar to those of the <u>Tuma</u> case. Special permission to use the case was granted by both Rod Yarling (the author), and Leah Curtin, editor of <u>Supervisor Nurse</u> in which the case was originally published.

In the <u>Yarling</u> case, an adult female patient questioned the nurse about her prognosis. The questions arose when the patient was a few days postoperative. At that time, the nurse knew from the patient's chart that surgery had established a diagnosis of carcinoma with metastasis which indicated a

progressing terminal prognosis. Two adult children and the physician wanted that information withheld from the patient because of her recent divorce and their desire to protect her from the further trauma of learning that she had a terminal illness. The nurse was faced with a conflict between a desire to meet the patient's request for information and the nurse's obligation to abide by the physician's plan of care.

An analysis of the theoretical legal areas pertinent in the <u>Yarling</u> case also involved the issues of due process, unprofessional conduct, and professional nursing. These issues paralleled those of the <u>Tuma</u> case. The American Nurses' Association's <u>Nursing Practice Act: Suggested State Legislation</u> (1980) was used as a source of information about the American Nurses' Association's recommended definition of professional nursing. Local attorney consultants also provided additional information about the legal issues in the Yarling case.

The issues used to analyze the <u>Yarling</u> case in the professional area were the same as those used in the <u>Tuma</u> case. Data sources were also the same in these two cases. A summary of these areas is presented in outline format in Figures 1 and 2.

Two ethical theories of utilitarianism and Kantianism provided the theoretical framework for this study. The theories are presented in detail in Chapter II. These two theories are identified by Curtin (1978a), B. Bandman (1978), and Jones (Note 2) as those which are used most often in nursing practice. Two major principles of utilitarian theory are the utility of the consequences of actions and the happiness of participants. Major premises in Kantianism are universal principles as actions and the consideration of persons as both means and end.

Human or other animal subjects were not involved in this research activity. Therefore, this study qualified for exemption from institutional review procedures. The term "patient" was used because it occurs more consistently in the literature of the various disciplines that were reviewed in this study. The personal pronoun "she" was used to describe a nurse and the pronoun "he" was used when a patient was discussed; no sexual bias was intended by the use of either term.

FIGURE 1

OUTLINE OF CONTENT ANALYSIS ISSUES AND DATA SOURCES

Content Issues

Data Sources

Case 1 Tuma (Actual Idaho Case)

- A. Legal Area
 - 1. Due Process
 - 2. Unprofessional Conduct
 - 3. Definition of Professional Nursing

Legal Area

Nurse Practice Act Idaho 1974

Attorney Briefs

Literature

- B. Professional Area
 - I. Health Care Provider-Consumer Relationships
 - a. Rights
 - b. Responsibilities
 - c. Conflict
 - 2. Informed Consent
 - 3. Disclosure
 - a. Confidentiality
 - b. Deception in Terminal Illness

Professional Area

ANA <u>Code for Nurses</u> with <u>Interpretive Statements</u>

AHA Patient's Bill of Rights

Literature

FIGURE 2

OUTLINE OF CONTENT ANALYSIS ISSUES AND DATA SOURCES

Data Sources

Case 2 Yarling (Theoretical Case)

A. Legal Area

Content Issues

- 1. Due Process
- 2. Unprofessional Conduct
- 3. Definition of Professional Nursing

Legal Area

American Nurses' Association
The Nursing Practice Act:
Suggested State Legislation

Attorney Briefs

Literature

B. Professional Area

- 1. Health Care Provider-Consumer Relationships
 - a. Rights
 - b. Responsibilities
 - c. Conflict
- 2. Informed Consent
- 3. Disclosure
 - a. Confidentiality
 - b. Deception in Terminal Illness

Professional Area

ANA <u>Code for Nurses</u> with Interpretive Statements

AHA Patient's Bill of Rights

Literature

Organization of the Dissertation

The report of this study consists of five chapters. Chapter I provides an introduction to the problem, significance of the problem, research questions, assumptions, definition of terms, limitations, procedures, and organization of the dissertation. The second chapter presents the two ethical theories, Kantianism and utilitarianism, as well as a review of literature related to the research questions. Chapter III includes an analysis of the <u>Tuma</u> case according to content issues, sub-issues, and the ethical theories. An analysis of the <u>Yarling</u> case according to content issues, sub-issues, and the ethical theories is presented in Chapter IV. Chapter V includes a summary of findings, conclusions, implications, and recommendations for future study.

CHAPTER II

REVIEW OF RELATED LITERATURE

The purpose of this chapter is to present a theoretical perspective from literature studies related to the legal, professional, and ethical responsibilities of registered nurses for disclosure of prognostic information to dying adults. The chapter is divided into two major areas. First, overviews of the ethical theories of Kantianism and utilitarianism are presented. Secondly, studies related to the research questions are presented.

Kantianism

Kantianism is a classic deontologic ethical theory which describes rules or principles of action that have moral validity independent of the consequences of individual actions (Brody, 1981). In Kantian theory, categorical imperatives are unconditional commands that are morally necessary and obligatory under any circumstance (Kant, 1965). Examples of categorical imperatives in Kantian theory are: to act only on maxims which one could consistently choose to be universal laws governing the behavior of everyone; never to treat other people merely as a means to some end; and to treat other people with autonomy which respects their freedom to make their own choices (Feldman, 1978).

Paton (1964) wrote that a maxim is a subjective principle of behavior. Pence (1980) indicated that a maxim is a rule of conduct which allows no exceptions. Pence (1980) and MacIntyre (1966) indicated that in Kantian theory

nothing is unconditionally good except a good will. Attention is focused upon the agent's will, motives, and intentions rather than upon his actions and their consequences. The motive of a good will is for one to do his duty merely because it is his duty (MacIntyre, 1966). Kant's view of practical reason presupposes a belief in God, freedom, and immortality. MacIntyre (1966) wrote that duty in Kantian theory is defined as obedience to categorical imperatives. Some selective examples of categorical imperatives as stated by MacIntyre (1966) are not to break promises, not to tell lies, and not to commit suicide.

Davis and Aroskar (1978) contended that Kantian theory indicates that when one makes a judgment about right or wrong human conduct in a given situation, one will make the same judgment in similar situations regardless of time, place, or persons involved. These authors described categorical imperatives as unconditional commands which are necessary and obligatory. These imperatives can be viewed as principles one would wish everyone to apply in all circumstances. Thus, one can understand why Kantian theory has sometimes been called universalism.

A key problem with Kantianism is its disregard of consequences as influential factors in moral acts. According to Kant (1965), moral rules have no exceptions; in difficult circumstances one must continue to abide by a rule such as "not to lie even to save the life of another person" (Pence, 1980, p. 44).

MacIntyre (1966) wrote that Kantianism builds upon an existent morality. He indicated that a problem exists with Kantian theory because it gives direction on things one should refrain from doing but is unclear on the positive things one could do. Feldman (1978) suggested that the great defect of Kant's theory was that Kant failed to develop adequate principles. "The careful reader is rarely confident that he knows precisely what Kant wants to say. His meaning is unclear and obscure" (p. 133).

Utilitarianism

Teleological ethics (also called consequentialistic ethics) refer to theories in which actions are judged to be right or wrong by judging the consequences of the actions (Brody, 1981). First, what is good is determined and then right is defined as whatever promotes that good.

A well-known example of consequential ethics is utilitarianism. This theory specifies that the ultimate principle against which consequences are to be judged is the general happiness of all people concerned, or the "greatest net balance of good over evil" (Brody, 1981, p. 295).

There are two basic types of utilitarianism: act and rule. Act utilitarianism requires examination of the consequences of individual actions to determine if those actions produce the greatest utility or happiness for the involved persons. Rule utilitarianism requires one to examine the consequences of rules requiring actions to determine if those rules produce the greatest utility or happiness for the involved persons. There are some problems with both act and rule utilitarianism, but for the purposes of this study both categories will be considered as two aspects of one theory -utilitarianism. In summary, for the purpose of this study utilitarianism will be considered as a theory which requires examination of the consequences of individual actions or the rules requiring actions to determine if those actions or rules produce the greatest utility or happiness for the involved persons.

A classic statement in John Stuart Mill's description of utilitarianism was:

...actions are right in proportion as they tend to promote happiness and wrong as they tend to produce the reverse of happiness. Happiness is intended to mean pleasure and the absence of pain; unhappiness means pain and the privation of pleasure. (Piest, 1957, p. 10)

Feldman (1978) wrote that utilitarianism could best be stated by the following principle: "An act is right if, and only if, there is no other act the agent could have done instead that has higher utility than it has" (p. 26).

Bentham, the originator of utilitarianism, thought that all pleasures were equally good (Pence, 1980). MacIntyre (1966) concluded that in Bentham's summation of the pleasures of a number of people, each individual was counted only once; no one person counted more than another. According to MacIntyre (1966), it was John Stuart Mill who introduced the idea that there was a qualitative difference between higher and lower pleasures. Mill believed persons would naturally prefer higher pleasure and he wrote that it was "better to be Socrates dissatisfied than a fool satisfied" (Mill, 1979, p. 14).

Pence (1980) identified the flexibility of utilitarianism as a strength which made this theory adaptable in a wide variety of different cases. Utilitarianism opposes rigid and absolute rules which can not be broken regardless of the consequences of those actions.

Gorovitz (1971) and Feldman (1978) identified two major problems with utilitarianism. First, utilitarianism is more concerned with society than individuals. Second, in some instances there is a lack of sufficient time to compute the greatest good for the greatest number.

Pence (1980) stated that some of the problems in utilitarianism involved clarification of what was a good consequence, whether pleasures were of equal value, and whether fetuses, children, and animals counted when computing the greatest good for the greatest number. He wrote that a very difficult problem in utilitarianism became evident when computing the greatest good for the greatest number; one was required to consider the desires of fanatics, sadists, and evil persons as well as saints, heroes, and good persons. MacIntyre (1966) concluded

that a major criticism of utilitarianism was the possibility of an innocent person being hanged to create happiness for the majority.

Studies Related to Legal, Professional, and Ethical Responsibilities of Nurses

An overview of significant studies includes selective works by nurses, attorneys, philosophers, physicians, and professional researchers. Studies selected were those which were most relevant to the research topic — legal, professional, and ethical responsibilities of registered nurses for the disclosure of prognostic information to terminally ill adults. Legal issues will be reviewed first. Studies were classified as legal when attorneys researched and reported on the effects of case law upon topics such as informed consent, therapeutic privilege, and duties of consulting physicians. Studies of the <u>Patient's Bill of Rights</u>, malpractice litigation, and the scope of nursing functions were classified as legal studies when they related directly to the influence of law upon nursing.

Professional studies were designated as those which involved topics such as nurse and physician attitudes toward dying patients, the information dying patients wanted to know, hospice care, and administrative influences upon nursing. Some studies on professional topics were done by experts in the care of terminally ill patients such as Hinton and Kubler-Ross. Studies of deception were conducted by Bok and Sheldon, philosophers, and are classified as philosophic research studies because of the type research which was conducted.

Ethical issues were involved in the legal areas such as informed consent and in professional areas such as deception. In some instances, as in the "Code of Ethics: An Ethical Basis for Nursing in Canada," principles identified both professional and ethical responsibilities. Ethical issues were not dealt with as a

separate category; rather, specific guidelines for determining ethical responsibilities were included in the discussion of ethical theories.

Legal Issues

Studies on the Patient's Bill of Rights

Kelly, a nurse, published a detailed study of the patient's right to know (1976). She proposed that eight of the twelve rights included in the American Hospital Association's Patient's Bill of Rights (1970) relate to a patient's desire to know information, or to be informed. A conclusion reached by Kelly from a review of numerous studies and popular surveys was that a majority of patients are tired of medical secrecy and are capable of coping with information regarding their health. She referred to the "Principles of Practice" of a health care center associated with the University of Vermont, which indicates that the best patient care is assured when the patient is part of the health care decision team and the patient and health care providers share medical records. National Commission on Medical Malpractice suggested a relationship between closed medical records and increased incidences of malpractice suits. Kelly stated that medical and administrative displeasure, subtle punishment, and loss of one's job were consequences with which a nurse might be faced if she informed a terminally ill patient of his condition when the physician refused to do so. She further indicated that the legal answer to such a situation confronting the nurse was unclear.

Sandroff (1978), a nurse editor of RN, indicated that by 1978, 28 states had enacted laws affirming basic tenets in the Patient's Bill of Rights despite opposition from some state associations of hospitals and physicians. She noted in a survey of RN readers that 302 of 431 respondents indicated their hospitals were taking positive action to insure patient rights (1978), while 129 of the

respondents stated their institutions were doing nothing to assure patient rights. The RN survey indicated that the 1974-1975 publication by the Department of Health, Education and Welfare of its Bill of Rights for Residents in Skilled Nursing and Intermediate Care Facilities had a stronger and quicker effect on resident care than the American Hospital Association document. The RN survey indicated that laws relating to patient rights had been enacted in California, Colorado, Minnesota, New York, and Rhode Island by 1978. Legally, patients at that time had access to medical records in Colorado, Illinois, Louisiana, Massachusetts, Mississippi, New Jersey, Oregon, Pennsylvania, Utah, Vermont, Wisconsin, and Wyoming (Sandroff, 1978). By 1978, legislation for informed consent had been passed in California, Delaware, Florida, Georgia, Idaho, Kentucky, Louisiana, Nebraska, Nevada, New Mexico, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, Texas, Vermont and Washington (Sandroff, 1978). A nurse from Minnesota wrote:

Our nurses are allowed to answer patient requests for information about their diagnosis, and to review anything in the chart with the patient unless the physician has specified to the contrary. If we do have a problem we can count on our supervisors backing us up. (Sandroff, 1978, p. 43)

The Sandroff study indicated that access to medical records created openness which permitted nurses to respond to patient requests for information about their condition.

Study on Open Access to Records

A Hasting's Center article, entitled "Giving Patients Their Records" (1982), indicated that for 25 years a hospital in Pamplona, Spain, has routinely given discharged patients a complete report on their diagnosis, treatment, and prognosis. The view in that hospital is that the patient is less disturbed about

what happens when the physician voluntarily shares information with him. Only two departments in the hospital are exempted from sharing directly with patients - psychiatry and psychology.

Studies on Scope of Nursing Functions

Two attorneys, Rozovsky (1978 and 1981) and Regan (1980a) provided reviews to guide nurses on legal aspects of nursing. These reviews included two examples of nurses who, according to state nurse practice acts, exceeded the scope of nursing practice. One nurse performed a tracheostomy in a hospital without first attempting to contact a physician. The other nurse inserted a stylet through a patient's subclavian line without having been taught that procedure. These authors advise nurses to delay executing a physician's order which they question and to contact the physician and also to seek direction from supervisory personnel such as nursing or medical administrators. Nurses were advised by Rozovsky (1978) to refuse executing orders if no reasonable, prudent nurse would carry them out. Regan (1981a) advised that the nurse would clearly be practicing medicine and violating the nurse practice act of every state if the nurse substituted her own judgment for that of the physician once a matter had been resolved by an attending physician or other medical authority. attorney advised that nurses record the steps they take when resolving doubts about a physician's orders. The legal reviews cited above provide insight into some of the legal responsibilities of nurses when they are in disagreement with physician directives.

An analysis of all 50 state nurse practice acts was reported by a nurse-attorney author team (Trandel-Korenchuk & Trandel-Korenchuk, 1980). Their analysis indicated that only two states, Oregon and Washington, give independent authority to nurses to prescribe medications for patients. They warned that

nurses often are not covered by malpractice insurance policies if they are practicing nursing activities which could be defined as outside the scope of nursing practice. Cobin (1980) confirmed that politicians have the final legal authority on the scope of nursing practice. Whether or not a nurse could disclose prognostic information to a terminally ill patient if the physician objected is a relevant scope of practice question.

Studies on Malpractice Litigation

Compazzi (1980), a nurse-researcher-consultant, studied malpractice litigation involving nurses during the years 1967-1977. She identified Louisiana as the state having the most lawsuits. States having no lawsuits were Hawaii, Maine, New Hampshire, and Rhode Island (1980). Alabama had 16 lawsuits while Idaho had only one.

Compazzi's study (1980) revealed several legal trends which may be significant to nurses. First, it was concluded that nurses are not now protected as employees of hospitals as they were in the past. Secondly, evidence indicates that courts have begun to consider national standards rather than locality rules during litigation. Thirdly, courts view nurses in a dependent role subject to the order of physicians although courts and physicians expect nurses to use independent judgment in supervision of patients and execution of medical orders. Based on the trends reported by Compazzi, it appears that nurses should seriously consider the lack of understanding shown by most courts regarding what a nurse does and the degree of professional judgment involved in direct patient care.

Morris (1981), an attorney, indicated that courts place nurses in a dilemma when nurses are expected to follow physician orders and also are expected to refuse to follow orders that they consider contraindicated in normal practice. He indicated that a combination of the emergence of the nurse as independently

responsible for her actions and an expansion of nursing roles has changed the emphasis from a nurse-physician relationship to that of a nurse-patient relationship. Indications are that the time span between these two studies (1967-1981) reveals a change in court attitudes toward a more independent role for nursing actions.

Study on the Duties of Consulting Physicians

Remaining legal studies deal with the duties of consulting physicians and with informed consent. A study aimed at identifying the duties of consulting physicians was conducted by Pope in 1977. Findings revealed that a consulting physician is customarily expected to report findings directly to the attending physician who then decides whether or not to share the information with the patient. In one court case a consulting radiologist failed to inform a patient that a needle had been left inside her abdomen during surgery. The consulting physician was named as a co-defendant with the surgeon in the ensuing lawsuit and was held liable for one-third of the damages (Pope, 1977).

Montange (1974) reported that failure to obtain an informed consent constituted malpractice and was viewed as negligence by some courts. He defined competency of a person as the ability at the time to understand the nature, terms, and effect of an agreement. Montange stated that the Supreme Court of Washington concluded that competency was presumed. He suggested that therapeutic privilege not be allowed as an excuse for failure to disclose to competent patients. Montange indicated that it was contradictory to view one as competent to consent and yet incompetent to receive upsetting information.

Schneyer (1976) reported a study done in Wisconsin where legal standards of informed consent had recently changed from a standard of adequate disclosure as defined by physicians to a standard of disclosure as defined by laypersons, a

jury, or a reasonable, prudent person. His study reviewed legal informed consent cases in order to explore the influence of medical bias upon informed consent practices. This study revealed that unequal power in the physician-patient relationship and the monetary interests by physicians in some forms of treatment could create a bias in the physicians' recommendations for treatment. Schneyer wrote that both American and British patients were more dissatisfied with the information they received or failed to receive from physicians than with any other aspect of medical care. She concluded that patients increasingly desired information related to decisions about treatment and that physicians often failed to satisfy those wishes.

Schneyer (1976) also revealed that some cases involving informed consent had been tried in court as battery cases and as examples of negligence. This procedure for litigating informed consent cases is similar to the previously discussed Montange study (1974) in which the informed consent cases were legally handled as malpractice and negligence cases. The Schneyer study quoted Judge Robinson, of the <u>Canterbury v. Spence</u> case, who stated that a patient's rights are "to receive, unsolicited, that information which the patient may require to make an intelligent decision" (p. 149). The term "unsolicited" indicated that patients should be informed without having to ask for information.

The Rice study on informed consent (1974) dealt primarily with the topic of therapeutic privilege defined as "an exemption of a physician from the obligation to inform a patient fully of his/her condition and of any recommended procedures prior to obtaining the patient's consent to proceed" (p. 503). This privilege is recognized if such communication would cause a patient's mental or physical condition to deteriorate. Recent decisions have placed some limitations on the exemption of therapeutic privilege. One limitation was that courts require patients to have complete information on new or radical procedures. A second

limitation resulted from the reluctance of courts to recognize therapeutic exemption when a patient had received no information about a proposed medical treatment. The trend was to require abbreviated disclosure if the news would unduly upset a patient. A 1960 Kansas case, Natanson v. Kline, contained a review of cases in which a diagnosis of cancer or some other dreaded disease could be withheld if its revelation would seriously jeopardize the recovery of an unstable, temperamental, or severely depressed patient (Rice, 1974). In that case, a patient's potential apprehensiveness about a procedure was sufficient to justify uninformed consent. Two major recommendations for limitations upon the use of therapeutic privilege were made in the Rice study:

- 1. Therapeutic exemption should not be used to excuse misrepresentation, overselling, or other forms of inducement. Untruthful or exaggerated disclosures are not compatible with the fiduciary relationship which should exist between physician and patient.
- 2. If the motive for incomplete disclosure is other than the prevention of injurious reaction to disclosure, the privilege should be disallowed. Carelessly applied, therapeutic privilege can make a mockery of a patient's right to choose treatment.

Studies related to legal issues were conducted primarily by attorneys. Topics such as informed consent, therapeutic privilege, and the duties of consulting physicians involved a review of case law. Studies on the <u>Patient's Bill of Rights</u>, malpractice litigation, and the scope of nurse functions have been cited because of their legal effects upon nursing.

Professional Topics

The final literature review section includes studies dealing with professional nursing issues. These studies focus on such areas as deception, what to

tell dying patients, what dying patients want to know, nurse attitudes toward the dying, physician attitudes toward the dying, hospice care, and administrative influences upon nursing.

Studies on Nursing Practice

Alford (1981) concluded from a descriptive study on legal hazards in nursing that nurses have a legal duty to make nursing diagnoses and to take appropriate action to meet the nursing needs of patients. One of the nursing needs of patients is for additional information about a patient's condition.

A group of nurses in Massachusetts stated their beliefs in relation to cancer patients in a study reported by Kastenbaum and Spector (1978). Their beliefs were that a patient has a right to know his diagnosis and treatment and to request and receive clarification from whomever the patient wished. They believed that the patient's right to have knowledge of his diagnosis in order to make decisions about care superceded the rights of family members. The nurse group agreed that a role for nursing existed in relation to a patient's diagnosis, but the role was poorly defined. Nurses believed that their role overlapped with the physician's responsibility to inform patients of their diagnosis, treatment, and prognosis.

Whitman and Lukes (1975) concluded in their case analysis study of behavior modification in terminally ill persons that patients must have honest, complete, and accurate information about diagnosis, prognosis, and estimated life span in order to make realistic plans for short- and long-range care. They stated that a dying person's bill of rights included receiving honest answers to questions and not being deceived.

In a study on ethical issues in cancer nursing, Whitman, Donovan, Spross, and Gadow (1980) wrote that a partial truth may help a patient to maintain hope,

but the entire truth allows a patient and family to make realistic plans and intelligent treatment decisions. Whitman et al. cited a study by Murphy (Note 3) which revealed that nurses reason in a manner reflective of obedience to authority and that nurses try to maintain harmonious relationships even when patients' rights are in jeopardy. Whitman et al. (1980) suggested altering organizational structures to allow clinical nurses to have a central role in decision making.

Fagin (1975), Wandelt, Pierce & Widdowson (1981), and Hayes (1982) concluded that dissatisfaction among nurses is largely due to inadequate decision-making power in nursing. In an article entitled "Panel recommends decision making by R.N.'s" (1981) which was published in <u>American Medical News</u>, it was suggested that nurses should become part of the clinical decision-making team. The recommendation resulted from a National Commission on Nursing study conducted by nurses, hospital management, medical, academic, and business leaders. The Commission reported that the national turnover rate in nursing is 30 percent and that exclusion of nursing from decision-making authority is a key factor in nursing dissatisfaction ("Panel recommends," 1981).

Studies on Nurse and Patient Attitudes

Studies of nurses' attitudes toward dying persons and about the information dying persons want to know are presented in chronological order to depict attitude changes over time. A study by Brown, Thompson, Bulger, and Laws (1971) revealed that patients talked to nurses more about euthanasia than they did to physicians. Dodge (1972) administered a 60-item questionnaire to 139 general hospital patients and 62 nurses to identify their beliefs about what patients should be told. Both patients and nurses agreed that it was important

for patients to be informed of their diagnoses and prognoses and how patients could participate in their own care while hospitalized.

Yeaworth, Kapp, and Winget (1974) studied 108 freshman and 69 senior nursing students to determine if there were differences in their attitudes or beliefs about death and dying. The conclusion was that senior students had become more receptive to patients' expressions of feelings and seniors were more open in their communication as a result of their nursing educational experiences.

A <u>Dealing with Death and Dying</u> study (1977) of nurses' attitudes included 15,430 nurse participants. When asked how they responded to a terminally ill patient's questions about his prognosis when the physician did not want the patient told, 82 percent of these nurses said they would distract the patient by getting him to talk about his feelings. Only one percent of the nurses indicated they would answer the patient's question honestly. A majority of nurses (85%) indicated that it was harder to care for a dying patient who had not been told the prognosis.

A clinical study by Keith and Castles (1979) on the expected and observed behavior of nurses in the care of dying patients indicated that terminally ill patients feel obligated to be cooperative patients. Nurses were more willing to accept idiosyncratic behavior from dying patients than patients were willing to accept in themselves.

A study by Barrett and Schwartz (1981) included interviews with 15 patients to discover what patients wanted to know about their illness. All 15 patients stated a desire to know their diagnoses, 14 of the patients wanted to know how illness affected their bodies, and 13 patients wanted to know their prognoses.

Mandel (1981) reported a study to determine nurses' feelings about working with dying patients. Forty nurses were asked to list issues that bothered them most when working with dying patients. They indicated feeling "caught in the middle" when a physician, for whatever reason, was not disclosing information to the patient. Withholding information from patients inhibited nurses from discussing psychological concerns with terminal patients.

A descriptive study reported by Sandroff (1981) involved 12,500 nurses in an attempt to discover the responses of nurses to physician actions in certain clinical situations such as in the care of dying patients. One item on the questionnaire used in the study stated that if the physician would not dicuss alternative treatments with patients, then nurses should. Eighty-three percent of the nurse respondents agreed with that statement. The remaining 17 percent of the participants responded that nurses are not qualified to discuss treatment alternatives with patients.

Eight studies involving the attitudes of nurses toward dying patients and the information dying patients wanted to know have been reviewed. Most of those studies were conducted between 1971 and 1981. One study conducted in 1977 revealed that approximately one percent of 15,000 nurses would tell a patient the prognosis if the attending physician did not want the patient to be informed. By 1981, another study involving 12,500 nurses revealed that 83 percent thought nurses should discuss alternative treatment information with patients if physicians would not do so.

Informed Consent Practices of Physicians

Rosoff (1981) reported study findings regarding informed consent practices of physicians. Of the 3,400 physicians who received the questionnaire, 800 chose to respond. Although the results were inconclusive, some important findings

emerged. Rosoff reported that physicians complained that disclosure required too much time, but results of the study indicated that two-thirds of all disclosure sessions consumed less than 15 minutes. Providing information, informed consent, and disclosure were used interchangeably in the Rosoff study. When asked who provided information to patients, 80 percent of the physicians reported they did themselves, and four percent allowed nurses or other non-physician professionals to provide information to patients. The Rosoff study clearly indicated that nurses sometimes provide diagnostic and prognostic information to patients with physician approval.

Studies on Physicians' Attitudes

Research studies about physician attitudes toward dying patients revealed contradictory results, but one consistent finding was that physicians are reluctant to discuss their attitudes about dying patients. Caldwell and Mishara (1972) reported that only 13 physicians out of a total sample of 73 consented to be interviewed about their attitude toward dying patients. After indicating an initial interest in the research project, most physicians refused to be interviewed when the topic was revealed to them. The interview involved a 32-item multiple-choice questionnaire. Results are inconclusive due to sample size. When asked if a patient has a right to know his diagnosis, all 13 physicians replied affirmatively. Eleven physicians indicated that they did not tell patients about their terminal diagnoses; all 13 physicians, however, said they did tell the family. Additionally, the physicians indicated that they thought patients knew they were dying without anyone telling them. Despite the limited number of participants, there is some evidence from this study that physicians do withhold diagnostic information from dying patients.

Novack, Plumer, Smith, Ochitill, Morrow, and Bennett (1979) reported on changes in physician attitudes about disclosure of cancer diagnoses to terminal patients. They found that in 1961, 90 percent of the 219 physicians at a university hospital who were studied through the use of questionnaires and personal interviews indicated a preference for not telling cancer patients their diagnoses. In 1979, the same questionnaire was given to 699 physician members of a university hospital medical staff. Responses were received from 264 physicians (40%). At that time 97 percent of the respondents stated preference for telling the cancer patient his diagnosis. Although this finding could signify a complete reversal of attitude the results from the small sample must be interpreted with caution. Perhaps physicians in a university setting are more progressive in their responses to the emotional needs of patients than physicians in other settings.

"Doctors shun telling patients they are dying" was the conclusion reported in <u>The Birmingham News</u> (1982) as the result of 3,000 questionnaires to members of the Texas Medical Association. Details of the study were not reported but the results varied from those reported by Novack et al. (1979). Of the respondents, 78 percent indicated that it was essential for a dying patient to be told his prognosis but 47 percent said they try to avoid directly telling a person that he is dying. Some physicians (27%) admitted that they try to avoid contact with dying patients. These results appear to reflect differing views of physicians toward what is told to terminally ill patients about their prognoses.

Tiger (1976), a physician, formulated three principles for dealing with persons who are terminally ill. He emphasized telling the patient the diagnosis, keeping communication open, and maintaining a team approach.

Veatch (1980) discussed two principles of physicians' ethics which deal with patient relationships. These principles dictate that physicians should deal

honestly with patients. Veatch indicated that physicians have traditionally considered honesty with patients to be secondary to their more fundamental commitment to protect the patient from harm. If dishonesty were required to protect a terminally ill patient from bad news, the deception was both permitted and required. Current Opinions of the Judicial Council of the American Medical Association (1982) states:

the social commitment of the physician is to prolong life and relieve suffering. Where observance of one conflicts with the other, the physician, patient, and/or family of the patient have discretion to resolve the conflict. (p. 9)

<u>Current Opinions of the Judicial Council of the American Medical</u>

<u>Association</u> (1982) further indicates that principles of medical ethics

require a physician to make relevant information available to patients, colleagues, and the public. The physician must properly inform the patient of the nature and purpose of the treatment undertaken or prescribed. The physician may not refuse to so inform a patient. (p. 28)

Recent revisions in the <u>Current Opinions of the Judicial Council of the American</u>

<u>Medical Association</u> reflect more open attitudes toward disclosure than in the past. Nevertheless, some physicians, as evidenced in some of the previously cited studies, continue to avoid contact with dying patients.

Studies on Hospice Care

Brief reviews of studies about hospice care are presented because it has been postulated that the hospice movement arose out of dissatisfaction with care for the terminally ill (MacElveen-Hoehn and McIntosh, 1981). Hospices in the United States have grown from one in 1974 (Wald, 1979) to 440 functioning hospices in 1980 (Smith and Granbois, 1982). Desires to improve care for the terminally ill led those involved in hospice care to advocate that patients be informed of their prognoses. Hospices define the unit of care as the patient and

the family. Death is accepted in hospices as a natural aspect of life where care can be provided to prevent patient isolation and abandonment. Interdisciplinary teams direct hospice care, but it is generally agreed that the bulk of care is provided by nurses.

Studies by Experts in Terminal Care

The final section in the review of literature deals with philosophic research on deception in terminal illness and data from experts on the care of persons with terminal illness. Kubler-Ross (1969) proposed that the question is not "should we tell ...?" but rather "how do I share this with my patients?" She reported that all patients knew about their terminal illness whether or not they had been explicitly informed. Her opinion is that the physician can do a great service if he can tell a patient about a malignancy without equating it with impending doom. She also mentioned that patients may lose confidence in physicians who deceive them or fail to help them face their serious illness.

Hinton (1967), a British psychiatrist who has expertise in care of the terminally ill, presented arguments for full disclosure to patients and arguments for non-disclosure. He presented data from the 1950s and 1960s to support the position that most physicians would not tell patients of a fatal prognosis. He advised that "in practice, the best and easiest way to broach the matter of dying with a mortally ill person is just to allow him to speak of his suspicions or knowledge of the outcome" (p. 132). He stated also that most medical personnel, including nurses, do not receive the help they need to deal with the problems that arise in caring for the terminally ill. His comments support the need for additional research in the care of terminally ill persons.

"The Code of Ethics: An Ethical Basis for Nursing in Canada" includes a statement of need for open communication with terminally ill persons. "Caring

dictates that the client and significant others have the knowledge and information adequate for free and informed decisions concerning care requirements, alternatives, and preferences" (1980, p. 19). The reality of death as a natural part of life is acknowledged and the Canadian Code encourages support to the dying person and family to enable them to prepare for and cope with death when it is inevitable.

Davies (1972), a British jurist, concluded that there may be no legal duty to warn patients that they are dying, but certain circumstances could create that duty. One of those circumstances would be if a patient and physician mutually agree that the patient will be told the truth by the physician.

Philosophic Research Studies

Both Bok (1978) and Sheldon (1982) published philosophic research studies that deal with deception in medical practice. Each writer presented comments to distinguish between lying, truth, truth-telling, and deception. Both writers presented arguments for and against disclosure to terminally ill persons. Sheldon concluded that all the writers quoted in his study, including Bok, advocated that a physician should inform a person that an illness is terminal. Physicians were cautioned that even patients who do not ask about their illness may want to know when an illness has been determined to be a terminal one.

The purpose of Bok's study (1978) was to examine those cases in public and private life where many people see good reasons to lie. One chapter was devoted to the topic of lies to the sick and dying. An important conclusion made in that chapter was:

If one wishes to lie to a patient, the decision must be filtered through showing how a patient may be harmed by disclosure or why a patient cannot cope with truthful information. To deceive must be seen as an unusual step. To deceive should be talked over with colleagues. For the great majority of patients the goal must be disclosure and the atmosphere one of openness. (p. 252)

She adds that patients fundamentally need to be able to trust their caregivers. Trust requires honesty in almost all cases. Bok advocated that open disclosure should be the usual health care practice in terminal illness.

Conclusions from Literature Review

This literature review indicated that nurses and patients desire an open approach to communication in terminal illness. There are conflicting data on physicians' attitudes toward communication in terminal illness. Legal studies reflected a trend toward openness, but they recognized a physician's prerogative to withhold upsetting information from patients. A relationship exists between job dissatisfaction in nurses and their exclusion from important administrative and patient care decisions. Philosophic studies indicated a strong value for openness and honesty to maintain trust in relationships. Conflicting influences create a lack of clarity about nurse responsibilities for disclosure to terminally ill adults. Since nurses provide sustained care to terminally ill patients, it is important to understand their legal, professional, and ethical responsibilities.

Summary

Two ethical theories — Kantianism and utilitarianism — have been presented in summary form as the theoretical framework for this research study. Significant studies on legal and professional issues pertinent to this study have also been reviewed; issues frequently overlap. Philosophic research studies identified some ethical responsibilities of health care personnel. Other ethical dimensions were discussed in the sections related to Kantianism and utilitarianism.

CHAPTER III

TUMA CASE ANALYSIS

The case analysis methodology utilized to examine the research questions in relation to the Tuma case is presented in Chapter III. The research questions include: what are the legal responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults; what are the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults; and based upon Kantian and utilitarian theories what are the ethical responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults? Tuma v. Board of Nursing (197.9) was the actual legal case chosen for analysis in this chapter. Content analysis of legal issues identified from an examination of the Tuma case included due process, unprofessional conduct, and professional nursing. Content analysis of professional issues included health care provider-consumer relationships, informed consent, and disclosure. Sub-issues in the relationship area included rights, responsibilities, and conflict. Sub-issues in the disclosure area included confidentiality and deception in terminal illness. Kantianism and utilitarianism provided the theoretical ethical structures by which the selected case was analyzed.

Tuma v. Board of Nursing - Case Overview

The first research question involved the legal responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults. It provided the direction to examine the legal issues in the <u>Tuma</u> case.

In March 1976, Jolene Tuma was employed by the College of Southern Idaho Division of Nursing as a clinical instructor (Regan, 1979b). She performed nursing services while supervising nursing students at the Twin Falls Clinic and Hospital. An examination of the literature did not reveal any information related to whether Tuma served as an employee of the hospital. Mrs. W., a hospital patient, was informed by her attending physician, whom she had known for two days, that her only hope for survival from leukemia was chemotherapy. Mrs. W. was informed by the physician that the drugs were life threatening and had undesirable side effects, including lowered resistance to infection which would require her to be placed in reverse isolation. Mrs. W. consented to the chemotherapy. Orders were written by the physician for the chemotherapy. The physician did not discuss laetrile or other forms of alternative treatment with Mrs. W.

Since Mrs. Tuma had a special interest in the needs of terminally ill persons, she requested that both she and a nursing student be assigned to Mrs. W. This assignment included administration of the initial dose of chemotherapy. When Mrs. Tuma and the student went to initiate the chemotherapy, they found Mrs. W. crying. The patient explained that she had controlled her leukemia for 12 years by eating natural foods, by avoiding drugs, and by practicing her Mormon religion. Despite Mrs. W.'s consent to the chemotherapy, she requested information from Tuma on natural alternatives to the chemotherapy. Tuma and

the nursing student initiated the intravenous chemotherapy while Mrs. Tuma discussed reflexology, nutrition, and laetrile with Mrs. W.

Only Mrs. Tuma, Mrs. W., and a nursing student were present at this initial treatment and information session. Mrs. W. asked Mrs. Tuma to return later that day in her off-duty hours to discuss natural therapy with her son and daughter-inlaw. Mrs. Tuma consented to return that evening when Mrs. W.'s family would be present. Mrs. Tuma did not report any of these interactions with Mrs. W. to the physician. One family member contacted the physician to inform him of the proposed evening session with Mrs. Tuma. The physician ordered chemotherapy stopped at 8:00 p.m. because he believed Mrs. W. had withdrawn her consent for the treatment. At the conclusion of the family discussion, a family member contacted the physician again. He was informed that all those who were present at the family discussion had agreed that Mrs. W. should remain in the hospital and continue the chemotherapy. The physician then ordered chemotherapy to be restarted at 9:00 p.m. The chemotherapy was interrupted for approximately one hour. Mrs. W. died two weeks later despite continued chemotherapy. Approximately two weeks after Mrs. W.'s death, the Idaho Board of Nursing received a complaint that Mrs. Tuma had been accused by the hospital on behalf of the physician of interfering with the physician-patient relationship.

The board established a hearing date for deliberation of the complaint against Tuma. It was alleged that Mrs. Tuma had interfered with the physician-patient relationship. It was determined by a hearing officer that Mrs. Tuma had violated the Idaho Professional Code by interfering with the physician-patient relationship; consequently, she had engaged in unprofessional conduct. After approving the hearing officer's findings, the board suspended Tuma's license for six months. Upon appeal the District Court upheld the action of the hearing

officer and the nursing board. This series of actions and appeals occurred over a two-year period.

Another year elapsed during which Tuma appealed to the Supreme Court of Idaho. That court determined that the nursing board had no rules or regulations which adequately warned Mrs. Tuma that her actions were prohibited. Therefore, the state statute which permitted the suspension of her professional nursing license could not be invoked merely because Mrs. Tuma discussed alternative treatments at the patient's request. The court ruled as follows:

We find nothing in the statutory definition of unprofessional conduct which can be said to have adequately warned nurse Tuma of the possibility that her license would be suspended if she engaged in conversations with a patient regarding alternative procedure. (Regan, 1979b, p. 4)

With no forewarning, Mrs. Tuma could not know that her actions constituted unprofessional conduct.

The <u>Tuma</u> case gained national nursing attention and generated the heaviest reader response in <u>Nursing Outlook</u>'s history ("Jolene Tuma Wins," 1979). Numerous nurse leaders responded in <u>Nursing Outlook</u>'s editorial letters (Bullough, 1977; Kohnke, 1977; Peplau, 1977; and Phaneuf, 1977). The case was analyzed in the literature by several attorneys (Gargaro, 1978a; Regan, 1979b; and Gouge, 1980). It was also analyzed by nurses and philosophers (Stanley, 1979; Bell, 1981; Benjamin & Curtis, 1981; Purtilo & Cassel, 1981; Thompson & Thompson, 1981; and Murchison et al., 1982).

Legal Issues

The classification scheme used in this study emerged from the research questions. The major categories in the study involved legal issues, professional issues, and ethical issues. Issues and sub-issues were identified as a result of a

content analysis of the literature. Agreement on the face validity of the issues and sub-issues was reached by consensus among two nurse experts and the investigator. In addition, two local attorneys were consulted independently about the key issues in the case. Issues were selected based upon the frequency of their occurrence in the literature, the comments of local attorney consultants, and the consensus among selected nurse experts and the investigator.

Content analysis of the legal issues in the <u>Tuma</u> case included due process, unprofessional conduct, and professional nursing. Each issue was defined and analyzed according to information in the data sources.

Due Process - Legal Issue

Gouge (1980), educationally prepared as an attorney, a nurse, and a physician, defined due process as a course of legal proceedings or fair procedures to protect individual rights. She identified four essential aspects of due process as follows:

- 1. An ascertainable standard of conduct
- 2. A fair procedure for accusation
- 3. Proper jurisdiction
- 4. A fair tribunal unbiased judge and jury, a reasonable prosecutor, and the assistance of counsel. (Gouge, 1980, p. 74)

Cazalas (1978) wrote that due process in nursing involved a procedure whereby a nurse would be notified of charges with sufficient certainty and definiteness for the nurse to prepare a defense and to present evidence at a hearing. Due process originated from the Fifth Amendment to the Constitution of the United States which indicates, ... "nor be deprived of life, liberty, or property, without due process of law" (Declaration, 1976, p. 31). The Fourteenth Amendment indicates, "... nor shall any state deprive any person of

life, liberty, or property without due process of law" (<u>Declaration</u>, 1976, p. 34). The Fifth Amendment prohibits any federal action against a person without due process, and the Fourteenth Amendment prohibits any similar state action (Dickson, Note 4).

Due process is concerned with both procedural and substantive processes (Watson, Note 5). Procedural due process requires the use of a fair decision-making process. Substantive due process requires an examination to determine the compatibility of law or governmental action with the Constitution. The Tuma case focused on procedural aspects of due process; the specific question was whether or not the Idaho Board of Nursing could revoke a nurse's license when the nurse had no prior notice that her action was prohibited by that board.

A spokesperson for the Idaho Board of Nursing stated that the Board did not have to forewarn by statute or regulation what constituted unprofessional conduct because the Board could hear evidence of a nurse's conduct and, based upon the expertise of the Board members, reach a conclusion regarding unprofessional conduct. The Idaho Supreme Court rejected the Board's argument by stating that a board could not define unprofessional conduct on a case-by-case basis, after the fact, because such a standard would vary with the changing composition of a board ("Tuma v. Board of Nursing," 1979).

In conclusion, the <u>Tuma</u> case set a far-reaching precedent in nursing. This case clearly established that nurses have a right to due process in relation to their professional nursing functions (Gouge, 1980). The significance of due process is that a state cannot deprive anyone of a valuable property right, such as the opportunity to practice professional nursing, without adhering to the safeguards involved in fair proceedings.

Unprofessional Conduct - Legal Issue

The Nurse Practice Act in effect in Idaho in 1974 defined unprofessional conduct:

Without intent to limit the general term unprofessional conduct, as used in this chapter, or without intent to limit the board in exercising its powers as provided in this nurse practice act, the following are declared to be acts of unprofessional conduct:

- (a) Any practice or behavior of a character likely to deceive or defraud the public.
- (b) Obtaining any fee or compensation by fraud, deceit, or misrepresentation.
- (c) Advertising by any means whatsoever of the practices of nursing in which untruthful or misleading statements are made. ("Nurse Practice Act," 1974, p. 12)

The Idaho Board of Nursing ruled that Tuma had interfered with the physician-patient relationship and that such interference constituted unprofessional conduct ("Tuma v. Board of Nursing," 1979). Conversely, the Idaho Supreme Court ruled that items (a), (b), and (c) did not apply in the Tuma case; thus, since there was no definition of unprofessional conduct in the practice act which could have forewarned Tuma that her actions constituted unprofessional conduct, the Supreme Court determined that her actions could not be judged as unprofessional conduct.

Regan (1981c) contended that there is a problem in many nurse practice acts regarding the definition of unprofessional conduct. The conviction of a person for the commission of a felony such as murder, robbery, arson, and rape is evidence of unprofessional conduct. He advised that boards of nursing make serious efforts to define unprofessional conduct if they expect the phrase "unprofessional conduct" to receive support by courts during litigation cases.

Three cases were selected for discussion because they involved unprofessional conduct. The first case, <u>Leib v. Connecticut Board of Examiners for</u>

Nursing (1976), concerned a nurse who asserted that she should not be accused of unprofessional conduct for personally using a patient's narcotic because the nurse practice act did not specify that personal use of a patient's drug constituted unprofessional conduct.

In <u>Kansas State Board of Healing Arts v. Acker</u> (1968), a physician asserted that immoral conduct, dishonorable conduct, and unprofessional conduct were so vaguely defined in the medical practice act that they were meaningless, unless each separate action of which one could be accused had been specified in the statutes. The conclusion of the court provided direction to the medical board.

In <u>Chastek v. Anderson</u> (1981), a dentist was charged with negligence as a result of repeated damages to a patient's jaw, gums, and teeth. The dentist asserted that the definition of unprofessional conduct was too vague to adequately forewarn him that repeated acts of negligence might result in charges of unprofessional conduct.

In <u>Leib v. Connecticut Board of Examiners for Nursing</u> (1976), the Connecticut Supreme Court found the nurse guilty of unprofessional conduct because she charted that Demerol was given to a patient when, in fact, she had personally taken the Demerol. In <u>Kansas State Board of Healing Arts v. Acker</u> (1968), the court concluded that a statute does not have to list every specific act or course of conduct which might constitute unprofessional conduct. By specifying certain actions which are examples of unprofessional conduct, a medical board can make a judgment about similar actions. In <u>Chastek v. Anderson</u> (1981), the Supreme Court of Illinois concluded that a statute which listed 20 grounds for which a dentist could have his license revoked provided adequate warning that repeated acts of negligence could constitute unprofessional conduct.

From these cases one may determine that Tuma's actions could not be called unprofessional conduct because there was no information in the Idaho Nurse Practice Act which adequately forewarned her. Illinois and Kansas courts established that statutes are not required to specify every act that constitutes unprofessional conduct. Sufficient examples are necessary to aid practice boards when they are required to make judgments in unprofessional conduct actions which are not specified in the practice acts. Some actions, such as distortion of records regarding drug administration, personal use of drugs, and repeated acts of negligence, were identified by courts as unprofessional conduct even when these actions were not specifically mentioned in practice acts.

Definition of Professional Nursing - Legal Issue

The Idaho Nurse Practice Act (1974) defined professional nursing as:

The performance for compensation of any act in the observation, care, and counsel of the ill, injured, or infirm, or in the maintenance of health or prevention of illness of others, or in the supervision and teaching of other personnel, or the administration of medications and treatments as prescribed by a licensed physician or dentist; requiring substantial specialized judgment and skill based on knowledge and application of the principles of biological, physical, and social science. The foregoing shall not be deemed to include acts of medical diagnosis or prescription of medical therapeutic or corrective measures, except as may be authorized by rules and regulations jointly promulgated by the Idaho State Board of Medicine and the Idaho Board of Nursing which shall be implemented by the Idaho Board of Nursing. (p. 1)

This particular definition of nursing was in effect in Idaho in 1976, when Tuma was involved in the case which resulted in the suspension of her nursing license.

Proceedings from the Idaho Supreme Court's review of the <u>Tuma</u> case indicated that the Idaho Board of Nursing published a pamphlet entitled <u>Minimum</u> Standards, Rules and Regulations for the Practice of Nursing just prior to the Tuma hearing. These rules modified or amplified the legal definition of

professional nursing. <u>Tuma v. Board of Nursing</u> (1979) indicated that the registered nurse shall:

- 1. Assess and evaluate health status of the individual based upon a thorough understanding of the physiological processes involved, and the emotional needs of the particular individual.
- 2. Make judgments and decisions regarding patient status and take appropriate nursing interventions.
- 8. Promote, and participate in, patient education based on the individual and family for a better understanding and implementation of immediate and long term goals.
- 9. Recognize, understand, and respect cultural backgrounds, spiritual needs, and religious beliefs. (p. 718)

While these rules were not considered to be decisive in the <u>Tuma</u> case, they influenced the presiding judge to comment that "the minimum standards promulgated by the Board seem to support her decision to have such a discussion with the patient" ("Tuma v. Board of Nursing," 1979, p. 720).

Since nurses and courts may differ in their interpretation of definitions and rules that are relevant to the practice of nurses, a question arises regarding who decides the scope of nursing practice. Nuckolls (1974) and Hershey (1980) concluded that nurses; politicians; state agencies, officials, and associations; and the public decide through legislative and legal processes the scope of nursing practice.

Hershey (1980) commented regarding the Tuma case that,

There appears to be a willingness on the part of some nursing boards to pursue disciplinary action against professional nurses in situations where the facts, ascertainable by a thorough investigation, would indicate that such action was unwarranted. (p. 12)

Hershey's statement implied that nurses may be their own worst enemies. He cited a Pennsylvania case in which a nurse was reprimanded by the state nursing

board for slapping a patient's hand. A legal review of that particular case revealed that the nurse was justified because the patient had failed to release his grip on the nurse's arm after the nurse had requested him to do so and after the nurse had attempted to pry his fingers from her arm. The nursing board had censured this nurse, but the Pennsylvania courts reversed the board's action.

It can be determined from the discussion about the definition of professional nursing that nurses and others disagree in their interpretations of specific actions according to the definitions of professional nursing. Sometimes nurses interpret the definitions in such a rigid manner that other nurses are unfairly disciplined by their inflexible interpretations.

In summarizing the legal issues in the <u>Tuma</u> case, a nurse was liable for an unprofessional conduct charge because she revealed alternative treatment information to a questioning patient. The nurse did not consult with the physician about her actions and he instituted legal action against her. Whether her actions exceeded the scope of professional nursing as indicated in the Idaho Nurse Practice Act was not conclusively determined by the courts. The Idaho State Board of Nursing and the District Court deemed her actions to be unprofessional. A Supreme Court judge, however, commented that her actions were consistent with Idaho minimum standards for nurse practice even though the case was not determined on that basis. The case was determined on the basis of due process which required a reasonable definition of unprofessional conduct to forewarm Mrs. Tuma adequately. Due process additionally required a fair procedure for suspending or revoking a nurse license.

Professional Issues and Sub-Issues

Professional issues in the <u>Tuma</u> case include health care provider-consumer relationships, informed consent, and disclosure. Professional sub-issues include rights, responsibilities, conflict, confidentiality, and deception.

Health Care Provider-Consumer Relationships - Professional Issue

Attempts to define the relationships that exist among patients, families, nurses, and physicians revealed varying perceptions which may establish some explanations for the conflicts which may occur in such interactions. These relationships are sometimes referred to as consumer-provider relationships whereby consumers include both patients and their families and providers include both physicians and nurses. Problems can occur in any of the following relationships: patient-family, patient-nurse, patient-physician, family-nurse, family-physician, nurse-nurse, and nurse-physician. The <u>Tuma</u> case primarily involved problems in the patient-family relationship, the patient-physician relationship, the nurse-physician relationship, and the nurse-nurse relationship.

Travelbee (1966) defined the nurse-patient relationship in a manner similar to hospice definitions whereby the patient, family, and/or significant other comprise the unit of care: "an experience or series of experiences between a nurse and a patient and/or family member in need of the services of a nurse" (p. 125). Kastenbaum and Spector (1978) identified the existence of a nurse-patient-family relationship. They indicated that priority was given to the nurse-patient relationship when conflicts occurred between patients and their families.

Hershey (1980) concluded that occasionally nurses do not support each other in nurse-nurse relationships. Consequently, attorney-nurse relationships are sometimes more supportive to nurses than are nurse-nurse relationships.

Bates (1970) defined the physician-patient relationship as a partnership in the attainment of health. Pence (1980) defined the physician-patient relationship as a contract "where general obligations and rights of both parties are discussed and agreed upon" (p. 192). He also defined the physician-patient relationship as "an experience or series of experiences between a physician and a patient in which the virtues are practiced" (Pence, p. 199).

Davis and Aroskar (1978) described the nurse-physician relationship as "characterized by medical authoritarianism on the one hand and nursing's acceptance of dependence or even deference, on the other hand" (p. 38). Hoekelman (1978) proposed nurse-physician relationship as interactions in which nurses share in the medical decision making concerning patient care without seeming to be involved and without sharing responsibility for those medical decisions which remain with the physician. Monteiro (1978) concluded that nursing articles about nurse-physician relationships emphasize a complementary role for nurses with physicians; however, articles written by physicians emphasize that nurses assist physicians and work under physician supervision.

From the discussion of relationships one can determine that the possibility exists for conflict among patients, families, nurses, and physicians. Health care professionals seldom identify strategies for potential actions in predictable conflict situations prior to the actual occurrence of such situations.

The 1982 <u>Current Opinions of the Judicial Council of the American Medical Association</u> stipulated, "A physician shall respect the rights of patients, of colleagues, and of other health professionals, and shall safeguard patient confidences within constraints of the law" (p. ix). This statement represents a recognition of both patient rights as well as nurse rights regardless of whether physicians classify nurses as colleagues or as other health professionals. This

new philosophy in medicine may offer some hope for improved relationships between physicians and nurses.

A mechanism which had been established to improve relationships between nurses and physicians was the National Joint Practice Commission. Without explanation, the American Medical Association withdrew its funding for the National Joint Practice Commission which effectively dissolved that organization in January 1981 (Steel, 1981). The dissolution of the National Joint Practice Commission removed one national forum whereby nurse-physician relationships had been discussed.

The foregoing discussion seems to imply that nurses and physicians vary in their basic concepts regarding their roles and relationships with each other. There is agreement, to some extent, regarding the role expectations between nurses and physicians for patient care. Of concern is the removal of an important mechanism, the National Joint Practice Commission, for promoting nurse-physician relationships.

Rights - Professional Sub-Issue

Key persons involved in the <u>Tuma</u> case were a patient, her family, a nurse, and a physician. The patient's right to information was a compelling factor in the case as was the patient's right to refuse the chemotherapy treatment.

Rights were defined by Benjamin and Curtis (1981) as,

claims or entitlements possessed by individuals which require that others not interfere with the exercise of them or, in the case of 'positive' as opposed to 'negative rights,' that they provide the rightholder with something he or she wants or needs. (p. 30)

Examples of negative and positive rights may aid in the clarification of the differences between them.

Negative rights are similar to those stated in the Bill of Rights or the Constitution. They are rights which prohibit others from interfering in a person's life. Examples of negative rights are those of life, liberty, and privacy. Negative rights can be accomplished when there is noninterference from others.

Positive rights are those which are associated with benefits. They require others to bestow benefits and may be harder to accomplish than negative rights. Some examples of positive rights are the right to an education and the right to health care. Benjamin and Curtis (1981) asserted that it was harder to justify the efforts expended on behalf of positive rights than to justify the effort expended to achieve negative rights.

From the American Hospital Association's <u>Patient's Bill of Rights</u> (1970), those rights most relevant to the <u>Tuma</u> case are quoted. In <u>A Patient's Bill of Rights</u> (Thompson & Thompson, 1981, p. 212) the second right specified:

the patient has the right to obtain from his physician, complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand.

The third right stipulated that "the patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment." Right number four stated, "the patient has the right to refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his action."

In the <u>Tuma</u> case, the physician informed the patient about chemotherapy as treatment for her leukemia. Thus, right number two had been provided, at least partially, by the physician. Because of her Mormon beliefs, the patient became concerned about the use of unnatural chemotherapeutic treatment for her leukemia and questioned nurse Tuma about natural alternatives to the chemotherapy. Right number three indicated that the patient had the right to

receive alternative treatment information from the physician; however, the physician had not supplied alternative treatment information to the patient's satisfaction.

Purtilo and Cassel (1981) concluded that the patient had a right to alternative treatment information and the nurse had a duty to provide the information if the physician had not done so. The <u>Patient's Bill of Rights</u> does not have legal authority in any state; thus, one could argue that those rights are not legally established ones.

In addition to the <u>Patient's Bill of Rights</u>, attention has been given to patient rights by others involved in that aspect of health care. Annas (1974) contended,

When a patient is categorized as terminal, he is often simultaneously deprived of his right to know the truth and his right to privacy, as well as his right to consent to treatment and to exercise discretion in choosing a place or time to die or to determine how his body will be disposed of after his death. Patients would be better served both medically and psychologically if physicians and nurses see to it that these rights are preserved. (p. 40)

It can be construed that Tuma was involved in helping the patient consent to treatment. Her actions seem to be supported by Annas (1982) who attested that the "primary argument against patients' rights is that patients have 'needs' and that defining those needs in terms of rights leads to the creation of an unhealthy adversary relationship" (p. 32).

Siegler, a physician, revealed his attitude toward patient rights when he asserted that, "medicine has functioned as a convenantal reciprocal relationship in which the rights of patients never had to be asserted, in part because physicians understood and accepted their obligations to patients . . . " (1980, p. 1591). Sieglar also contended that:

Many of the valid claims being presented today in rights language could more easily be presented and accommo-

dated without resorting to the uncompromising and contentious talk of rights. (p. 1592)

The Bandmans raised the question -- do nurses have rights? The philosopher, B. Bandman (1978), concluded that a professional role, such as physician or nurse, does not confer on the practitioner a right. A professional role confers on the practitioner a privilege. B. Bandman (1978) distinguished a right from a privilege: "A right is a just basis for making a claim while a privilege is an exceptional or extraordinary power or exemption, one that is revokable" (p. 84). He wrote that rights are reserved for persons and that nurses and physicians function in role capacities; thus, in professional roles, their rights as persons are somewhat constrained. A patient may cancel at anytime the professional privilege of a physician or nurse to treat the patient.

In contrast, E. Bandman (1978a), a nurse, concluded that nurses do have legally established rights. She professed that "nurses have the right to refuse to participate in situations in conflict with their preparation, competencies, and beliefs" (p. 85). E. Bandman argued that professional responsibilities require correlative rights.

Fagin (1975) defined a right as a "just claim to anything to which one is entitled, such as power or privilege" (p. 82). She advocated the use of the term prerogative as an adequate synonym for right. Nursing has emphasized responsibilities for nurses more than rights. Fagin concluded that only recently have nurses given any attention to their rights as human beings and workers. Fagin listed several nurses' rights. One of those rights is that nurses have the right to control what is professional practice within the limits of the law.

Fagin (1975) differentiated between nurses and other legally sanctioned health professionals in the area of direct access to service. Society grants

greater rights for direct service, such as occurs in medicine, than for indirect service such as occurs in nursing.

The <u>Tuma</u> case established that nurses have rights to legal due process. Tuma had argued that her discussion with the patient occurred in her off-duty time; thus, she contended that she was functioning as an individual and not in her role capacity as a nurse. The court rejected her argument but asserted her right to due process in her professional capacity as a nurse ("Tuma v. Board of Nursing," 1979). This court indicated that professional persons are never "off-duty" from professional responsibility for their actions.

Kelly (1976) asserted that patients have a right to information about themselves. A right to privacy indicates that a patient has the primary right to information about himself. Family members or significant others have access to the patient's diagnosis and treatment only if the patient wishes to share that information. Kastenbaum and Spector (1978) asserted that the patient's right claims priority over a family member's right when a conflict exists. This interpretation of patient rights may at times be disregarded by physicians according to the studies conducted by Caldwell and Mishara (1972) and Rosoff (1981). They indicated that physicians often tell family members the fatal diagnosis of a patient prior to or instead of telling the patient.

An examination of information on rights revealed that several authors believed that patients had rights to information about themselves. Selective physicians and attorneys argued that "rights language" sometimes created adversarial relationships between physicians and patients. Those persons who argued against the use of "rights language" preferred to use the term "patient's needs" instead of "patient's rights." Legal proceedings have established due process rights for nurses. Some authors argued that a patient's right to privacy

was violated whenever family members were informed of a patient's fatal diagnosis prior to or instead of informing the patient.

Responsibilities - Professional Area Sub-Issue

Responsibilities were defined by Benjamin and Curtis (1981) as "requirements to carry out or to refrain from certain actions" (p. 30). The <u>Encyclopedia of Bioethics</u> indicated that the professional nurse has ethical responsibilities to influence policy decisions within the profession and to make decisions as clinicians for quality nursing care of individuals, families, or groups (Reich, 1978). Patient education is an essential nurse responsibility recognized in the nurse practice acts of most states.

The American Nurses' Association <u>Code for Nurses</u> was evaluated as a superior code by the <u>Encyclopedia of Bioethics</u> (Reich, 1978). Statements three and four are especially relevant to the <u>Tuma</u> case ("ANA Guidelines," 1980c, p. 21). Statement three indicated, "The nurse acts to safeguard the client and the public when health care and safety are affected by the incompetent, unethical, or illegal practice of any person." Statement four stipulated that, "The nurse assumes responsibility and accountability for individual nursing judgments and actions."

In the <u>Tuma</u> case, the patient's questions created a responsibility to discuss alternative cancer treatments which Tuma believed was consistent with nurse actions as stated in the American Nurses' Association (ANA) <u>Code for Nurses</u>. However, the physician believed that Tuma's discussion of alternative cancer treatments interfered with the physician-patient relationship.

Purtilo and Cassel (1981), in analyzing the physician's responsibility to establish an adequate physician-patient relationship in the <u>Tuma</u> case, indicated that it was the patient who did not feel free to discuss her misgivings about

chemotherapy with the physician; thus, the physician-patient relationship was not optimal. The physician had only known Mrs. W. for two days and seemed to have a more satisfactory relationship with the patient's son than with the patient. During the Tuma trial, the physician admitted that he was not prepared to discuss laetrile and reflexology because of his limited knowledge of them as alternative therapy. Those alternatives were important to the patient because of her religious beliefs.

Walker (1980), an attorney, indicated that the modern nurse has a responsibility to participate in decisions that affect nursing and the resolution of health care issues. Walker concluded that nursing law is sometimes unclear. The modern nurse is often expected to exercise professional judgment in complex situations that have both ethical and legal implications.

Tuma was responsible, in cooperation with other nurses, for determining a nursing diagnosis and for intervening in the care of Mrs. W. Some aspects of the nursing intervention involved providing treatment information to the patient and/or the physician. Bruce and Snyder (1982) proposed that nurses are responsible for nursing diagnoses and intervention. Some nurse practice acts, such as those of New York and Washington, specifically use the term "diagnosis" to describe nurse responsibilities (Cazalas, 1978). Several standards for nursing practice developed by the ANA indicate that nursing diagnosis is an essential step in the nursing process. In some situations nurses have a responsibility to inform the attending physician and, if he fails to act, the nurse is then required to advise hospital authorities so that appropriate action can be taken. Some critics of Tuma indicated that she should have informed the physician of the patient's requests for information. If the physician failed to act, Tuma could then have advised hospital authorities. Tuma knew that the physician was partowner of the hospital and that his past behavior had led her to believe that he

had little interest in this patient's religious beliefs and their influence upon the therapy he had recommended (Purtilo and Cassel, 1981).

Sandroff (1981) reported that a patient's right to know was the reason many nurses believed that nurses had responsibilities to discuss treatment alternatives with patients. Nurses who participated in the Sandroff study indicated that it was a nursing responsibility to help patients implement their rights while they were hospitalized. Regan (1981b) informed nurses that following administrative channels and proper charting are nurse responsibilities when the physician is wrong or when substandard hospital practices exist.

Medical ethical responsibilities of consulting physicians (Pope, 1977) were presented in Chapter II. Pope's study indicated that consulting physicians provided less treatment information to patients than they did to attending physicians. Consequently, some patients were left uninformed. The nurses' responsibilities then became unclear when nurses were questioned by uninformed or misinformed patients.

Information presented in this section identified those responsibilities of professional nurses that were elicited from a literature review of the content issues. The determination was made that nurses are responsible for patient education and for influencing policy decisions about nursing. Additionally, nurses are responsible for establishing nursing diagnoses and nursing intervention and are accountable for their actions. Nurses are required to protect patients from the unethical actions of others. Nurses are also responsible for assisting patients to implement their rights especially while they are hospitalized. Other identified nurse responsibilities are to follow recommended administrative channels and to chart properly whenever nurses encounter physician errors or substandard hospital practices. Nurses and physicians disagreed about the responsibilities of nurses for discussing alternative treatment information with patients. One study

revealed that consulting physicians were more responsive to their duties toward attending physicians than they were toward their responsibilities to patients.

Conflict - Professional Area Sub-Issue

Nichols (1979) defined conflict as a state which exists when the action of "one person prevents, obstructs, or interferes with the action of another person" (p. 24). Nichols identified four characteristics of conflict situations:

(1) At least two parties (individuals or groups) are involved in some kind of interaction; (2) mutually exclusive goals and/or mutually exclusive values exist in fact or as perceived by the parties involved; (3) interaction is characterized by behavior designed to defeat, reduce, or suppress the opponent to gain a designated victory; and (4) the parties face each other with an imbalance or relatively favored position of power vis-a-vis the other. (p. 24)

The <u>Tuma</u> case involved conflict between the patient and her son and between the nurse and physician. Conflict between Mrs. W. and her son occurred due to the son's desire that she accept chemotherapy and the patient's desire to investigate natural alternatives for the treatment of her leukemia. The family did not complain about Tuma's actions to the Idaho Board of Nursing; it was the physician who registered his complaint with the college where Tuma was employed and also with the hospital administration (Benjamin & Curtis, 1981). There is no direct information in the literature to establish whether any previous conflict had existed between Tuma and the physician prior to this incident.

In personal correspondence, Tuma (Note 6) was asked specifically, "Were there special problems in your past association with the physician who was treating Mrs. W.?" (p. 1). Tuma's response was that there were no special problems with this particular physician:

In the past I picked up a chart he had thrown across the hall into the wall but that was a temper tantrum that

occurred months before this incident and involved another patient and nurse. He is a young and somewhat stubborn heart specialist. (Tuma, Note 6, p. 1)

These comments seem to indicate that there was no long-standing conflict between Tuma and the physician. However, they may reflect the possibility for conflicts between the physician and other nurses who were employed in the hospital where he was part owner.

Sheard (1980) concluded that conflict between staff nurses and physicians in hospitals frequently occurs as a result of a different orientation to six work dimensions: "(1) sense of time, (2) sense of resources, (3) unit of analysis, (4) work assignment, (5) type of rewards, and (6) sense of mastery" (p. 14). He further added that nurses are prohibited by hospital policy and by education from challenging physician requests or orders except in extreme situations.

Jameton (1977) asserted that the nursing role creates a host of conflicts in relation to autonomy, coercion, and personal identity. In addition, he identified the disparity in income, power to make decisions, and prestige between nursing and medical professions as sources of conflict between these professions. Aroskar, Flaherty, and Smith (1977) suggested that the nurse's obligation to a physician cannot survive a conflict with the nurse's obligation to a patient; obligations to patients should prevail. Furthermore, Horsley (1980) asserted that in certain conflict situations courts will protect nurses from disciplinary action when they refuse duty assignments based upon valid professional reasons.

There are, however, numerous examples arising from conflict situations recorded in the literature. In some situations administrative coercion and sanctions were imposed upon nurses who challenged medical or administrative authorities. Curtin (1978b) recorded a case study in which a staff nurse challenged medication orders written by one physician on a variety of occasions for dosages which exceeded safe levels by nine to 20 times. The nurse was

assigned to work excessive shifts (three shifts out of four), transferred to a unit where she was required to work 20 out of 30 days without an off day, and frequently called back to work double shifts. As a result, she lost 30 pounds in six months, received no help from her professional association, and, finally, resigned. Near the end of this nurse's six months of administrative persecution, the physician whom she had challenged lost his license to practice medicine in her state and moved away. Curtin concluded that nursing colleagues failed to support this nurse and "assisted in her persecution" (p. 23).

Bermosk and Corsini (1973) cited an incident involving a personal identity conflict in which a family friend who was a nurse told her patient friend immediately after surgery that her breast had been removed because it contained cancer cells. The nurse was not a hospital employee at the time of her friend's surgery. The patient directly asked her nurse friend if she had cancer. The nurse wondered how she would respond or if she should evade the question by referring it to the physician. The nurse responded to her patient friend:

The laboratory reported that there were cancer cells in the section, so the doctor had to remove your breast. Now it is reasonably certain that all the cancer cells have been removed. You are perfectly all right now. (Bermosk & Corsini, 1973, p. 18)

The patient responded with prolonged shrieking until she became exhausted.

Some colleague reviews of this incident included the following comments:

Informing the patient of her diagnosis belongs to the physician.

The patient was fortunate that she was attended by a knowledgeable, understanding, and honest nurse who gave her as correct and factual an answer as possible.

Whether or not a patient should be told that she has cancer seems to me to be the prerogative of the doctor and not of the nurse on duty.

Some of the people involved in the incident seemed to feel that the patient's screaming and getting upset was

such a horrible circumstance that it should be avoided at all cost. Shrieking might be a little loud and it might bother somebody, but it provided the necessary release to enable her to react to her loss. (Bermosk & Corsini, 1973, pp. 19-20)

These colleague reviews illustrated that nurses disagree about nursing functions. Additionally, the conflict incidents presented in this section indicated that nurses sometimes fail to support nurse colleagues when conflicts arise. Conflict continues to exist within nursing to some extent. Nurses wish to control their own practice and yet they are not in agreement about their actions.

Haw (1980) contended that it is sometimes a myth to believe that additional communication can resolve conflicts. She recommended bargaining as an alternative when additional communication does not resolve conflicts. It is impossible to know whether additional communication or bargaining would have worked to resolve the nurse-physician conflict in the <u>Tuma</u> case. Mrs. Tuma did not discuss with the physician Mrs. W.'s request for additional information. Mrs. W. had indicated to Tuma that she did not wish to discuss it with him. Both Mrs. W. and Mrs. Tuma believed the physician disapproved of the alternative treatments and would not have discussed them. Perhaps their lack of discussion with the physician could be attributed to their desire for confrontation avoidance.

The foregoing discussion suggests the conclusion that conflicts exist between nurses and physicians in relation to nursing autonomy, coercion, personal identity, and the power to make decisions. Conflicts exist over hospital policies whereby nurses are prohibited from challenging physician orders except in extreme situations. Experts in nursing ethics advocated that a nurse's obligation to a patient supercedes the nurse's obligation to carry out a physician's orders. There are numerous incidents in the literature which describe the imposition of coercion and sanctions upon nurses who challenged medical or

administrative authorities that nurses believed to be in error. There continued to be considerable diversity of opinion among nurses over appropriate nursing actions in controversial incidents. Selective nursing personnel have cooperated with administrative sanctions which were imposed upon nurses who challenged erroneous medical orders.

Informed Consent - Professional Issue

Annas, Glantz, and Katz (1981) have defined informed consent as:

a doctrine which states that before a patient is asked to consent to a risky or invasive diagnostic or treatment procedure he is entitled to receive certain information: (a) a description of the procedure; (b) any alternatives to it and their risks; (c) the risks of death or serious bodily disability from the procedure; (d) the probable results of the procedure, including any problems of recuperation and time of recuperation anticipated; and (e) anything else that is generally disclosed to patients asked to consent to the procedure. (p. 370)

An exception to the rule of consent concerns emergencies. Mancini and Gale (1981) stated that medical care to save a life or to prevent bodily injury can be given without consent in an emergency.

Gargaro (1978a, 1978b, 1978c), legal counsel for <u>Cancer Nursing</u>, devoted three articles to a discussion of the relationship of the <u>Tuma</u> case to informed consent. He indicated that California law has a "reasonable" disclosure standard which means that the physician or nurse should advise the patient of risks of death or serious bodily harm and explain in layman's language any complications which may occur. Gargaro (1978a) wrote that the "nurse should conceive of disclosure as an intrinsic nursing right" (p. 250). He concluded that when a nurse has knowledge or information which will help patients to evaluate data about their case, the information should be given directly to the patients by the nurse or indirectly by the nurse through the physician.

Gargaro (1978b) proposed that the <u>Tuma</u> case raises the question of whether a nurse may inform a patient of "medical alternatives and medical procedures where the nurse feels the physician has failed to fulfill his own duty to inform the patient" (p. 330). He further questioned whether the nurse can inform a patient of medical alternatives without first consulting the physician.

Gargaro (1978c) believed that his own analysis of the <u>Tuma</u> case stressed a distinction between nursing alternatives and medical alternatives. In practice, the "functions overlap and give scant guidance regarding what sort of action a nurse may take to inform a patient and not be accused of 'unprofessional conduct' " (Gargaro, 1978c, p. 467). He expressed that his sympathies were with Mrs. Tuma because she was giving priority to the needs of the patient. One nurse had advised Tuma to report the facts in the incident to a person in administrative authority over the physician. Since the physician was part owner of the hospital, her suggestion may have been futile because there was no one with administrative authority over the physician.

Holder and Lewis (1981) indicated that it is the responsibility of the person who will actually perform a procedure to obtain a patient's informed consent. They differentiate between informed consent and a consent form. Their advice to nurses who witness a patient signing a consent form is for nurses to annotate that their witness was for signature only. If a nurse discovers that a patient does not understand the consequences of surgery or therapeutic procedures which have already been discussed by the physician, the nurse is advised to notify the physician and/or to report the problem to a nursing administrator who has authority to deal with the situation. Such advice presumes that nursing administrators have authority which can and will be used in the patient's behalf.

Incidents in the literature revealed that some nursing administrators did not support staff nurse decisions to question excessive medication dosages

ordered by physicians or to discuss alternative treatment information with patients (Curtin, 1978b; and Regan, 1979a). Regan (1980b) reported a California case in which the complaints of both a nurse supervisor and a head nurse about an obstetrician's delivery room patient care were supported by nursing and medical administrations, as well as the legal system.

Discussion of the informed consent issue established that informed consent is required whenever a patient experiences surgery, or a risky diagnostic or treatment procedure. No informed consent is required for life-threatening emergency care. California law allows a physician or nurse to provide reasonable disclosure to patients. One legal expert stipulated that nurses should conceive of disclosure as an intrinsic nursing right. Problems exist in the overlapping functions between physicians and nurses for the discussion of medical or nursing health care procedures or alternatives. There is scant guidance available to nurses on actions they can take in the area of providing information to patients and remain exempt from accusations of unprofessional conduct. There is evidence in the literature that selective nurse administrators do not support staff nurse decisions in certain controversial situations. Consequently, nurses who discuss health care consent for treatment information with patients may not be supported by nurse administrators for such actions. In contrast, there is also evidence in recent literature that legal systems, nursing, and medical administrations have supported nurses' complaints about poor medical care.

<u>Disclosure - Professional Issue</u>

Disclosure was defined by Murchison et al. (1982) as the giving of knowledge or the release of information in order to achieve a desired therapeutic result. Disclosure is related to informed consent and sometimes includes

informed consent. Disclosure is included as an issue separate from informed consent because there are some instances in the course of terminal illness when no treatment or surgery is indicated. Disclosure is important to prevent one from evading the legal requirements for informing patients about their diagnoses or prognoses by rationalizing that no informed consent is needed because no surgery or therapeutic or diagnostic procedures are required.

Sklar (1978) stipulated that the free flow of communication between patient and nurse was a necessary element of patient care. Disclosure is closely related to a patient's right to privacy. The right to privacy in the United States is established by the Fourteenth Amendment. Privacy includes protecting one's private life from intrusion or exposure to public view. Disclosure of necessary and appropriate information to persons directly involved in a patient's care is a commonly accepted practice. In contractural relationships, such as those which may exist between a physician and patient or a nurse and patient, one may legitimately raise the question of who should first receive information about the patient.

Should information about a patient's terminal diagnosis and recommended treatment be first given to the patient and then shared with the family or significant others only after securing the patient's permission? Who should provide such information? Should disclosure be limited to the physician? These are a few of the questions raised about disclosure. Terminal illness seems to modify disclosure principles as several authors (Caldwell & Mishara, 1973; Tiger, 1976; Pope, 1977; Rosoff, 1981; and Siegler, 1983) have indicated that physicians are more likely to discuss terminal illness with family members than with the patient. Conversely, it is unlikely that a physician would discuss an infection or a condition such as pneumonia or hernia with a family member prior to discussing

it with the patient. The question arises, "Does a terminally ill person forfeit his right to privacy merely because he has a limited prognosis?"

E. Bandman (1978b) asserted that a nurse should assume the responsibility of assuring that a patient's need to know is met. She stated that physicians who refuse to be questioned by nurses or patients are relics of the past. She noted that 17 health professionals now amplify the work of each physician and thus many areas of overlapping responsibility are created. Communication within the health team is therefore essential.

Knapp and Huff (1975) analyzed the <u>Canterbury v. Spence</u> case in detail because of its relationship to disclosure and informed consent. This case involved a 19-year-old male who had a laminectomy performed by Dr. Spence, a neurosurgeon. The patient injured himself soon after surgery while he was ambulating. Although he consequently underwent several more operations, he continued to suffer from urinary incontinence, paralysis of the intestines, and to require crutches to walk. Dr. Spence argued that disclosure of a one percent risk of paralysis following a laminectomy was not good medical practice because it might prevent the patient from consenting to necessary surgery. The court rejected Dr. Spence's argument, concluding that a "very small chance of death or severe disability may be material, as it poses a potential disability that outweighs the potential benefit" (Knapp & Huff, 1975, p. 33). As a consequence of the <u>Canterbury v. Spence</u> case, a physician is required to explain to the patient in lay terms any risk of death, serious harm, or complications that could potentially occur.

Lewis (1977), in writing about the <u>Tuma</u> case, concluded that the "judgment of one professional -- the nurse -- ran head on into the judgment of another professional -- the physician" (p. 561). Her view of the <u>Tuma</u> case was that the law and the professional practice of nursing seemed at variance. It is

noteworthy that the Lewis editorial opinion was expressed in 1977, two years prior to the final settlement of the <u>Tuma</u> case. Perhaps her opinion would have been different if based on the final outcome of this case. She might have concluded that the variance between the law and the professional practice of nursing was not as great as she had perceived it to be in 1977.

Davis (1981a) discussed a dilemma in nursing practice which involved a nurse caring for an inquisitive cancer patient whose physician had written an order that the patient was not to be told his diagnosis. Davis concluded that:

ethically right action for this nurse in terms of withholding versus providing information to the patient will depend on her acceptance or rejection of the ethical stance taken by the physician and the family, her understanding of the ethical principles involved, and the weight she gives to each (e.g., is autonomy more important than doing no harm?), and her view of her ethical obligations as a nurse. (p. 158)

One might add to Davis' comments that nurses would be well advised to familiarize themselves with legal-professional standards such as nurse practice acts and the <u>Tuma</u> case. Nurses must also determine whether they are willing to accept the possible consequences of legal proceedings, when deciding whether to disclose information.

Based upon the preceding discussion about disclosure, it is possible to conclude that persons could evade responsibility for informing terminal patients about their diagnoses or prognoses by strict adherence to the criteria for informed consent. However, there is precedent that not only permits but requires disclosure of risks of death and serious complications. The <u>Canterbury v. Spence</u> case extended disclosure standards to require that physicians explain even one percent risks of death, serious harm, or complications.

The Fourteenth Amendment established a person's right to privacy. Evidence exists in the literature that physicians are more likely to discuss a

terminal illness with family members than with the patient. The question arises of why a terminally ill patient forfeits his right to privacy because he has a limited prognosis. Nurses are encouraged to assure that a patient's request for information is met.

Confidentiality - Professional Area Sub-Issue

Confidentiality was defined by Cazalas (1978) as information or statements made to persons in positions of trust. She implied that confidentiality may also be defined as privileged communication. In selective situations, such as between a physician and patient, the information cannot be disclosed without the consent of the patient. In other instances, such as between an attorney and client, the law protects the information from being revealed in court. In additional situations, the law may require disclosure of confidential information when statutory requirements compel such action.

O'Sullivan (1980) proposed that the purpose of confidentiality in health care is to encourage the patient to disclose even embarassing information to health care workers when such information might aid in his treatment. Five states (Arkansas, New York, Oregon, Vermont, and Wisconsin) have statutes specifying privileged communication between registered nurses and patients. Thirty-three states have statutes that recognize physician-patient privileged communication and 17 states do not recognize this privileged communication (O'Sullivan, 1980). Some states extend physician-patient privileged communication to include nurse-patient relationships when the nurse is under the direction of a physician. Thus, these discrepancies in the statutes indicate that more states legally uphold physician-patient privilege than nurse-patient privilege.

The concept of privacy as it related to confidentiality may be very important in the psychological care of terminally ill adults. Rawnsley (1980)

wrote that some persons regard privacy as a necessary defense mechanism against the pressures of society. Others regard privacy as an actual condition for personal growth. Both views have implications for disclosure of information about terminal illness that patients may regard as their confidential information.

Samuels (1980) indicated that disclosure without justification constituted breath of contract. By contrast, he also stated that,

disclosure to the nearest relative, where in his professional judgment the doctor deems this to be in the best interests of the patient, and it is a very widespread practice, a hallowed convention, would be very probably upheld as lawful by the judge where the doctor had been acting in accordance with accepted professional practice. (p. 63)

In reality, situations exist in which patients may object for valid reasons to the disclosure of information to the nearest relative. Martin (1978) concluded that it is a tribute to the nursing profession that there are no cases on record in which a nurse has been accused of violating the confidential trust between nurse and patient.

Annas (1976) elaborated on <u>Tarasoff v. Regents of the University of California</u> because of its relationship between confidentiality and the duty to warn others. In this case, a college student confided to the campus psychologist that he planned to kill another student whom he had regarded as his girlfriend. The psychologist notified the campus police who briefly detained the student. At the order of a psychiatrist, who was the superior of the psychologist, no further steps were taken to detain the student or to notify his girlfriend. The student did kill his girlfriend by stabbing her; her parents filed suit. The effect of this case was significant because it indicated that a therapist has a duty to warn a potential victim of danger.

In relation to the <u>Tuma</u> case, one could question to what extent a nurse can answer patients' questions about the risks of therapeutic or operative procedures.

Also, could and should a nurse warn a patient that his diagnosis and prognosis are expected to result in death, especially if the physician has not warned him? The <u>Tarasoff</u> case (Annas, 1976) illustrated that the psychologist, his superior, and others were held accountable for not warning the victim. The question arises, "Might a nurse be held accountable for warning terminal patients without being given the legal authority to warn them?" In such a situation, the key factor is the degree of harm that a lack of information creates for the terminal patient.

Davis (1981b) responded to a clinical practice question about patient confidentiality when the family was informed but the patient was not told the diagnosis of cancer. She concluded: "It seems reasonable to assume that confidentiality would only be a problem when the patient had specifically asked the health care professionals not to tell others in his family his diagnosis" (p. 2078). The justification for not telling the patient, however, should be examined. Both Davis, a nurse, and Samuels (1980), a physician, recognized the commonly accepted practice in health care of sharing a diganosis of cancer with a patient's family prior to sharing it with the patient. They asserted that this practice should be restrained if the patient has specifically requested that he should be informed first. Annas (1974), an attorney, indicated that such an open disclosure practice essentially violated the patient's right to privacy.

In this section on confidentiality, it has been determined that while only five states recognize nurse-patient privilege, 33 states legally uphold physician-patient privilege. Disclosure of a terminal illness to the nearest relative was such a common health care practice that it was considered acceptable by those who wrote about it in the literature.

The <u>Tarasoff</u> case involved a duty to warn others to whom there was great likelihood of significant harm. There was no clear direction in the literature to assist nurses who must decide if they could or should warn a terminal patient

about his prognosis when the physician had not made this disclosure. The degree of harm a patient may suffer from failure to be informed of a terminal illness has not been established. There is agreement in the literature that the common practice of first telling a relative about a patient's terminal illness should be restrained whenever the patient requests that he be initially informed.

Deception in Terminal Illness - Professional Sub-Issue

Deception was defined by Bok (1978) as intentional communication of messages intended to mislead someone or to make one believe what others do not believe. Deception can be achieved by gesture, disguise, action or inaction, and even silence. Ramsey (1978) defined terminal illness as an incurable illness which, in reasonable medical judgment, will result in death regardless of the use of life-sustaining procedures.

Annas (1974) believed that the typical physician may describe a terminal patient as one for whom nothing can be done. He stated that a terminal diagnosis begins a process in which basic human rights are typically denied. He further contended that informing a patient he is dying is not the same thing as denying him all hope. The first thing a physician usually tells a nonterminal patient is the diagnosis, but this is the last thing a physician tells a terminal patient. Annas concluded with a plea that the terminally ill be afforded the same human rights as other patients.

Watson (1982) identified the dying as special subjects who require extra consideration before involving them in research. In the past, dying patients were used as research subjects without their knowledge. "The justification used was that they were dying anyway" (p. 45). Dying patients should not be deceived about the fact that they are participants in research.

Saunders (1973), who worked with terminally ill persons at St. Christopher's Hospice in London, commented about the deception of those who are dying. "So often people are just not protected from the truth that you think you are protecting them from; they are left alone with it instead" (p. 30). At her facility, one patient called his terminal illness a "bringing together illness" because the openness about his illness allowed him to share the experience freely with his family.

Cousins (1980) reminded his readers that there is an art to truth-telling in medicine. The real issue, he noted, "is not whether the truth should be told but whether there is a way of telling it responsibly" (p. 1930).

Student viewpoint (Note 7), elicited from a group of nursing students in a baccalaureate program, was presented via the student newspaper. Student opinions were discussed on how to handle situations in which a terminally ill patient questioned nurses about his diagnosis when the physician had chosen not to inform the patient. Student responses were varied indicating that they would notify the physician, distract the patient, reinforce the physician's information to the patient, allow the family to handle the situation, or, if necessary, withdraw from the patient's care because they believed patients had the right to know their diagnoses. None of the students indicated that they would openly tell the patient about his diagnosis. All of the students' responses involved some form of deception.

Stanley (1979) proported that the <u>Tuma</u> case caused much controversy among nurses. She reported that, based upon discussions with nurses in four states and scholars at the Kennedy Institute for Bioethics, nurses generally oppose the ruling by the Idaho Board of Nursing which was supported by the Idaho Nursing Association. Stanley listed eight important principles to remember in meeting the needs of a dying person:

- (1) Death is a fearful event.
- (2) There may be a fear of aloneness and isolation.
- (3) There may be some element of hope, because while there is life, there is hope.
- (4) A dying person may not hear that he or she is dying.
- (5) A dying person needs interpersonal relationships -- someone to trust and talk to.
- (6) A dying person must be met on his or her own terms.
- (7) Beliefs of others should not be imposed.
- (8) A dying person must be allowed to determine his or her own destiny. (p. 72)

It is important to note that a physician may inform a patient of her terminal diagnosis, and the patient may not hear due to denial. The physician providing care to the patient involved in the <u>Tuma</u> case was a cardiologist and was not previously known to the patient. There is no indication that he deceived Mrs. W. Stanley (1979) indicated that Mrs. Tuma's conversation with Mrs. W. provided hope which sustained her during the two additional weeks of her life.

The response of Annas et al. (1981) to the question of whether a nurse has a right to inform the patient of a terminal diagnosis if the physician orders her not to was:

Yes, if the patient indicates a desire for the information. The nurse has an independent obligation to the patient, and physicians have no authority to order nurses either to lie to patients or to withhold critical information from patients who ask to be told. The nurse can, and probably should, carefully discuss the rationale for withholding the information with the physician, but should make it clear that the ultimate decision rests with the patient, not the physician. Again, the best strategy is to always answer questions honestly. This is not only best for the patient, it is also best for health care workers in general. There are times where nurses may be placing their jobs on the line in pursuing such a course - and the law may not recognize their right to be reinstated if they are summarily discharged for fulfilling their professional

obligation - but unless professional nurses are willing to take some risks, patients will continue to suffer. (p. 216)

An extension of the Annas et al. (1981) viewpoint about the nurses' right to discuss a terminal diagnosis with a patient was expressed by two authors. Cowles and Murphy (1982) postulated that nurses can reduce the conflict over nondisclosure of terminal illness to patients by assuring discussion of the situation in an interdisciplinary forum where nurses participate.

In this section, it has been asserted that dying patients have the same rights to information about their illness as other patients. Dying patients should not be deceived as research subjects, just as other patients should also not be deceived.

The literature revealed that deception of dying patients left them feeling abandoned to face their final illness. Nursing students continue, to some extent, to accept deception in terminal care. Even though the legal system may not support them, nurses continue to be challenged in the literature to share critical information with terminal patients who request it. Interdisciplinary forums were suggested as one method by which nurses could assure that terminal patients were provided with the information which they requested.

In this section, the analysis of the <u>Tuma</u> case according to legal issues, professional issues, and professional sub-issues is concluded. The final section of this chapter includes the application of Kantian and utilitarian ethical theories to nursing actions and decisions involved in the Tuma case.

Application of Kantian Ethical Theory to the Tuma Case

The application of Kantian ethical theory to the <u>Tuma</u> case was focused primarily upon the decisions of the nurse. Despite extensive review of the literature for details of the case and personal correspondence with Mrs. Tuma,

the possibility is acknowledged that some essential aspect of the case may have inadvertently been overlooked; this omission could modify the analysis.

Kantian theory involves rules or principles of action. A good will is an essential aspect of the theory. The will, motives, and intention of the nurse must be examined. In Kantianism, one applies a rule or principle which one would wish to have applied in all circumstances. Specifically, one would determine what rule can be consistently universalized without contradiction.

Tuma decided to respond to a patient's request for natural alternatives to chemotherapy as treatment for leukemia. This request to the nurse represented a patient need or claim for information. Tuma believed that the patient had a right to the information and that it was the duty of health care professionals to provide that information. Tuma further believed that she was prepared as a nurse to supply the patient with information on nutrition, reflexology, and Laetrile as a means to meet the patient's religious needs.

Tuma had obtained a master's degree in nursing from the University of Colorado in Denver (Tuma, Note 6) where she had been taught that nurses function by professional codes of ethics and nurse practice statutes. She also had been taught the team concept approach to patient care, in which nurses, physicians, and other health care professionals function as colleagues.

Tuma may have identified two duties in relation to the patient's request for information. One was her duty to consult with the physician and allow him the opportunity to discuss in more detail alternative therapy that was more compatible with the patient's beliefs than the recommended chemotherapy. Purtilo and Cassel (1981) indicated that Tuma believed the physician would not take time to discuss alternative therapies because he did not endorse their use and was not sufficiently well informed to discuss them with the patient.

The second duty was to the patient. Mrs. W. did not feel comfortable about discussing the alternative treatments with the physician because he did not endorse their use. Mrs. Tuma indicated that most nurses working in her area did not have baccalaureate degrees in nursing while she held a master's degree. This educational experience had supposedly prepared Tuma to supply the requested information. Tuma decided that her duty to provide information to the patient was more compelling than her duty to communicate with the physician.

Tuma could have fulfilled both duties by informing the physician of Mrs. W.'s requests for information and allowing him to respond. If he failed to supply the requested information, then Tuma could have notified the physician that she would provide the information. Such confrontation may have produced significant conflict between the physician and the nurse. Open dialogue between the physician and nurse could have fulfilled the duty of members of the health care team to communicate and cooperate in patient care.

Based upon how Kantian theory might apply to the <u>Tuma</u> case, Tuma would have decided that the patient was an autonomous person capable of making her own decisions about care. The patient had the prerogative to examine alternative therapy which would also be compatible with her Mormon beliefs. Mrs. W. could change her consent for chemotherapy at any time. In a letter to <u>Nursing Outlook</u>, Tuma (1977) indicated a personal belief that patients have a right to information and that it is the duty of health professionals to provide the requested information. Tuma's belief was consistent with Kantian theory which requires the application of a rule or principle one would wish to have universally applied. If Tuma's will was to meet the patient's need and request for information, if her motive was to provide the patient with appropriate health care, and if her intention was to recognize the patient's autonomy, then her will, motive, and intentions were consistent with Kantian theory. Case reviews

indicated that Tuma's will, motive, and intentions were to meet the patient's need for treatment information.

According to Bell (1981), important issues in the <u>Tuma</u> case which related most directly to Kantian theory were those of informed consent and the relationship between health care providers and patients. She concluded that informed consent was logically incompatible with paternalism (acting on behalf of another without being requested to do so). Paternalism in relation to informed consent is justified in emergency situations or whenever patients request that they remain uninformed in circumscribed situations.

In the <u>Tuma</u> case, Mrs. W. had consented to the chemotherapy. She also requested alternative treatment information from the nurse. No emergency existed and Mrs. W. had not requested the withholding of any information. The physician and Mrs. W.'s son apparently believed they were acting in her best interests when they encouraged Mrs. W. to consent to chemotherapy. By their failure to consider Mrs. W.'s desire for natural alternative therapies, their actions could conceivably reflect unjustified paternalism.

As early as 1914, informed consent established that adults of sound mind could determine what would be done to their bodies (Bell, 1981). The issue of informed consent affirms both individual autonomy and respect for persons. Both of these goals are consistent with Kantian theory. In Kantianism, the absolute worth of persons is an overriding value, one which supercedes the treatment of persons as passive subjects who can be acted upon at a physician's or a relative's discretion.

Even though Mrs. W. consented to chemotherapy, she requested additional information on alternative treatments that was more consistent with her lifestyle than was the chemotherapy. Mrs. W. was not in any circumstances which justified paternalism on the part of the physician or her son. The

physician obtained her consent for chemotherapy, but he did not provide her with the information which she requested from Mrs. Tuma. Indeed, he did not have the opportunity to provide the information since he was not informed of the patient's request. In customary hospital practice, nurses are expected to communicate important patient requests to the physician. Mrs. Tuma failed to convey Mrs. W's request for information to the physician because she believed he disapproved of the alternative treatments. Kantian theory would oppose her action in this instance because one could not wish to establish as a general rule or principle that nurses fail to convey important information to physicians because they believe physicians disapprove the treatments involved in the requested information.

Kantian theory would oppose the chemotherapy treatment of Mrs. W. if the therapy were used only as a means of making her son feel better to believe that his mother was receiving acceptable therapy. Kantianism would also oppose the physician's failure to discuss nutrition and other alternative treatment information requested by the patient merely because he did not believe in those treatments. Kantianism advocates respect for the entire person including a respect for Mrs. W.'s request for information on non-chemical treatments that were compatible with her Mormon beliefs.

A second issue involved the provider-patient relationship. Both the physician and nurse were involved as providers of care for Mrs. W. Both providers were known by Mrs. W. for only a short time - the physician for only two days and Mrs. Tuma in the hospital while she was providing care for Mrs. W. Because of Tuma's special interest in, and request to be assigned to, care for terminally ill persons such as Mrs. W., she met Mrs. W. on the second day of her hospitalization.

Bell (1981) argued that the <u>Tuma</u> case made a mockery of patient autonomy and informed consent. She established that the physician-patient relationship was inadequate because the patient felt that she could not discuss with the physician those therapies that she considered to be viable options in her care. Bell asserted that the nurse did not impair the patient-physician relationship since the physician had done that when he conveyed by attitude his disapproval of the alternative treatments in which Mrs. W. was interested.

According to Kantian theory, was Mrs. Tuma right to discuss alternative treatment information with Mrs. W.? In some states such as California, nurses are also accountable, to some unclear extent, for informed consent. Bell (1981) argued that informed consent weighs as heavily upon a nurse as it does upon a physician. Conversely, other experts would disagree with Bell's assertion about the role of the nurse in relation to informed consent. Bell also stated that the role of the nurse required the nurse to communicate patient requests for additional information on alternative treatments to the physician. Bell maintained that if the physician refused to supply information requested by the patient, the nurse would then be required to provide the patient with adequate information to assure informed consent.

As a general statement, most health care workers would accept that a patient's request for treatment information should be honored. Customarily, in the hospital the physician is primarily accountable for providing such information. If the physician failed to provide the information, would anyone else be accountable for providing it? There would be much disagreement over who should provide treatment information to patients if physicians did not. Perhaps agreement could be established that anyone who possesses the requested information and a sufficient relationship might be responsible for providing it. Yarling (1978b) asserted that patients do request information from persons based

upon a special relationship with that person. Yarling's assertion provides some insight into the reasons for Mrs. W.'s selection of Mrs. Tuma as the person to provide the alternative information she requested.

Considerations involved in Mrs. W.'s request to Mrs. Tuma about alternative treatment information included the following factors. First, Mrs. W. selected Mrs. Tuma to provide her with information. Mrs. Tuma possessed the information which was requested. The physician did not possess some of the information such as reflexology which Mrs. W. requested. Both Mrs. W. and Mrs. Tuma believed that it was appropriate for a nurse to discuss alternative treatment information with a patient. Mrs. W. preferred to discuss alternative treatments with Mrs. Tuma rather than with the physician. Both the nurse and the patient believed that the patient had a right to know the information which the patient requested. These factors seem to support the fact that a relationship had been established between Mrs. W. and Mrs. Tuma that had not been established with the physician.

Kantian theory supports health care professionals meeting patient requests for treatment information. In accord with Kantian theory, such a general rule would be good for society in general. Kantian theory, with its emphasis upon respect for persons, implies that health care providers such as physicians and nurses communicate with each other to provide effective care for patients. For Mrs. Tuma to withhold important information from the physician would violate the general rule that patients are best served when their providers communicate and cooperate in patient care. If a physician refuses to supply a patient with treatment information, Kantian theory would still maintain that the patient's request should be met. The request could be met by a nurse or other health care provider who possessed the information and had a sufficient relationship with the patient to provide the requested information in an appropriate manner.

A weakness of Kantian theory is that it does not provide a way to solve conflicts among universal duties (Pence, 1980). In the Tuma case, the nurse had universal duties both to communicate with the physician and to assist the patient to obtain requested treatment information. Tuma made a choice to provide the requested information herself, rather than to communicate with the physician and allow him the opportunity to decide whether he would provide the requested information. Both Tuma and the patient believed that the physician would not discuss alternative treatment information. They also believed that he disapproved of some of the treatments which were involved. Tuma may have believed that she faced a conflict between universal duties. Kantian theory does not provide any direction for resolving the conflict she faced. Tuma, however, resolved the conflict by her decision to place her obligation to the patient above her obligation to the physician. It is possible that Tuma could have fulfilled both obligations if she had communicated the patient's request for additional treatment information to the physician. He could have delegated the task to Mrs. Tuma since she possessed some treatment information which he did not possess. If the physician had ordered Tuma to withhold treatment information from the patient, she could have informed him that she felt obligated to provide the patient with the requested information. Such direct action probably would not have produced any worse effects than her decision to omit informing the physician.

Application of Utilitarian Ethical Theory to the Tuma Case

Utilitarian ethical theory specifies that the ultimate principle against which consequences of actions, or the rules requiring those actions, are to be

judged is the general utility or happiness of all concerned people. In utilitarianism, each person counts as one in the computation of pleasures.

Rule Utilitarianism

The relevant principle in the <u>Tuma</u> case involved how people should relate to each other concerning truth telling to dying patients. Posed as a general statement in rule utilitarianism, the specific question is, "Does the rule dictating telling the truth in a situation such as the <u>Tuma</u> case create the greatest good for the greatest number?" A sub-question of this larger point involves the action of a nurse in such a situation.

Since the greatest good for the greatest number cannot be limited to the locale, action, or persons involved in the <u>Tuma</u> case, one must generalize about the consequences of the actions upon society at large. The specific truth requested by Mrs. W. was for alternative treatment information. Would the provision of such information by health care providers create the greatest good for the greatest number? Additionally, would the provision of such information by a nurse when the physician disapproves of the alternative treatments create the greatest good for the greatest number? These questions are discussed in the following sections.

Bok (1978) challenged three primary arguments that advocated withholding the truth from dying patients. Those arguments stated that truthfulness was impossible, that patients did not want to discuss bad news, and that truthful information harmed patients. She asserted that it is possible to share with patients whatever health care information the providers believe to be true. Research data (Caldwell & Mishara, 1972; and Barrett & Schwartz, 1981) indicated that patients wanted to be informed and that most patients cooperated

better and recovered more rapidly and effectively when they had been adequately informed.

Harm accrues to society when information is withheld from patients who are then manipulated into accepting treatment alternatives they might not choose for themselves if they had been adequately informed. When physicians withhold relevant information from patients they increasingly involve co-workers such as nurses and others who may consider the action to be unwise and inhumane (Bok, 1978). The harm thus caused to the patient as a member of society affects society as a whole.

One consequence of withholding relevant information from patients has been the development of a lack of trust in health care professionals. Bok (1978) contended that omitting key information from patients had resulted in their deception and manipulation. Pence (1980) asserted that the withholding of requested information from patients sometimes served the interests of physicians who wished to avoid the discussion of such unpleasant topics as the potential death of a patient.

The acting-omitting principle has been generally discussed by Pence (1980). It was also discussed by Rachels (1975) in relation to active and passive euthanasia. Pence indicated that the direct statement of a falsehood was lying. He further added that omitting key information could be construed to be an indirect form of lying. One could also lie by communicating technical jargon in such a manner that patients were deceived. Pence identified a frequent health care practice whereby physicians were willing to tell all when asked but to assume that patients did not want any more information than specifically requested. He equated such a practice by physicians with the assumption that active lying was bad, but that lying by omitting key information was not bad.

Pence affirmed (1980, p. 80) that "Passive lying is as much lying as is active misstatement." In his discussion of active and passive euthanasia, Rachels (1975) asserted that, depending upon one's motives, it is no worse morally to kill than it is to let die.

Pence (1980) asserted that there are some overruling considerations which make lying permissible, but he specified that those circumstances occur only on rare occasions. The physician's withholding of pertinent treatment information from Mrs. W. in the <u>Tuma</u> case occurred because he was not aware of her request, he did not possess the requested information on reflexology, and he did not approve of laetrile as an acceptable treatment for cancer. Rather than attempting to deceive Mrs. W. by withholding information from her, the physician imposed his own attitude upon the patient by conveying to her that he did not wish to discuss any treatment information except chemotherapy. He thus failed to allow her the opportunity to discuss her need for information with him. Tuma also failed to convey directly to the physician the patient's request for treatment information; thus, she short circuited the physician's opportunity to discuss the information with the patient.

In rule utilitarianism, one would examine whether the nurse should withhold from a physician significant patient information simply because the nurse believed the physician disapproved the treatments about which information was requested. As a general utilitarian rule, such a practice could not be justified. Withholding such significant patient information from a physician could seriously compromise the quality of patient care. It could also place nurses in positions in which their judgments about treatments could supplant, usurp, or replace the judgments of physicians. Such practices would run counter to acceptable and customary health care practices.

In rule utilitarianism, it has been established that there are best consequences for health care providers, for patients, and for society when persons comply with the general rule that treatment information is shared between providers and patients. The best consequences for all occur when patients are usually not deceived.

Justification for nurses sharing treatment information with patients on those occasions when physicians are unwilling to do so for reasons other than the patients' interests involve the following factors. The nurse has more frequent contact with the patient than the physician. The nurse is more often the health care provider from whom treatment information is requested by patients. The nurse is usually educationally prepared to supply the requested information. Often a significant nurse-patient relationship exists which motivates a patient to request information from the nurse. The patient has a need for the information. Many persons assert that the patient has a right to treatment information. Society is best served when health care providers and patients communicate in such a manner that patients are not deceived or left uninformed. If one health care provider fails to supply a patient with relevant information, another health care provider is justified in doing so.

Act Utilitarianism

The key issue in act utilitarianism in relation to the <u>Tuma</u> case was whether Tuma's specific act of telling the truth about nutrition, reflexology, and Laetrile in response to the patient's request for alternative treatment information created the greatest good for the greatest number. An additional issue was whether Tuma's specific act of withholding from the physician the patient's request for alternative treatment information created the greatest good for the greatest number. In act utilitarianism "an act is right if and only if there is no

other act the agent could have done instead that has higher utility than it has" (Feldman, 1978, p. 26).

Tuma's action to discuss alternative treatment information with Mrs. W. met the patient's need for information. Stanley (1979) asserted that Tuma's action provided Mrs. W. with hope which sustained her during the final two weeks of her life. An action to withhold treatment information from an adult patient who requests such information is not justified merely because a health care provider is uninformed about the treatment alternatives or because the provider disapproves of some of the treatment alternatives.

An important consequence of Tuma's specific act to disclose information and the subsequent legal case is that it established due process rights for nurses. Her case also focused attention upon the unclear definitions of unprofessional conduct in most nurse practice acts. Such attention could serve to improve legal proceedings for the entire nursing profession and, indeed, for other professions. Such consequences could have great benefit for society at large.

National nursing attention was focused on the <u>Tuma</u> case as a result of publicity it received in <u>Nursing Outlook</u> (1979). Persons who are well known in nursing and ethics commented upon the case (Bullough, 1977; Kohnke, 1977; Peplau, 1977; Phaneuf, 1977; Bandman, E., 1978b; Ferguson & Fletcher, 1978; Stanley, 1979; Benjamin & Curtis, 1981; Purtillo & Cassel, 1981; Thompson & Thompson, 1981; and Curtin & Flaherty, 1982). Nationally known attorneys explored the case at length (Gargaro, 1978a, 1978b, 1978c; Regan, 1979b; and Hershey, 1980).

Tuma was not in a position to foresee the widespread attention her actions would receive. Subsequently, the national nursing attention her case attracted also influenced the utility of the case. When questioned about whether she thought her actions in the case were worth the costs to her and her loved ones,

Tuma replied, "Yes, I still think I did the right thing and it was worth all the trouble it caused me. Better the discomfort of one to lessen the discomfort of many" (Tuma, Note 6, p. 1).

Other act utilitarian considerations which affected Mrs. Tuma involved monetary considerations. She lost her job at the college, the case lasted for three years during which time she was unable to work, and her attorney and court fees were approximately \$2,500. She possessed a nursing liability insurance policy, but she did not place a claim on it because she thought it would not cover action taken against her by the Idaho State Board of Nursing. Mr. Tuma, her husband, owned a radio station and some of his advertising clients threatened to withdraw their business. A dress shop, whose clientelle consisted mainly of physicians' wives, created the biggest business threat to Mr. Tuma. However, after several years his business has grown so much that Mr. Tuma now owns two radio stations (Tuma, Note 6).

In <u>Nursing Outlook</u>, (1979), Tuma wrote that she believed the results of her Idaho Supreme Court case indicated a victory for nurses, allowing them the option to inform patients. Most of the assessments of her case indicated that her victory established due process rights for nurses, but it did not establish the certainty that nurses would have legal assurance of their rights to inform.

By applying act utilitarian reasoning, it can be asserted that Tuma's action to withhold the patient's request for alternative treatment information from the physician cannot be justified. Tuma's action created costly consequences for herself as an individual. Similar actions on a generalized basis would create so many hazards for nurses, patients, and physicians that society-at-large could be placed in unsafe situations whenever health care providers did not communicate effectively among themselves.

This analysis of the application of both rule and act utilitarian theory to the <u>Tuma</u> case is made three years after the case was settled. As a result of several analyses of the case in the literature, it is now possible to determine many more actions and consequences than were possible when the initial decisions were made. Sufficient time has elapsed to permit consideration of long-range and unexpected consequences.

Mrs. Tuma's values and assessments of the personal consequences of her actions may vary from those of other nurses in similar cases. For example, Mrs. Tuma had sufficient financial resources as a result of her husband's business to allow her to pursue legal action despite the loss of her job. Many other nurses might not have such resources. Mrs. Tuma also felt a deep commitment to what she had been taught about nursing and patient advocacy. She indicated that most nurses in her area had not been as well educated as she. Mrs. Tuma placed a high priority on Mrs. W.'s right to information to assist her physically, psychologically, and spiritually. Mrs. Tuma determined that the benefits which resulted from her actions outweighed the costs; such a calculation is consistent with utilitarian theory. Since values influence an individual's personal assessment of the consequences of actions, individual assessments of utility may vary slightly from person to person. However, in utilitarianism, the overall utility of a specific action or a rule requiring an action will be assessed in a similar manner based upon the greatest good for the greatest number.

The <u>Tuma</u> case analysis illustrates a few of the problems of utilitarianism as an ethical theory. First, some philosophers question utility as the ultimate principle by which actions are judged. Second, it is difficult and time-consuming to compute the consequences of actions or rules that require action. Lastly, in utilitarianism there are no supererogatory actions. The <u>Tuma</u> case illustrates that Tuma experienced such major consequences as a result of her actions that

one might raise the question of whether or not a person should be required to pay so great a price for doing the "right" thing. Utilitarianism asserts that the only right action or rule requiring action is the one which produces the greatest good for the greatest number.

Summary of Tuma Issues and Research Questions

Legal issues identified in the <u>Tuma</u> case included due process, unprofessional conduct, and the definition of professional nursing. Professional issues included provider-consumer relationships, informed consent, and disclosure. Professional sub-issues included rights, responsibilities, conflict, confidentiality, and deception in terminal illness. Kantianism and utilitarianism provided the theoretical ethical structures by which the <u>Tuma</u> case was analyzed. The issues and sub-issues were examined to determine responses to the following three research questions: What are the legal responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults; what are the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults; and based upon Kantianism and utilitarianism what are the ethical responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults?

The <u>Tuma</u> case involved the disclosure by a registered nurse of alternative treatment information to a dying adult. Alternative treatment information differs from prognostic information, but the information derived from the <u>Tuma</u> case is believed to be pertinent also to the disclosure of prognostic information to dying adults. Alternative treatment information may include prognostic

information especially if a prognosis is so poor that no treatment becomes one of the options among the alternative treatment recommendations.

Legal Responsibilities

As a result of an analysis of the <u>Tuma</u> case the legal responsibilities of the registered nurse are identified. Included among those responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults are the following.

The registered nurse is required to practice nursing according to the state legal statute which defines professional nursing. Some nurse practice acts are sufficiently broad to permit nurses to discuss alternative treatment information; in some instances alternative treatment information could be extended to include prognostic information. For example, if radiation, chemotherapy, or surgery cannot extend or improve the quality of life for a dying person, the competent patient may select no treatment as the best alternative available in that situation.

The registered nurse is expected to practice nursing in such a legal manner as to avoid charges of unprofessional conduct. The nurse needs to be aware that most statutes contain such inadequate definitions of unprofessional conduct that it would be almost impossible for nurses to be successfully prosecuted for unprofessional conduct except in instances where tangible evidence exists that crimes have been committed, where medical records on drug administration are distorted, where patients' drugs are consumed for personal use by nurses, and for repeated acts of negligence. Disclosure of prognostic information to dying adults by registered nurses would not meet the defined criteria of unprofessional conduct in most statutes because unprofessional conduct is limited to criminal activity, misuse of drugs, or repeated negligence.

Registered nurses should be aware that a diversity of opinion continues to exist within the nursing profession in relation to the appropriate action for their disclosure of alternative or prognostic information to dying adults. Some boards of nursing vary in their interpretation of the definitions of professional nursing and unprofessional conduct. Thus, a board may support or fail to support a nurse's decision to disclose prognostic or alternative treatment information based upon the interpretation of professional nursing and unprofessional conduct. When nurses make decisions about the disclosure of prognostic information to dying adults they should consider the precedent established in the <u>Tuma</u> case that they are never off-duty from their legal obligations.

An additional legal responsibility of registered nurses as they make decisions about their disclosure of prognostic information to dying adults is to be aware that they are protected by due process procedures. Due process protects nurses, as well as others, from unfair proceedings that could deprive them of valuable property such as a license to practice a profession. In those instances when registered nurses are accused of unprofessional conduct for discussing alternative treatment or prognostic information with dying adults, they can be protected against unfairness by the implementation of due process procedures.

Professional Responsibilities

As a result of an analysis of the <u>Tuma</u> case the following are identified as the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults. The responsibilities are listed sequentially for both the issues and sub-issues of relationships, rights, responsibilities, conflicts, informed consent, disclosure, confidentiality, and deception.

Professional responsibilities of registered nurses include the realization that nurses place high priority upon patient and family communications. Nurses view themselves as equal partners with physicians in consumer-provider health care relationships. However, nurses must also be alert to the fact that many physicians view themselves as employers of nurses and desire to control the communication of nurses regarding alternative treatment or prognostic information to dying adults. Physicians may also view themselves as assuming primary responsibility for patient care while nurses and other health care professionals assume secondary responsibilities.

When considering rights, the professional responsibilities of registered nurses are to recognize that patients have rights to receive prognostic information from physicians. In some states those rights have achieved legal status, whereas in other states the right to information is established by institutional policies or social expectations. Registered nurses are expected in some instances to help patients achieve their right to information. When deciding about the disclosure of prognostic information to dying adults, registered nurses should be aware of their own right to control the practice of nursing in conjunction with others.

Nurses also must be knowledgeable about their right to refuse to participate in situations which conflict with their moral beliefs, competencies, or preparation. For example, if a physician withholds the prognosis from an inquisitive dying patient, a registered nurse who disagrees with that decision because it conflicts with her moral belief about truthfulness may refuse to participate in the situation.

When considering the sub-issue of responsibilities, the registered nurse is required in some states to notify the physician when nursing care is compromised, in some states the nurse is required to follow administrative procedures,

and in some states the nurse is obligated to provide direct information to educate patients. In those instances when physicians fail to inform patients of a terminal prognosis or alternative therapy, registered nurses may decide that their responsibility to provide patient education permits or obligates them to provide the information directly. In other states, nurses may decide that they have fulfilled their responsibility when they inform the attending physician or the appropriate hospital administrative personnel.

In the sub-issue of conflicts, the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults include the acknowledgement that some nurses believe that when conflict occurs they have higher obligations to patients than they do to physicians. Nurses should know that the Idaho Supreme Court supported Tuma who revealed alternative treatment information to a dying adult. Nurses must also consider the risks involved whenever they decide to discuss alternative treatment or prognostic information with dying patients because other nurses and physicians may challenge such actions or decisions.

When considering the issue of informed consent, the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults include the fact that registered nurses are answerable for the information which they discuss with patients. Registered nurses must realize that medical and nursing care alternatives overlap. There may be some risk involved for a registered nurse who discusses alternative treatment or prognostic information with a dying adult, but both registered nurses and physicians are responsible for discussing health care alternatives with patients in at least two states.

When considering the issue of disclosure, the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic

Spence case established that patients should be informed of any risks of death, serious harm, or complications that could occur with treatment or non-treatment. Both physicians and nurses must be accountable for such disclosures. Registered nurses are thus responsible for knowing that some nurse practice statutes allow them to discuss alternative treatment information, whereas in other states nurses may refuse to do so because the state nurse practice act does not permit registered nurses to disclose such information.

In considering the sub-issue of confidentiality, the professional responsibilities of the registered nurse for decisions about disclosure of prognostic information to dying adults include the recognition that society has placed greater legal authority upon physician-patient confidentiality than it has upon nurse-patient confidentiality. Nurses are responsible for knowing that society has not clearly articulated the duties of nurses who are confronted with situations where physicians inform family members and not patients about a terminal illness. Registered nurses need to consider that some authorities expect nurses to inform patients directly of a fatal prognosis, but other authorities expect nurses to advocate with the physician on behalf of the patient.

The last sub-issue to be considered in relation to professional responsibilities of registered nurses for disclosure of prognostic information to dying adults is that of deception. Registered nurses are responsible for knowing that some research consent protocols were established in order not to deceive dying patients; therefore, health care personnel should also be expected to openly discuss alternative treatment or prognostic information with dying adults in order not to deceive them. Both registered nurses as well as physicians are responsible for not deceiving dying adults unless there is sufficient justification for deception to occur. Registered nurses are responsible for knowing that

authorities in the care of dying adults believe that deception does not protect patients from discovering their fatal illness. When nurses make decisions about disclosing a prognosis to a dying adult, registered nurses are responsible for knowing that many dying adults feel abandoned by health care providers who refuse to discuss terminal illness with patients.

Ethical Responsibilities

As a result of an analysis of the <u>Tuma</u> case and based upon Kantianism, rule utilitarianism, and act utilitarianism, the following are identified as ethical responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults. Kantian responsibilities are discussed first. Second, responsibilities according to rule utilitarianism are reviewed. Lastly, the responsibilities according to act utilitarianism are identified.

Important factors related to Kantianism and the ethical responsibilities of registered nurses for the disclosure of prognostic information to dying adults were derived from an analysis of the <u>Tuma</u> case. In Kantianism the perceived will, motives, and intentions of Tuma were examined. Two consistent rules which could be applied are not to deceive a patient about treatment information and not to withhold relevant information from collaborating health care providers.

The nurse in the <u>Tuma</u> case was responsible for communicating relevant information to the physician which she failed to do. Health care providers are responsible not to deceive the patient; thus, they are required to provide the patient with treatment information. The physician was perceived by the nurse and patient to be unable to provide the treatment information to the patient who requested it. The nurse was justified in providing such information because the patient requested it, the nurse possessed the information, and the nurse had a

sufficient relationship with the patient which allowed her to communicate in an effective manner.

Important factors related to rule utilitarianism and the ethical responsibilities of registered nurses for the disclosure of prognostic information to dying adults were also determined by the analysis of the <u>Tuma</u> case. General rules which were determined to produce the greatest good for the greatest number include that a rule of telling the truth to dying patients produces the greatest good and a rule requiring health care providers to communicate relevant information among themselves produces the greatest good for society.

A nurse would, thus, be responsible for communicating relevant prognostic information to a physician. A physician would be responsible for communicating the information to a patient but a nurse would also be responsible for communicating with the patient when the physician, for invalid reasons, failed to provide the requested information. Actively lying to a patient about a prognosis or merely allowing a patient to believe an inaccurate prognosis through passive deception can culminate in a patient believing information that others perceive to be false and inaccurate. Since active lying or passive deception can both result in a patient's deception, neither practice was justified in the <u>Tuma</u> case.

Important questions about act utilitarianism were examined in the <u>Tuma</u> case. Two questions were examined regarding her specific actions. The first action was to examine whether or not Tuma's act of discussing alternative treatments with an inquiring patient created the greatest good for the greatest number. Consequences such as loss of job, legal expenses, suspension of a nursing license, attention to unclear definitions of unprofessional nursing, attention to due process rights for health care workers, and national nursing attention to the <u>Tuma</u> case were examined. It was determined through act utilitarian analysis that the nurse was justified in discussing alternative treat-

ment information based upon accomplishing the greatest good for the greatest number.

A second question was examined by determining whether Tuma's action of withholding relevant treatment information from the physician was justified. According to act utilitarianism, this action by Tuma was not justified because the greatest good for the greatest number cannot be accomplished if nurses withhold relevant treatment information from physicians. Thus, the ethical responsibilities of a nurse for disclosing prognostic information to dving adults are to accomplish the greatest good for the greatest number in both act and rule utilitarianism. A registered nurse would be responsible for communicating relevant prognostic information to a physician. A physician would be responsible for communicating the information to a patient, but a nurse would also be responsible for communicating with the patient when the physician, for invalid reasons, failed to provide the needed or requested information. Active lying or passive deception were not justified in the Tuma case merely because the physician and family wished to spare the patient from the pain associated with learning that she had a fatal illness. Deception can be justified whenever it is necessary to save a life. Since it was impossible to save the patient's life. deception could not be justified in the Tuma case.

CHAPTER IV

YARLING CASE ANALYSIS

The format of Chapter IV illustrates the case analysis of a hypothetical incident used to examine further the research questions raised in the study. The research questions included: What are the legal responsibilities of registered nurses as they make decisions about disclosing prognostic information to dying adults; What are the professional responsibilities of registered nurses as they decide about disclosing prognostic information to dying adults; and, based upon Kantianism and utilitarianism what are the ethical responsibilities of registered nurses as they decide about disclosing prognostic information to dying adults?

Analysis of legal issues included due process, unprofessional conduct, and professional nursing. Professional issues included health care provider-consumer relationships, informed consent, and disclosure. Sub-issues included rights, responsibilities, conflict, confidentiality, and deception in terminal illness. Kantianism and utilitarianism provided the ethical theoretical frameworks by which the selected case was analyzed.

Issues and sub-issues were defined in Chapter III and are used similarly in this chapter. The <u>Tuma</u> case, analyzed in Chapter III, involved a situation which actually occurred in Idaho. It involved the disclosure of alternative treatment information by a registered nurse to a dying adult. The <u>Yarling</u> case was selected for analysis in Chapter IV because it involved a theoretical incident similar to <u>Tuma</u>. The <u>Yarling</u> case provided the opportunity to explore various

alternatives and to analyze possible consequences for a nurse who disclosed the prognosis to a dying adult whose family and physician intended to withhold that information from the patient. When relevant in the discussion of issues, comparisons and contrasts between Tuma and Yarling were made in Chapter IV.

Yarling Case Overview

A 50-year-old, recently divorced mother of two adult daughters, Mrs. X., underwent surgery which established a diagnosis of colon cancer with liver and lung metastasis. The diagnosis reflected a grave condition with a prognosis of less than one year of life despite surgery, radiation, and/or chemotherapy. A staff nurse with four years of oncology experience was assigned to Mrs. X. for three days preoperatively, but she was not on duty on the day of surgery.

When the staff nurse returned on Mrs. X.'s second post-operative day, she discovered that Mrs. X. had not been told about her condition. Mrs. X. asked the nurse for information about various tests and when she would be able to return to work. When the nurse avoided direct answers, Mrs. X. asked if everything was all right. Meanwhile, her daughters introduced diversionary remarks into the conversation. When the nurse left the room, one daughter followed her outside to explain that they wished to spare their mother pain that the knowledge of her condition would bring since she had just gone through a long and difficult divorce. Clearly, the physician had talked to the family but not with the patient.

The staff nurse listened to the daughter but offered her no assurances that information would be withheld. With the arrival of the attending physician who was not Mrs. X.'s long-standing personal physician, the nurse asked about what he had told the patient. She mentioned the patient's requests and that she, the nurse, wished to be open and supportive to Mrs. X. who trusted her.

The physician responded that Mrs. X. had not been told that she had cancer and that he did not intend to tell her since he wished to spare her the anxiety which knowledge of her condition would create. The physician further informed the nurse that he would consider any disclosure on her part to be inappropriate and contrary to the well-being of Mrs. X.

At this point, the nurse sought advice from her head nurse who acknowledged that the physician's reaction created a serious dilemma because she faced a conflict between adhering to the physician's directives or relating openly with Mrs. X. The head nurse advised rather reluctantly that it was probably best to follow his directives and to deal with Mrs. X. accordingly. The staff nurse carefully deliberated and concluded that since Mrs. X. had a right to have her questions answered she should answer them openly. She was uncomfortable about withholding information from a questioning adult patient who trusted her. However, the nurse was hesitant to act in a manner contrary to the wishes of the family, the physician, and the head nurse. The staff nurse was also unsure about her own legal rights in this situation (Yarling, 1978a).

The Yarling case, a hypothetical incident, provided data for case analysis in this chapter. Special permission to use the case was granted by both the author, Rod Yarling, and Leah Curtin, editor of Supervisor Nurse in which the case was originally published. The original case was modified by the researcher to the extent of specifying that the diagnosis of carcinoma with metastasis indicated a rapidly progressing terminal prognosis in spite of therapeutic measures. The Yarling case and its variations have been discussed in the literature by Yarling (1978a, 1978b), Stanley (1981), Voorhis and Dunne (1981), and Curtin and Flaherty (1982).

Legal Issues

The initial analysis of the <u>Yarling</u> case was related to issues which included due process, unprofessional conduct, and professional nursing. Each legal issue was defined in Chapter III; therefore, the analysis in Chapter IV involved amplification of the issues with specific application to Yarling.

Due Process - Legal Issue

Because the <u>Yarling</u> case involved a theoretical situation, there were no state statutes to provide direction for due process. For that reason direction was obtained from the American Nurses' Association's <u>Guidelines for Implementing the Code for Nurses</u> (1980).

Guidelines (1980) contained two interpretations of due process: First, due process involves different rules of fair play for different proceedings; second, due process procedures balance the individual's right not to be deprived of liberty or property against the need of government (or an association) to dispense with a particular procedure. Fair and open procedures are needed to assure against vindictive and arbitrary actions.

A variety of actions were available to the nurse in the <u>Yarling</u> case. These actions may or may not result in disciplinary actions against the nurse. Several courses of action could be included in nursing intervention for Mrs. X.

First, the nurse might respond that she was unable to answer the questions and she might encourage Mrs. X. to question the physician directly. Such a nursing action could involve guiding Mrs. X. to select the most pertinent questions without the nurse actually disclosing the prognosis to her. This nursing action could represent a compromise between the nurse "telling the patient" or "not telling" her. Second, the nurse might evade the patient's questions and discuss them with the physician. In <u>Yarling</u> such a nursing action might result in

a lack of disclosure by the physician or family to the patient; a lack of disclosure could result in the patient's being deceived about her diagnosis and prognosis. Conversely, she might attempt to persuade the physician and family that Mrs. X. should be told her diagnosis and prognosis. Third, she might attempt to seek assistance from nursing, medical, and hospital administrative personnel to persuade the physician and family that the patient should be informed. She might be successful or unsuccessful in her attempts to persuade others that the patient should be informed. Next, if she were unable to persuade others who were concerned about Mrs. X.'s care that Mrs. X. should be informed, the nurse might pursue her efforts through her local and state nurses' association to obtain support for a position statement regarding the nurse's role in such a situation. Such action could be so protracted and time-consuming that little guidance could be obtained for the nurse in a specific incident. However, if such action resulted in specific directives, guidance could be available for nurses whenever such future incidents occurred.

The nurse might respond to the patient's request for information by telling her the diagnosis and prognosis. An open disclosure by the nurse might temporarily upset the patient, family, and physician. If the patient, family, and physician eventually benefit from the open disclosure there may be no further conflict that would result in disciplinary action against the nurse. If Mrs. X. did not benefit from the open disclosure, disciplinary action might be instituted against the nurse. It also might be initiated against the nurse because she failed to function in the usual "team spirit" of cooperation among nurses, physicians, and the family of a patient.

From <u>Tuma</u> it was possible to conclude that certain aspects of due process such as an ascertainable standard of conduct and fair proceedings were necessary whenever a nurse was accused of professional misconduct. Rulings from the

<u>Tuma</u> case established that boards of nursing must define unprofessional conduct with sufficient clarity to allow practitioners and board members to know in advance sufficient examples to allow them to make judgments whenever unspecified examples were being considered. Boards of nursing cannot decide specific actions that constitute misconduct, ex post facto, on a case by case basis.

Based upon the <u>Tuma</u> analysis, one can postulate that if the <u>Yarling</u> case were reviewed by a board of nursing, to assure due process for the nurse, the board would be required to examine the applicable definition of unprofessional conduct. The specific point to be determined by such a definition as applied to <u>Yarling</u> would involve whether or not open disclosure of a terminal diagnosis or prognosis by a nurse to a competent adult exemplified unprofessional conduct. If there was no clear definition to guide the nurse and members of the board of nursing in determining the ascertainable standard of conduct in such an incident, according to the rules of due process the board could not legally discipline the nurse. Ultimately a profession regulates its own practice; therefore, the issue of disclosure by nurses must be decided first by nurses and then supported by others through legislative action (Regan, 1981c).

Unprofessional Conduct - Legal Issue

In 1980, the American Nurses' Association published the results of a two-year study by the Ad Hoc Committee on Legal Aspects of Practice. The results were published as recommendations for legislation in a publication called <u>The Nursing Practice Act: Suggested State Legislation</u> (ANA, 1980d). The purpose of the study was to examine position statements of the American Nurses' Association, the model nurse practice act of 1976 by ANA, and current statutes

and regulations governing nursing practice in order to make suggestions for future legislation.

This publication contained a section on discipline which identified several pertinent facts about unprofessional conduct. Section 702 (1980) contained 13 statements descriptive of nursing actions that could result in disciplinary action by a board of nursing. Two items related to unprofessional conduct: (1) "engages in unprofessional conduct of a character likely to deceive, defraud, or harm the public; or (2) engaged in any other unprofessional conduct as identified by the board in its rules" ("The Nursing Practice Act: Suggested State Legislation," 1980d, p. 21). A suggestion was made that boards further identify reasons for discipline in their rules and regulations. Boards were advised to use phrases such as "including but not limited to" (1980, p. 21). Nursing boards were alerted that court decisions such as occurred in <u>Tuma</u> had reversed disciplinary actions by licensing boards because of inadequate statutes or rules and regulations.

It is possible that a nurse who told the patient about her fatal prognosis contrary to the physician's and family's wishes might be accused by the physician of unprofessional conduct. If such accusation occurred, it is clear from the Tuma case that an adequate definition of unprofessional conduct was needed to forewarn the nurse. A clear a priori definition would also allow members of boards of nursing to make judgments about unprofessional conduct in disputed instances.

Regan (1981c) suggested that boards of nursing should make serious attempts to define unprofessional conduct. He advised that the best way to approach such a task was for boards to use legal counsel to discover cases in which courts had concluded that unprofessional conduct existed. Additionally, Regan advised that state boards of nursing determine what they considered to be unprofessional conduct. After items that constitute unprofessional conduct had

been determined by the nursing boards, those items should be presented to the state attorney general for an advisory opinion regarding both the legality of the proposed definition of the unprofessional conduct as well as legality of the items which are suggested as examples of unprofessional conduct. Such a process of deliberation would require nurses with varied opinions about unprofessional conduct to arrive at sufficient agreement in order to accept a proposed definition and examples.

Greenlaw (1981) indicated that nursing has performed poorly in dealing with controversy. She stated that nursing's difficulty in dealing with controversy has been more harmful to the profession than any other single factor. She wrote that nurses must develop strategies for dealing with controversy among themselves as well as with others. Nursing will not be taken seriously, according to Greenlaw, until it can formulate reasoned arguments for views with which it disagrees. The Tuma case created much disagreement among nurses regarding appropriate nursing actions and it is anticipated that the Yarling case could evoke a similar response. Even though there was disagreement over Tuma's actions, most nurses who wrote about her case either in editorial opinions, letters to the editor, or journal articles indicated their approval of her actions as appropriate or correct for a nurse.

Definition of Professional Nursing - Legal Issue

ANA <u>The Nursing Practice Act: Suggested Legislation</u> recommended the following definition of professional nursing,

the practice of nursing means the performance for compensation of professional services requiring substantial specialized knowledge of the biological, physical, behavioral, psychological, and sociological sciences and of nursing theory as the basis for assessment, diagnosis, planning, intervention, and evaluation in the promotion and maintenance of health; the case-finding and

management of illness, injury, or infirmity; the restoration of optimum function; or the achievement of a dignified death. Nursing practice includes but is not limited administration, to teaching, counseling. supervision, delegation, and evaluation of practice and execution of the medical regimen, including the administration of medications and treatments prescribed by any person authorized by state law to prescribe. Each registered nurse is directly accountable and responsible to the consumer for the quality of nursing care rendered. (1980d, p. 6).

Subsequently, the American Nurses' Association Congress for Nursing Practice voted to reconsider the phrase "prescribed by any person authorized by state law to prescribe" (1980d, p. 6). Forthcoming publications may modify that phrase. The impact of such a modification might be that physicians alone will prescribe medications and treatments, or, in some instances, others, such as nurse practitioners or optometrists, may be allowed to prescribe.

Two aspects of the definition of nursing contained in <u>The Nursing Practice</u>

<u>Act: Suggested State Legislation</u> (ANA, 1980d) were especially pertinent to the possible nursing actions in the <u>Yarling</u> case. Those aspects of the definition most related to the case were "the achievement of a dignified death" and "each registered nurse is directly accountable and responsible to the consumer for the quality of nursing care rendered" (1980d, p. 6).

Ultimately, nursing actions in the <u>Yarling</u> case reduce to two alternatives. Either the nurse will disclose to the patient her prognosis or she will not. The nurse should be able to receive guidance for her decision based upon the definition of professional nursing. There is no clear guidance on unprofessional conduct in <u>The Nursing Practice Act: Suggested State Legislation</u> (ANA, 1980d) because state boards of nursing were encouraged to define and itemize that category in a separate section on rules and regulations.

Thus, a nurse providing care to the adult patient in the <u>Yarling</u> case might still be uncertain about whether or not she would be accused of unprofessional conduct if she told the patient her prognosis or diagnosis. Some guidance might be obtained by reviewing the appropriate state nurse practice act.

Additional guidance can be obtained by determining whether or not state statutes allow patients open access to their medical records. When patients have open access to their medical records, they can easily discover their diagnoses and may gain clues about the prognoses. Nine states provide patients access to their charts either directly or through their attorneys (Yarling 1978a). California, Illinois, and Utah allow the patient's attorney access to records. Massachusetts, Wisconsin, New Jersey, Louisiana, Mississippi, and Connecticut allow patients direct access to their charts under certain conditions, such as at discharge, or upon request, or upon the payment of reasonable fees for reproducing the records (Yarling, 1978a).

In reviewing the legal issues in <u>Yarling</u>, this analysis examined the following considerations: the liability of an unprofessional conduct charge if the nurse revealed a fatal diagnosis or prognosis to a questioning adult patient against the wishes of the physician; if such a disclosure by the nurse exceeded the scope of practice according to the definition of professional nursing; and, the steps that were necessary to assure due process if the nurse were charged with unprofessional conduct. In relation to the latter consideration, Gouge stated the essentials of due process succinctly. They are: "an ascertainable standard of conduct, a fair procedure for accusation, proper jurisdiction, and a fair tribunal" (1980, p. 74).

The <u>Yarling</u> analysis revealed that a nurse probably could not be successfully prosecuted for unprofessional conduct unless there were clear definitions to forewarn her about disclosure of a fatal prognosis to a questioning adult patient

when both the physician and family wanted to withhold such information from the patient. Members of boards of nursing who might be required to deliberate about such disputed cases would be required to make judgments which might not be supported by the courts if definitions were too vague to supply the necessary guidance for both the board members and practicing nurses.

The Nursing Practice Act: Suggested Legislation (ANA, 1980d) contained several items to provide for the discipline of a nurse who divulges information to a patient in a situation such as that presented in the <u>Yarling</u> case. Section 702(c), which deals with discipline, states that a nurse may be disciplined upon proof that the person "has negligently or willfully acted in a manner inconsistent with the health or safety of the persons under her care" (1980d, p. 20). If the physician had determined that the patient might experience great anxiety which could endanger her health or safety if she were informed of her diagnosis or prognosis, the nurse's decision to reveal such information could be interpreted as willful violation of Section 702(c) (Watson, Note 5, 1982).

Section 702(f) of <u>The Nursing Practice Act</u>: <u>Suggested Legislation</u> (ANA, 1980d) requires a nurse to be disciplined if the person "has negligently or willfully practiced nursing in a manner that fails to meet generally accepted standards of nursing practice" (1980d, p. 20). Disciplinary action brought against a nurse under this provision could be defended on the basis of aspects from the <u>Tuma</u> case which established that there were no generally recognized standards for nurse disclosure in such situations (Watson, Note 5, 1982).

The recommended definition of nursing in <u>The Nursing Practice Act:</u> <u>Suggested Legislation</u> (ANA, 1980d) indicated that nurses assisted patients in the achievement of a dignified death. Whether disclosure of a fatal diagnosis or prognosis to a patient would assist a person to achieve a dignified death is a debatable issue. Much evidence exists that openness helps patients, but some

evidence exists to indicate that some physicians and patients wish to avoid openness. In sum, a nurse's right to due process of law would appear to be a substantial defense to any charges brought against the nurse for violation of disclosure standards (Watson, Note 5, 1982).

In summary of the potential legal issues in the <u>Yarling</u> case, a nurse might be liable for an unprofessional conduct charge if she disclosed the prognosis to a terminally ill adult. A board of nursing might be required to determine if such action exceeded the scope of professional nursing as indicated by the locally applicable definition of professional nursing. Principles of due process would seem to provide an adequate defense for a nurse who might be accused of unprofessional conduct for disclosing a prognosis to a dying adult who indicated a desire to know about her illness.

Professional Issues and Sub-Issues

Professional issues which may emerge in the <u>Yarling</u> case include health care provider-consumer relationships which encompass those relationships that exist among patients, families, nurses, and physicians. Other professional issues were informed consent and disclosure. Professional sub-issues include rights, responsibilities, conflict, confidentiality, and deception.

Health Care Provider-Consumer Relationships - Professional Issue

Analysis of this issue in the <u>Tuma</u> case revealed varying perceptions among patients, families, nurses, and physicians regarding their interrelationships. Potential problems in the <u>Yarling</u> case may include those in the patient-family relationship, the patient-physician relationship, the family-nurse relationship, the nurse-nurse relationship, and the nurse-physician relationship.

Nurses wrote that they functioned as colleagues with physicians, but physicians contended that nurses worked for them and required physician supervision. To discuss conflicting and difficult practice questions some hospitals established joint practice committees that proposed models for nurse-physician cooperation.

The Yarling case was submitted for consideration to the National Joint Practice Commission, which was established in 1978 to discuss mutual concerns of physicians and nurses. Yarling (1978a) wrote that the case involved a significant problem which affected the lives of many patients, their families, nurses, and physicians. He indicated that some movement toward a resolution of the case issues was overdue. Curtin (1979) asserted that the Yarling case had been sent to the National Joint Practice Commission because the case involved a patient's right to know and because it represented a common problem in nurse-physician relationships. The Commission dissolved in 1981 without any deliberations about issues raised in the Yarling case.

According to Veatch, "one moral problem for any ethical theory is what an individual's moral obligations are when the person feels an act is wrong, but that act has been ordered by someone else" (1981, p. 18). He recognized that nurses often faced such problems in their interactions with physicians. He indicated that the difference between nursing ethics and physician ethics in relation to power and authority was one of degree, with nurses being expected to participate more frequently in practices that violated their consciences, while physicians more frequently acted from positions of relative moral autonomy. Veatch stated that nurses were more often involved in situations where they had to decide whether to execute ordered acts to which they morally objected. He indicated that both physician and nursing ethics involved ethical problems of role relationships. He rejected the physician as the captain of the health team in

which the nurse was only a player. The real captain of the health team was not the physician or the nurse; it was the patient. If this concept were applied to the Yarling case, it would be easy to conclude that either the physician or nurse could disclose to the patient her prognosis or diagnosis.

The President's Commission for the Study of Ethical Problems in Medicine ("Making Health Care Decisions", 1982) discussed two models of the professional-patient relationship. They were "medical paternalism" and "patient sovereignty." Each model was described as inadequate by the Commission. It recommended that the relationship between patients and professionals be characterized by mutual participation, respect, and shared decision-making. The Commission noted that the strength of a professional-patient relationship depended upon the trust and confidence exchanged between the participants in the relationship. A decision in Yarling to withhold diagnostic and prognostic information from a questioning, competent adult could threaten the trust and confidence of the entire professional-patient relationship.

Wandelt et al. (1981) indicated that nurses left nursing because the work environment did not provide them with a sense of worth as a health care team member, and there was a lack of positive professional interactions with physicians. Lieb (1978) wrote that nurses needed to elicit the assistance of health care consumers to examine problems related to authority within the present health care system. She stated that a major goal of professional nursing was to deal with patients and families in a helping relationship which required authority to function independently in some instances.

Yarling (1978b) indicated that the nurse who responded openly to the question of a dying patient about his condition, with accurate and sensitive information, with trust and rapport, and with the full knowledge of colleagues,

was well within the law in most states even if the family, physician, and other nurses disagreed. Kastenbaum and Spector (1978) wrote that nurses usually identified both patient and family as the unit of patient care. Nurses have most often placed priority upon the patient's needs and requests when a conflict existed between the patient's needs or the family's needs. This priority of emphasis in the nursing care of a dying patient varied from that demonstrated by the physician in the <u>Yarling</u> case who discussed the patient's diagnosis and prognosis with the family and not with the patient.

Rights - Professional Sub-Issue

The <u>Tuma</u> analysis of rights revealed that several authors believed that patients had rights to information about themselves. Selective physicians and attorneys argued that "rights language" created adversarial relationships between physicians and patients. Those persons preferred to use terms such as "patient's needs" instead of patient's rights. Legal proceedings have established due process rights for nurses. Some authors contended that a patient's right to privacy was violated whenever family members were informed of a patient's fatal diagnosis (or prognosis) prior to or instead of informing the patient. The <u>Tuma</u> analysis dealt primarily with the patient's right to information, the patient's right to refuse treatment, the patient's right to privacy, and with the nurse's due process rights.

The <u>Yarling</u> case deals primarily with the patient's right to information, to privacy, and to have access to medical records. It also deals with a nurse's right to practice nursing and a physician's right to utilize "therapeutic privilege" in medical practice.

Kelly (1974) asserted that a current social revolution, called consumerism, had greatly influenced health care. The growth of consumerism encouraged

patients to become more concerned about their rights. She indicated that the Privacy Act of 1974 permitted a person to have access to information about himself which was contained in federal agency records and to have a copy made of such records. Annas et al. wrote that the Privacy Act of 1974 provided patients in Veterans Administration hospitals with access to their charts. "Upon request, an individual who is the subject of a medical record maintained by a medical care provider... should be allowed access to that medical record including an opportunity to see and copy it" (1981, p. 159). Benditt (1982) asserted that persons had rights to privacy regarding information about themselves.

Smith and Davis (1980) contended that a nurse's license granted a legal right (or at least a legal privilege) to practice nursing as defined in the state practice act. They warned, however, that the protection for nurses from interference by others in the exercise of legal privileges was usually less than that provided to physicians. Fagin asserted that nurses had made clearer statements regarding their rights not to act than their rights to act. She expressed hope that nurses would rapidly "delineate what they have the right to do as well as not to do" (1975, p. 84).

Data reviewed on rights in <u>Tuma</u> are also pertinent in <u>Yarling</u>. The AHA <u>Patient's Bill of Rights</u> (1970) gave the patient the right to obtain diagnostic and prognostic information from her physician. The physician has a legally recognized privilege (therapeutic privilege) to withhold a diagnosis of cancer if revealing the diagnosis would seriously jeopardize the recovery of an unstable, temperamental, or severely depressed patient (Shannon & Manfra, 1982). <u>Natanson v. Kline</u> (1960) recognized the physician's use of therapeutic privilege. If the patient lives in a state where she has access to her medical records, the patient could discover her diagnosis by reading her chart. The 1974 Privacy Act

specifically established that a patient could read her medical record if she were a patient in a Veterans hospital.

Attitudes sometimes change slowly over time. Changes in attitudes may precede legal processes that assert various rights. Natanson v. Kline occurred in 1960 and The Privacy Act and the Patient's Bill of Rights were prominent in 1974. On the basis of these influences, one might speculate that attitudes toward patients receiving information from physicians were changing between 1960 and 1974. Literature sources (Annas, 1974; Gargaro, 1978c; Tuma, 1979; and Annas, 1982) revealed a gradual tendency between 1974 and the present time towards greater openness with patients. Literature sources that reviewed physician's attitudes and practices in the care of dying adults revealed contradictory results (Davies, 1972; Bok, 1978; and Sheldon, 1982). Some physicians were convinced that open disclosure was better for terminally ill adults (Tiger, 1976). Other physicians (Caldwell & Mishara, 1972) remained reluctant to discuss a diagnosis such as cancer with a patient.

The <u>Tuma</u> analysis provided direction for a nurse who might be confronted with a situation such as that portrayed in the <u>Yarling</u> case. Annas et al. (1981) clearly emphasized that nurses have the right to inform a patient about a terminal illness even when the physician objects. Data from <u>Tuma</u> revealed that a nurse's right to due process could protect her from disciplinary action in states where definitions and examples of unprofessional conduct were so ambiguous that reasonable persons could not decide disputed cases. Annas (1974) and Purtilo and Cassel (1981) maintained that a nurse has a right to provide a questioning adult patient with treatment information if the physician failed to provide the information.

Responsibilities - Professional Sub-Issue

An analysis of <u>Tuma</u> in Chapter III established that nurses were responsible for patient education and for influencing policy decisions about nursing. They were additionally responsible for their actions in relation to nursing diagnoses and interventions. They were challenged by others to assist hospitalized patients to implement their rights. Nurses were responsible for following recommended administrative channels and charting properly whenever they encountered substandard hospital practices or physician errors. In <u>Tuma</u>, nurses and physicians disagreed over nurse responsibilities for the discussion of alternative treatment information with patients.

Data published by the American Nurses' Association on standards for cancer nursing practice, the scope of medical-surgical nursing practice, and the Code for Nurses with Interpretive Statements (1976) are presented because they identify the responsibilities for nurse generalists who would most commonly be involved in the Yarling case. The involved nurse in Yarling was experienced in oncology nursing. The case did not imply that she was a nurse specialist or a nurse practitioner. By contrast, Tuma was a master's degree prepared nurse educator. The data that follow are applicable to nurse generalists who are often involved in the care of patients who are undergoing treatment for cancer.

The ANA <u>Code for Nurses with Interpretive Statements</u> indicated, "whenever possible, clients should be involved in the planning and implementation of their own health care" (1976, p. 4). The <u>Yarling</u> case involved an adult patient who questioned the nurse about her care by asking if anything was wrong. Her interest could be interpreted as a desire to be involved in her health care, and the Code statement held the nurse responsible for involving the patient.

Section 1.6 of the Code (1976) discussed the dying person:

Measures used to provide assistance should enable the client to live with as much comfort, dignity, and freedom from anxiety and pain as possible. The client's nursing care will determine to a great degree how this final human experience is lived and the peace and dignity with which death is approached. (1976, p. 6)

Both the family and physician in the <u>Yarling</u> case wanted to spare Mrs. X. the trauma they expected to be associated with her learning of the diagnosis. By contrast, persons who wrote about dying adults maintained that patients knew their diagnoses even when they had not been told (Hinton, 1967; Kubler-Ross, 1969; and Saunders, 1973).

Extrapolating from the Code (1976), it is apparent that a nurse has the responsibility to help a dying patient face the experience of death with dignity and freedom. It would be impossible for a patient to face death with freedom if she were denied by the physician and family the opportunity to learn her diagnosis and prognosis. Mrs. X. asked if everything was all right when she noticed that others were evading her questions. Her actions reflected her sensitivity to the actions of those around her.

Section 2.1 of the Code (1976, p. 6) discussed disclosure, "when knowledge gained in confidence is relevant or essential to others involved in planning or implementing the client's care, professional judgment is used in sharing it." Ordinarily, a patient's diagnosis and prognosis are not considered confidential from the patient. Annas (1974) specified that it was not unusual for a terminal illness to be kept confidential from a patient; however, he believed that such a practice violated the patient's freedom.

Section 2.2 of the Code (1976, p. 7) stated, "the nurse-client relationship is built on trust." Therefore, it is reasonable to assume that it is impossible for nurses to have trusting relationships with patients if nurses are required by

physician orders or family wishes to deceive patients about their diagnoses and treatments.

Section 3.2 of the Code (1976) revealed:

When the nurse is aware of inappropriate or questionable conduct in the provision of health care, concern should be expressed to the person carrying out the questionable practice and attention called to the possible detrimental effect upon the client's welfare... similar action should be directed to the responsible administrative person. If indicated, the practice should then be reported to the appropriate authority within the institution, agency, or larger system. (p. 8)

Such action recommended by the Code might not assist the nurse in making a decision in the <u>Yarling</u> case. Regan (1979a) indicated that a nurse could be accused of practicing medicine if she tried to substitute nursing judgment for medical judgment. By contrast, Yarling (1978b) proposed that issues of disclosure should not be decided based upon medical expertise. It is doubtful that a nurse would be able to secure the administrative support within a hospital for a nurse to tell a dying adult her diagnosis and prognosis against the wishes of a physician and the patient's family. However, if disclosure issues could be decided on some basis other than medical expertise, then a nurse, family member, or member of the clergy might be more appropriate disclosers than physicians on some occasions.

Section 4.2 of the ANA Code (1976) identified responsibilities expected of nurses:

Data collection and assessment of the health status of the client; determination of the nursing care plan directed toward designated goals; evaluation of the effectiveness of nursing care in achieving the goals of care; and subsequent reassessment and revision of the nursing care plan as defined in the ANA <u>Standards of Nursing Practice</u>. (1976, p. 10)

The ANA Statement on the Scope of Medical-Surgical Nursing Practice (1980b) included decision-making, personal choice, the dying process, and death as

aspects of medical-surgical nursing practice. Medical-surgical nurses were described as possessing knowledge and skills to assist both families and patients with the dying process and death; to assist patients who experienced grief, loss, anxiety, and depression; and to assist families and patients as they made choices about care and treatment. Such statements indicated that nurses were both capable of and responsible for effective nursing care to patients and families who experienced depression, grief, loss, and death.

The ANA <u>Outcome Standards for Cancer Nursing Practice</u> (1980a) revealed that both patients and family members needed accurate information about a disease and recommendations for treatment in order to cope effectively with the situation. Mrs. X. might have difficulty coping with her illness when she does not know her diagnosis or prognosis.

Section 4.3 of the Code (1976) mentioned:

Neither physician's prescriptions nor the employing agency's policies relieve the nurse of ethical or legal accountability for actions taken and judgments made. (1976, p. 10)

This statement implies that a nurse will be held accountable for her actions in both the legal and ethical domain. Based upon a value choice, a nurse in the Yarling incident might determine that her responsibilities to the patient have been fulfilled when she alerts both the physician and family that their protective actions toward Mrs. X. may result in deceiving her about her own illness. Some nurses might decide that the legal system would extract too heavy a price for disclosure by the nurse against physician and family wishes. Other nurses would place greater emphasis upon their ethical responsibility to tell the patient the truth. Still other nurses might decide that they had fulfilled their professional responsibilities when they reported the incident to proper administrative authorities and charted it. A nurse might decide that she was responsible for

disclosing the prognosis to her patient in order to plan effectively and implement care to a dying adult or to educate the patient about her condition.

The daughters in the Yarling case demonstrated family responsibilities toward the care of their mother. The case depicted them as caring persons who wanted to protect their mother from pain. It is possible that a nurse could assume responsibility for educating them about the benefits and liabilities to their mother of open disclosure about her diagnosis and prognosis. Kubler-Ross (1969) has widely influenced lay persons such as family members to become more aware of the needs of dying persons. Perhaps the daughters could be influenced by the nurse who might refer them to Kubler-Ross's writings in an effort to change their attitude.

It is possible for the nurse to assume responsibility for attempting to change the physician's attitude toward disclosure to this client by presenting evidence of research and opinions of experts in the care of dying adults. A nurse might volunteer to assist the physician in discussing the diagnosis with the patient if he has difficulty handling such situations. Such action was supported by Rosoff (1981) who revealed that some physicians delegated to nurses the responsibility for telling patients about a fatal diagnosis.

If all efforts failed to convince the physician and the family that the patient should be informed, the nurse is then left to evaluate her own degree of commitment to the patient's right to know, and the nurse's resources and willingness to face the consequences of her decision to inform the patient. A nurse who discloses a terminal prognosis to a patient might predicate her actions upon a disregard for the customary role of hospital nurses that are expected to carry out physician orders rather than upon what the nurse perceives to be civil disobedience to unfair laws. Ultimately, nurses and others must face the responsibility to decide this question because new definitions of unprofessional

conduct are waiting to be written in most states. In spite of the controversy over <u>Tuma</u>, the data generated by that case revealed that most nurses supported Tuma's responsibility to discuss alternative treatment information with a questioning patient.

The <u>Tuma</u> case also established that the nurse had to pay a significant price as a consequence of her actions. There are many nurses who would be unwilling or unable to pay such a price for disclosure. The <u>Yarling</u> case would present the nurse with a difficult choice. Therefore, nurses might determine their responsibilities in a variety of ways depending upon the value they place upon the choices which are available to them. Some nurses could perhaps determine that they must disclose the prognosis to a patient in order to plan effectively and implement the nursing care of a dying adult. Other nurses could perhaps determine that their responsibilities ceased when they alerted the physician and family about the hazards that deception about diagnosis and prognosis presented for Mrs. X. Other nurses might determine that Mrs. X. should be informed but the consequences to them personally might be too great for them to risk directly informing the patient.

Conflict - Professional Sub-Issue

The <u>Tuma</u> analysis revealed that conflicts existed between nurses and physicians in relation to nursing autonomy, coercion, personal identity, and the power to make decisions. Conflicts existed over hospital policies that prohibit nurses from challenging physician orders except in extreme situations. Experts in nursing ethics advocated that a nurse's obligation to a patient superceded the nurse's obligation to execute a physician's order. Diversity of opinion continued to exist over appropriate nursing actions in controversial incidents. Some

nursing personnel have cooperated with administrative sanctions which were imposed upon nurses who challenged erroneous medical orders.

Possible primary conflicts in the <u>Yarling</u> incident include nurse-physician, nurse-family, and nurse-nurse. In <u>Yarling</u> the staff nurse was warned by the physician that he would consider any disclosure on her part to be inappropriate and contrary to the well-being of Mrs. X. However, Curtin and Flaherty (1982) asserted that a physician does not have absolute control over information regarding a client. Courts can impose requirements upon physicians to supply information about patients.

A physician has no moral or legal right to force a person to remain silent about his condition or to force a patient's family to withhold information about him. (1982, p. 331)

Curtin and Flaherty maintained that a physician is best qualified to discuss a patient's medical condition, medical prognosis, and proposed treatment. They differentiated between explaining the nature of an illness or treatment and answering a patient's questions about his impending death. It is questionable whether or not a physician's authority can require others to withhold information or to lie. Curtin and Flaherty (1982, p. 332) stated that "attempting to forbid another to respect a person's human rights is at least as reprehensible as attempting to force others to violate a person's civil or legal rights" (1982, p. 332). They indicated that physicians have the power to withhold information from patients, to lie to them, and to require others to do so. Furthermore, they suggested that it is unlikely that nurses will disclose information to patients, in any great numbers, as long as physicians have the power to coerce and punish them for doing so.

In <u>Yarling</u> one daughter explained to the nurse that the family did not wish to tell the mother her condition because she had just gone through a difficult divorce. The question arises as to whether or not a nurse is responsible for

attempting to resolve a nurse-family conflict such as the disagreement over disclosure in Yarling. Nichols (1979) and Haw (1980) proposed that additional communication could sometimes resolve conflict. A nurse might be responsible for presenting convincing information to the family members to enable them to change their attitude about disclosure. Their mother's best interests were also their objectives for her care. If family members are not convinced, then the nurse is faced with deciding priorities which most often favor the patient's wishes (Kastenbaum & Spector, 1978; and Yarling, 1978b).

The head nurse-staff nurse conflict in Yarling illustrated a nurse-nurse conflict. Curtin and Flaherty (1982) criticized the actions of the head nurse in the Yarling case because she failed to confront the physician about his nondisclosure, and she failed to seek assistance from a higher authority. The actions of the head nurse were consistent with findings by Murphy (Note 3) who studied Kolberg's stages of moral reasoning. Her results revealed that nurses functioned at conventional levels of moral development and often sought to avoid conflict even when patient care might be compromised. The Yarling head nurse-staff nurse conflict may have occurred because the head nurse wanted to avoid conflict with the physician.

It seems reasonable to assume that nurse-nurse cooperation would favorably affect patient care. Curtin and Flaherty (1982) advised that nurses should adopt a mutually supportive process which could be institutionalized through administrative procedures. American Nurses' Association guidelines in Roles, Responsibilities, and Qualifications for Nurse Administrators (1978) indicated that practicing nurses are individually responsible for patient care and that administrators support the role of nurses as patient advocates.

Informed Consent - Professional Issue

The <u>Tuma</u> analysis of informed consent as a professional issue determined that informed consent was required whenever a patient experiences surgery or a risky diagnostic or treatment procedure. No informed consent was required for life-threatening emergency care. Problems existed in the overlapping functions between physicians and nurses for the discussion of medical or nursing health care procedures or alternatives. Informed consent was differentiated from disclosure because there were some instances in the course of terminal illness when no treatment or surgery was indicated. Disclosure may be pertinent in such instances even if informed consent is not technically required.

The <u>Yarling</u> case raises a question of whether informed consent is required in cases where no additional surgery or therapeutic procedures are required. The question arises as to whether or not a diagnosis of cancer for which there is no effective therapy requires that a patient be informed. One who interprets the rules of informed consent strictly might say that no consent is required. Others would say that the spirit of informed consent applied to the <u>Yarling</u> case, especially since surgery established the definitive diagnosis of metastatic cancer and a prognosis of less than one year in spite of any therapy.

The President's Commission for the Study of Ethical Problems in Medicine stipulated in Making Health Care Decisions (1982) that the fundamental values which informed consent intended to promote were self-determination and patient well-being. The Commission further asserted that the ethical foundations of informed consent allowed information to be withheld from patients only when they requested such withholding or when the information would cause considerable damage to the patient's well-being. The Yarling incident illustrated a disagreement over the factors one should consider in determining a patient's well-being. The physician and family were concerned about sparing the patient

pain, but the nurse was also concerned about helping the patient to adjust realistically to her illness.

Barber (1980) described two models of authority and power patterns in medical relationships which were important influences upon informed consent. The collegiality model whereby participants relate to each other as cooperating colleagues was described as the ideal one for achieving the greatest satisfaction and effectiveness for all participants. The dominance model was described as the authority relationship which actually existed in most health care systems. Barber discussed a study conducted by Freidson on professional dominance which indicated that physicians were not inclined to authorize other health care workers to communicate information to patients. In <u>Yarling</u>, the physician cautioned the nurse against providing any diagnostic or prognostic information to the patient.

Rosoff (1981) indicated that four percent of the physicians involved in his study on informed consent allowed nurses or other health professionals to provide informed consent information to patients. Barber (1980, p. 65) wrote, "One of the few aspects of the medical system where we can see the professional dominance of the physician most clearly is the relations between nurses and physicians in the hospital." Despite Barber's comments, four percent of the physicians involved in the Rosoff study must have believed that nurses and other health professionals were capable of providing informed consent information to patients. Barber also suggested that most physicians disapproved of patients having free access to their medical records, but most physicians had not considered the advantages of such a new practice. One major advantage of free access to medical records could be the facility with which informed consent information could be transmitted to patients who had open access to their records.

Besch (1979) suggested that the physician may introduce an element of coercion into the consent procedure because of his authoritative role. She believed that when one professional group fails to provide information to patients that is needed for decision-making, it becomes the responsibility of another profession to meet those needs. A different aspect of informed consent was discussed by the Trandel-Korenchuks (1981). They discussed a California case (Truman v. Thomas, 1980) in which the Supreme Court determined that a physician must warn a patient of the risks that a reasonable person would want to know regarding refusing a diagnostic test such as a pap smear. The reasonable person standard is consistent with informed consent standards that were established by the Canterbury v. Spence case.

If a nurse decided to discuss diagnostic and prognostic information with a patient, she would be held to the same requirements for informed consent as a physician. In <u>Yarling</u>, the diagnosis was established by surgery and the grave prognosis was determined as a result of the diagnosis. Once such information was established, the nurse would possess the necessary information to enable her to discuss the diagnosis or prognosis. Yarling (1978b) wrote that the discussion of a terminal illness was a sacral event which required a greater degree of communication skills than knowledge of diagnostic or therapeutic procedures. He stated that nurses were especially well equipped to communicate sensitive information to others.

<u>Disclosure - Professional Issue</u>

Based upon the <u>Tuma</u> analysis of disclosure, it was possible to conclude that persons could use the strict criteria of informed consent to evade responsibility for informing dying adults about their diagnoses or prognoses. However, a precedent-setting case, <u>Canterbury v. Spence</u> (1972) extended

disclosure and informed consent standards to require that physicians explain to patients even one percent risks of death, serious harm, or complications. Evidence also existed in the literature that physicians were more likely to disclose a terminal illness to family members than they were to the patient. Nurses were encouraged to assume responsibility for assuring that a hospitalized patient's need or request for information was met.

The <u>Yarling</u> incident involved a decision by a physician and family not to disclose a terminal illness to an adult. The nurse was placed in a difficult position whereby she was questioned by Mrs. X about her condition and informed by the physician and family that a lack of disclosure was planned in Mrs. X.'s care. To analyze such a situation, a nurse should be aware of the background influences upon both the physician and family. For that reason, various studies about disclosure and nondisclosure are presented.

Bok (1978) listed the reasons most commonly given by physicians for withholding diagnostic and prognostic information from persons who were dying. Her reasons included the following: not to confuse the patient needlessly; not to cause unnecessary pain or discomfort; not to deprive the patient of hope; and to improve the chances of cure by encouraging certain therapeutic measures. These reasons can be summarized as fundamental principles of doing good (beneficence) and avoiding harm (nonmaleficence). Yarling raises the point of whether patients benefit more from disclosure of a fatal illness or whether they benefit more from nondisclosure.

Hinton (1967), by contrast, discussed reasons dying patients should be told their diagnoses and prognoses. One reason was to prevent the patient from feeling isolated. He believed that patients need sincere talk with others to ease their passage through the last stages of their lives. Patients may need to put

their business and spiritual affairs in order. Hinton compared the experience of deception with terminally ill patients to a woman's first pregnancy.

It would be thought preposterous and cruel if throughout a mother's first pregnancy and delivery all around conspired to treat it as indigestion and never gave her an opportunity to voice her doubts. (1967, p. 127)

Bok (1978) also identified reasons why dying patients should be informed about their diagnoses and prognoses. A patient needs to be free to consider his life in totality with both a beginning and ending. Deception fundamentally deprives the patient of his chance to be truly human, to make choices about treatment, and to make choices on how to spend his last days of human existence. Fears of dying patients are compounded by their growing loss of trust in health professionals. The pain associated with disclosure of sad news was less than previously believed; benefits of being informed included that pain was tolerated more easily, recovery from surgery was quicker, and cooperation with therapy was greatly improved.

Bok (1978) conceded that there were times when concealment, evasion, and withholding information were necessary. Patients may request that sad news not be given to them and their requests need to be respected. When someone (a health care professional) decided to deceive a patient, Bok suggested that such a decision should be examined from the following perspective. The health care professional should show why he feared a patient would be harmed or how he knew that truthful information would overwhelm the patient. A decision to deceive should be viewed as an unusual step which required special justification. She advised that correct information must always be given to someone closely related to the patient.

Brody (1981) wrote that ethics involved making choices about right and wrong human actions based upon what one ultimately believes are the best

reasons. A nurse might determine that the patient would benefit most from disclosure but a physician might determine that maximum patient benefit supported nondisclosure. A nurse would then be required to determine whether or not her actions, with and without administrative support, could convince the physician to disclose. If all efforts to convince the physician were unsuccessful, the nurse would next be faced with deciding whether or not she would disclose against the wishes of her physician. Such a position reflects the role of the nurse in the <u>Yarling</u> case.

Confidentiality - Professional Sub-Issue

Results of the <u>Tuma</u> analysis on confidentiality established that society values physician-patient confidentiality more than it does nurse-patient confidentiality. More states legally uphold physician-patient confidentiality than nurse-patient confidentiality (O'Sullivan, 1980). Those who wrote about a physician discussing a patient's terminal illness with the nearest relative prior to or instead of discussing it with the patient considered that the practice occurred so frequently that it was considered acceptable.

There was no clear direction in the literature to aid nurses who must decide if they could or should inform terminal patients about their prognoses if the physician had not informed them. There was agreement in the literature that the common practice of first telling a relative about a patient's terminal illness should be restrained whenever a patient requested that she be initially informed. To provide the nurse with some guidance to determine her responsibility for responding to confidential information in <u>Yarling</u>, several pertinent studies and one legal case review were examined.

Tarasoff v. Regents of the University of California (1976) established that psychotherapists were required to warn potential victims when there was a

serious threat which might endanger life. A nurse should determine if the need to prepare for one's impending death necessitated that someone warn a patient. The law recognizes a physician's therapeutic privilege to withhold distressing news, in certain limited situations, from patients. Therapeutic privilege, thus, allows some patients to face their death without physician forewarning. Nurses are not legally required to forewarn patients; however, one may consider that compelling arguments for disclosure of a terminal illness create persuasive moral or ethical reasons for informing patients.

In <u>Secrets</u>, Bok (1982) asserted that the justification for confidentiality rested upon four premises. Three of these premises supported confidentiality in general and the fourth premise supported professional secrecy in particular. The three premises which supported confidentiality in general were concern for human autonomy regarding personal information, respect for relationships, and respect for the bonds and promises that protect shared information. The fourth premise which supported professional secrecy in particular was based upon the benefits of confidentiality to those in need of advice, sanctuary, and aid. The decision to withhold information from Mrs. X. in <u>Yarling</u> violated all the premises upon which confidentiality were originally established.

Samuels (1980) and Davis (1981b) both commented that disclosure of a terminal illness to the nearest relative prior to or instead of discussing the illness with the patient was such a common practice that it was an accepted aspect of health care. By contrast, Annas (1974) wrote that such disclosures violated a patient's right to privacy and constituted a violation of confidential relations between patients and health care providers.

Payton (1979) questioned whether or not the nurse had a role in information control. In asserting that health professionals attempted to control information because of the uncertainty of some health care information, Payton wrote that

within the patient-professional relationship there was an implied promise to tell the truth. Deceit, even for the best reasons, often produced negative results. In advocating that the patient should be the "captain-of-the-ship" and health care workers should be navigators, Payton (p. 28) suggested that physicians and nurses would then be co-navigators who shared their different information for the patient's benefit. She stated that all members of the health team needed to support patient autonomy.

One must consider whether or not the physician violated his contractual obligation to the patient in the <u>Yarling</u> case when he discussed the diagnosis with Mrs. X.'s daughters and not Mrs. X. In the strictest sense he did violate Mrs. X.'s right to privacy, but his disclosure was an example of a commonly accepted medical practice. Samuels (1980) and Davis (1981b) conceded that such disclosures were acceptable because they occurred so commonly. Annas (1974) questioned such a practice and stated that it caused terminally ill persons to be treated less effectively than other patients.

In summary of the issue of confidentiality in Yarling, the physician and family wished to withhold the knowledge of a fatal diagnosis and prognosis from Mrs. X. The reasons for such a decision were benevolent since they wished to spare Mrs. X. the pain of learning such bad news. Confidentiality was originally established and recognized to support individual autonomy regarding personal information. Failure to share knowledge of a terminal diagnosis or prognosis with a competent adult violated the basic premise upon which confidentiality was established. Sharing a terminal diagnosis and prognosis with a relative prior to or instead of sharing such information with a patient also constituted a violation of confidential relationships even if the practice occurred commonly in health care, sometimes for understandable reasons of convenience.

Deception in Terminal Illness - Professional Sub-Issue

The <u>Tuma</u> analysis of the professional sub-issue of deception revealed that dying patients should not be deceived when research subjects just as other patients should not be deceived. Deception of dying patients left them feeling abandoned by health care professionals to face their final illnesses. Some evidence existed in the literature that nursing students continued to accept deception, to some extent, in terminal care. Nurses continued to be challenged in the literature to share critical information with dying patients who requested it even if the legal system failed to support nurses for such sharing. Interdisciplinary forums were suggested as one method by which nurses could assure that dying adults were provided with diagnostic or prognostic information which they requested.

A nurse involved in <u>Yarling</u> needed to be well informed about deception in terminal illness. Philosophers, such as Bok (1978), and attorneys, such as Annas (1974), lamented that deception was so common among dying patients. They indicated that public trust in the health care system has been seriously eroded and that patients' rights have been violated for unjustifiable reasons even when the reasons were intended to be benevolent ones.

To provide direction for the nurse involved in Yarling, significant literature sources on deception and terminal illness were reviewed. Amenta (1981) wrote that terminal care required special people. It required persons who enjoyed unpredictable work, who possessed skills in human relations, who enjoyed teamwork, who were rarely depressed, and who were busy people involved in numerous activities to augment their work experiences. Williams (1982) indicated that nurses were more involved on a continuous and intimate basis with dying persons than were other health professionals. She proposed that dying persons needed to disengage gradually from the world, they needed exemption

from social duties, they needed continuous care despite loss of health, and they needed the support and care of family and/or health professionals. The dying person cannot effectively live out his life without knowledge of his prognosis. Failure of communication by health professionals produces a conspiracy of silence that can alienate patient-professional relationships. Williams suggested that as the patient shifted from a sick to a dying role that the influence of the physician decreased while the role of the nurse increased. "Just as the nurse supports the treatment efforts of the physician when the patient is in the sick role, the physician supports the supportive role of the nurse when the patient is in the dying role" (Williams, 1982, p. 9).

The physician in Yarling was not supportive of the nursing role. His decision to deceive Mrs. X. by not informing her about her prognosis created an interference in the nurse-patient relationship. Regan (1982, Note 8) was asked if a nurse could sue a physician for interfering with the nurse-patient relationship because he refused to tell a terminal patient her diagnosis. His response was that a physician who did not tell a patient her terminal diagnosis was guilty of gross misconduct, but the family should deal with the physician and the nurse probably should not sue the physician. His response indicated the existence of a variable standard. The physician in the <u>Tuma</u> case was able to institute legal action against a nurse for interfering with the physician-patient relationship. However, a nurse would be advised by Regan (1982, Note 8) not to institute legal action against a physician who interfered with the nurse-patient relationship.

Should the nurse in the <u>Yarling</u> case tell the patient her diagnosis and not the prognosis? Should she tell the prognosis and not the diagnosis? The physician had warned the nurse that any disclosure on her part would be considered by him to be contrary to the well being of Mrs. X. Thus, the physician would regard it inappropriate for the nurse to discuss either the

prognosis or diagnosis. Perhaps to tell the patient that she had a limited time to live without telling her the diagnosis would create greater anxiety than telling her both the diagnosis and prognosis. If such a disclosure by the nurse endangered the patient's condition, the nurse could be charged with unprofessional conduct. If such a disclosure facilitated the patient's adjustment to her illness, the nurse could probably not be successfully prosecuted for unprofessional conduct. Depending upon the effects of her disclosure upon the patient, a nurse could face a degree of risk of prosecution if she decided to tell the patient her diagnosis and prognosis.

How would a direct confrontation between the nurse and physician, with the nurse telling the physician in essence, "If you don't tell her, I will," affect Yarling? Such a confrontation could anger the physician enough for him to charge the nurse with unprofessional conduct. However, the Tuma decision indicated that a board of nursing would have a difficult time in bringing disciplinary action for such a relevation by the nurse (Watson, Note 5). Vague and non-specific definitions of unprofessional conduct make it difficult, at present, for nurses to be forewarned whether such a disclosure constitutes unprofessional conduct. However, it seems imperative that nurses decide such issues in order for nurse practice acts to be written to incorporate adequate legal protection for nurses.

Several alternatives are available for the nurse in the <u>Yarling</u> case. A nurse could evade the difficult issues by discussing the patient's feelings with her and referring her direct questions to the physician. She could aid the patient to formulate effective questions which Mrs. X. would ask directly of the physician. The nurse could suggest that Mrs. X. might wish to consult another physician for a second opinion. The nurse might persuade the family to tell Mrs. X. because her recent divorce might have compounded the need for putting business and

family affairs in order. The family might become convinced about the need for openness in order for Mrs. X. to participate in hospice or other types of special care. The nurse could withdraw from Mrs. X.'s care if she were morally opposed to the deception in the case.

The nurse involved in <u>Yarling</u> was a hospital employee. A variety of alternatives were considered by the staff nurse. She sought head nurse assistance but received very little support. She could pursue the issue through higher administrative channels such as nursing and hospital administration. The support, or lack of it, would probably vary. The hospital might have an ethics committee or a joint practice committee that could exert a questionable influence on the nurse's position for open disclosure. The nurse could involve her professional nursing association and elicit its support for a position statement. Such action might be too time-consuming to aid in <u>Yarling</u>, but it could provide guidance for future similar situations.

Nurse practice acts could be written to endorse the position for nurses to respond openly to patient's requests for diagnostic and prognostic information. If that occurred, physicians would probably become more active in providing patients with open disclosure unless patients requested otherwise. Most patients would then be informed by physicians, and nurses would not be placed in a middle position of being coerced to deceive patients for unjustified reasons.

Yarling (1978b) presented evidence that nurses possessed the knowledge and ability to discuss terminal illness with patients. American Nurses' Association guidelines indicated that nurses had special skills and knowledge to deal with loss and grief. Numerous studies indicated that nurses' attitudes toward openness in terminal illness correlated with the studies done on patients which indicated their desires for openness when they experienced a terminal illness.

The desires and abilities of one professional group (nurses) to meet the needs of patients could be utilized more effectively in future health care than they have been in the past. Support by society for nurse disclosure could result in more effective health care for dying adults.

Application of Kantian Ethical Theory to the Yarling Case

Analysis of Kantian theory which applied to <u>Tuma</u> and which also related to <u>Yarling</u> indicated that Kantianism advocated rules which could be universalized without contradiction. Such a rule established in <u>Tuma</u> was that health professionals should supply a competent patient's request for treatment information. Another universal rule established in <u>Tuma</u> was that patients were well served whenever health care providers communicated and cooperated to provide effective patient care.

Kantian theory emphasizes that persons should be treated with respect. Such a principle as applied to <u>Tuma</u> provided the basis for advocating that health professionals should effectively communicate with patients and with each other out of respect for personhood.

The <u>Tuma</u> analysis dealt with claims and rights of patients to receive treatment information and the rights and duties of health professionals to provide such information. Important ethical issues in <u>Tuma</u> involved informed consent, disclosure, and relationships between providers and patients. <u>Tuma</u> involved an actual case whereas, by contrast, <u>Yarling</u> involved a theoretical one.

Yarling was similar to <u>Tuma</u> because it involved many of the same important ethical issues. Specifically, <u>Yarling</u> involved an ethical conflict between respect for individual autonomy and acceptance of professional paternalism. <u>Yarling</u> also involved truth-telling, lying, and deception.

Bok (1978) and Veatch (1982) discussed factors involved in the deception of a patient. Bok defined a lie as "any intentionally deceptive message which is stated" (p. 14). She discussed deception as a practice whereby persons were misled through gesture, disguise, action or inaction, and silence into believing what others did not believe. Veatch (1982) suggested that physicians tried to make a sharp distinction between lying and withholding information. He also asserted that physicians deceived patients by communicating technically correct medical jargon on some occasions.

Pence (1980) speculated that paternalism was at the root of the deceptive practices of physicians. He maintained that physicians lied or deceived probably because they thought it was best for patients. He concluded, however, that physicians probably lied to, or deceived, terminally ill patients to satisfy some of their own needs such as avoidance of discussions of death. In <u>Yarling</u>, the physician and family decided to withhold the knowledge of Mrs. X's diagnosis and terminal prognosis. That decision would result in deceiving her about her condition whether they actively lied or passively omitted significant facts which misled her about her condition.

Veatch (1976) indicated that Kantian theory would question whether withholding information from a patient or deceiving her would be the right thing to do even if such deception would prevent harm such as suffering. Kant (1965) believed that deception violated a universal principle -- never to lie or deceive. He wrote that deception harmed the very fabric of society because honesty was necessary for social relationships. Any deception created a great harm because it reduced the trust that was needed in social relationships. For Kant, the duty of being truthful was unconditional.

Veatch (1982) argued that consent required knowledge of a diagnosis and prognosis in order for it to be called informed consent. The basic conflict over

withholding the knowledge of a terminal diagnosis and prognosis from a competent adult involved a fundamental difference between those committed to the principle of self-determination and those committed to the paternalistic responsibility of physicians to determine what was best for patients. Kantian theory would support the individual's right to self-determination with access to information in order to participate in health care decisions which affect the individual.

Veatch (1982) asserted that both ethics and law mandated that competent patients should be told about their conditions. The only exceptions involved emergency situations or whenever the patient waived his right to information. Mrs. X.'s situation in the <u>Yarling</u> incident was not an emergency and she had not waived her right to information. Indeed, she made inquiries requesting information about her condition.

Both Annas (1974) and Veatch (1982) indicated that a patient's privacy had been violated whenever a family learned about a patient's illness, diagnosis, or prognosis prior to the patient learning such information. Kantian theory would oppose practices that violate individual autonomy.

Bok (1982) indicated that confidentiality was based upon concern for human autonomy about personal information, respect for relationships, respect for promises that protect shared information, and the benefits to those in need of advice, sanctuary, and aid. Sharing a diagnosis with a family instead of the patient in <u>Yarling</u> violated all the basic principles inherent in confidential relationships. Kantian theory advocates respect for human autonomy and would oppose the decision by the physician and family to withhold significant information from Mrs. X.

Kantian theory would oppose the treatment of Mrs. X. as a means of making the physician and family feel better. Their desire to protect Mrs. X. may be commendable but their underlying motivation might also be to protect

themselves from the pain involved in open discussion of a fatal illness. Kantianism advocates respect for the entire person which would include respecting Mrs. X.'s request for information about her condition.

Especially important health care provider-patient relationships in Yarling included Mrs. X. and her family, Mrs. X. and the physician, Mrs. X. and the staff nurse, the staff nurse and the physician, the staff nurse and head nurse, and the family and the physician. Both the family and physician violated patient autonomy by discussing Mrs. X.'s diagnosis and prognosis instead of sharing such information with Mrs. X. The physician was not a long-standing family physician. He knew Mrs. X. for only a short time and was unable to know, based upon past experiences with her, how she would react to the news about her diagnosis and prognosis. A physician's therapeutic privilege to withhold distressing news from a patient applies to a long-standing physician-patient relationship whereby a physician can predict that a patient will react in a devastating manner to the distressing information. Since the physician in the Yarling incident had not known Mrs. X. long or well enough to predict her reaction to distressing news, he did not have a sufficient relationship with Mrs. X. to allow him to claim therapeutic privilege for withholding information from her.

The staff nurse also knew Mrs. X. for only a short time. However, the length of time she had spent with her may have contributed to the establishment of such an effective nurse-patient relationship that Mrs. X. asked the staff nurse what was wrong after her questions for information were evaded by the family. Corless (1982) asserted that the nurse was the professional caregiver who was most typically confronted by patient requests for information. Corless maintained that physicians and nurses should conduct joint conferences with patients whenever a prognosis involving uncertainty was discussed. Such a suggestion

could have produced an ideal situation for Mrs. X. in <u>Yarling</u> if the physician had been willing to discuss the patient's prognosis with her.

Veatch (1982) maintained that a family should not know about a patient's diagnosis and prognosis prior to or instead of the patient. Veatch asserted that a physician had violated his obligation to maintain confidentiality whenever he discussed a patient's diagnosis and prognosis with a family without the patient's permission. Yarling illustrated such a breach of confidence by the physician.

As a general rule, most health care professionals would accept that a patient's request for treatment information should be honored. Usually, in the hospital, the physician is primarily responsible for providing such information. If he failed to provide such information, as was the situation in <u>Yarling</u>, would another health professional be responsible for providing the information? Yarling (1978b) maintained that nurses could provide such information because they possessed the facts about diagnosis and prognosis, and they often possessed significant relationships with patients. The staff nurse in the <u>Yarling</u> incident met both of the specified criteria for someone who should disclose diagnostic and prognostic information to a patient.

Kantian theory provides for health care professionals to meet a patient's request for treatment information. Such a universal rule would be good for society in general. The <u>Tuma</u> analysis indicated that health care providers should communicate with each other to provide effective care for patients. Thus, in <u>Yarling</u> the staff nurse and physician should communicate with each other about Mrs. X.'s request for treatment information. If the staff nurse adhered to Kantian theory, she should discuss with the physician her belief that the patient should be informed about her diagnosis and treatment. The Kantian emphasis upon patient autonomy would support a nurse's decision to discuss diagnostic and prognostic information with a competent adult if the physician

refused to do so solely on the basis of what he and the family believed was best for the patient. Paternalism and therapeutic privilege in <u>Yarling</u> were inadequate justifications for overriding patient autonomy.

The staff nurse involved in <u>Yarling</u> concluded that the patient had a right to have her questions answered. She was also concerned that Mrs. X. trusted her in her role as a nurse. Kantian theory would encourage the young nurse to maintain a trusting relationship with Mrs. X. by not deceiving her.

The nurse also felt a conflict regarding her duty to support the physician's plan of care which reflected the family's wishes. Aroskar et al. (1977) wrote that a nurse must choose the patients' best interests whenever they conflicted with the physician's plan of care. Kantian theory would indicate that the physician's decision to deceive a competent adult by withholding knowledge of a serious diagnosis and a fatal prognosis could never survive the test of practicing deception as a universal principle. Few would advocate that deception be practiced as a universal principle.

A nurse who was applying Kantian theory to <u>Yarling</u> would refuse to participate in patient deception. Such a decision could result in two actions. The nurse could withdraw from the case or she would have to answer the patient's questions in an open, non-deceptive manner.

Application of Utilitarian Ethical Theory to the Yarling Case

Utilitarian ethical theory specifies that the ultimate principle against which the consequences of actions, or the rules requiring those actions, are to be judged is the general utility or happiness of all concerned persons. In utilitarianism each person counts as one when pleasures are computed. Persons

involved in <u>Yarling</u> were a physician, a patient, a staff nurse, a head nurse, and two adult daughters of the patient.

Rule Utilitarianism

The relevant principle in <u>Tuma</u> was the same principle involved in <u>Yarling</u>. The pertinent principle involved how persons should relate to each other concerning truth-telling to a dying patient. In <u>Tuma</u> the dying patient requested alternative treatment information whereas in <u>Yarling</u> the dying patient requested information about her condition because she had not been told her diagnosis or her anticipated prognosis of less than one year of life.

The specific question according to rule utilitarianism in relation to <u>Yarling</u> is, "Does the rule dictating telling the truth about a terminal diagnosis and limited prognosis to a patient create the greatest good for the greatest number?" A supplemental issue involves the action of a nurse in a situation where the physician and family wish to withhold the distressing news of a fatal diagnosis and prognosis from a competent adult because they wish to spare her the pain of such news.

Just as in <u>Tuma</u>, the greatest good for the greatest number cannot be limited to the locale, action, or persons involved in <u>Yarling</u>. One must generalize about the consequences of the actions upon society at large. Mrs. X. requested information about her condition which was withheld from her by her family and physician for benevolent reasons. Would the provision of information about a person's diagnosis and prognosis by health care workers create the greatest good for the greatest number? In addition, would the provision of such information by a nurse when the family and physician opposed the patient knowing such information create the greatest good for the greatest number? Responses to these questions are discussed in the following sections.

In addition to Bok's (1978) arguments about withholding the truth from dying patients that were analyzed in relation to <u>Tuma</u>, Veatch (1982) discussed similar arguments which he called self-deceiving ones. Veatch's first self-deceiving argument can be called the "you can't tell them everything argument" (p. 82). Advocates of this argument would assert that since Mrs. X. could not know everything about her condition, she should be spared the pain of learning about her diagnosis and prognosis. Most people would reject such an argument because reasonable people would think it was essential to know their diagnoses and prognoses.

Another type of self-deceptive argument involved failure to disclose a fatal prognosis to a patient because a physician could never be sure that he was correct about a prognosis. This argument is often a rationalization for failure by a physician to disclose what he does know, or believe, that a prognosis is bleak and the likelihood of long-term survival is small (Veatch, 1982).

In disclosure, Veatch (1982) proposed that the physician could be seen as negotiating consent for possible further treatment. Withholding information, such as a fatal diagnosis and prognosis, in such a way that a patient like Mrs. X. was deceived into thinking that she would recover was very close to lying, according to Veatch. Bok (1978) and Pence (1980) would state that such deception was identical to lying.

Annas (1974) and Bok (1978) asserted that society is harmed whenever information is withheld from patients and they are thereby deceived about their conditions. A serious consequence of withholding significant information from patients has been the development of a lack of trust generally in health care professionals.

Both Bok (1978) and Veatch (1982) maintained that there were some overruling considerations which could make lying or deception permissible on

rare occasions. For Bok those rare occasions involved such limited circumstances as to save a life. For Veatch they involved rare occasions when the consequences of disclosure were so devastating and overwhelming that a patient would be rendered incapable of rational thought. Veatch described a patient who was intermittently suicidal and presently in an acute crisis of depression as perhaps justifying a physician to withhold only temporarily the knowledge of a terminal diagnosis. Mrs. X.'s condition in <u>Yarling</u> did not meet such unusual criteria to justify a physician or family to withhold her diagnosis and prognosis.

In rule utilitarianism as applied to <u>Tuma</u>, it was established that there were best consequences for health care providers, for patients, and for society when persons complied with a general rule that treatment information was shared between providers and patients. The best consequences occur for all when patients are generally not deceived.

In <u>Yarling</u>, the physician warned the nurse that he would regard any disclosure of diagnosis or prognosis by the nurse to the patient as not being in the patient's best interests. Justification for nurses to disclose diagnostic and prognostic information to terminal patients on those occasions when physicians are unwilling to do so supposedly for the patient's good involve the following factors.

The nurse often has the most frequent contact with the patient. The nurse is often the health professional from whom treatment information is most often requested by patients (Corless, 1982). The nurse is educationally prepared to discuss a diagnosis with a patient once it has been established by a physician. The physician is best prepared to discuss a diagnosis with a patient but a nurse may also possess information about diagnosis or prognosis once it is recorded in a patient's chart (Curtin & Flaherty, 1982). Rosoff (1981) indicated that some physicians permitted nurses to disclose fatal illnesses to patients. Once a

diagnosis has been established, general information about a prognosis could be quickly learned from health care textbooks or journals even by lay persons.

Additional justification for nurses disclosing diagnostic and prognostic information to terminal patients when physicians are unwilling to do so for paternalistic reasons included the following additional factors. Often a significant nurse-patient relationship exists which motivates a patient to request treatment information from the nurse. The patient has a need for such information to participate meaningfully in decision making. Many persons maintain that patients have a right to such information. Society is best served whenever health care providers and patients communicate in such a manner that patients are informed and not deceived about their conditions. If one health care provider, such as the physician, fails to disclose a terminal diagnosis and prognosis to a patient, another health care provider, such as a nurse, is justified in providing the information.

Act Utilitarianism

The significant issue in act utilitarianism in relation to <u>Yarling</u> concerned whether the nurse's potential decision and action to tell Mrs. X. the truth about her condition would create the greatest good for the greatest number. In act utilitarianism, "an act is right if and only if there is no other act the agent could have done instead that has higher utility than it has" (Feldman, 1978, p. 26).

The staff nurse's decision to disclose a terminal diagnosis and prognosis to Mrs. X. would meet Mrs. X.'s need for truthful information about her condition. The staff nurse applying act utilitarian theory would contemplate the effects upon Mrs. X. of informing her about her diagnosis and prognosis. Some of those effects might include pain, denial, anxiety, and depression. Effects could also include acceptance, openness, effective communication, freedom to choose her

treatment, freedom to put her affairs in order, and freedom to decide how she will live the last days of her life.

The staff nurse would assess the effects of deceiving Mrs. X. about her diagnosis and treatment. Some of those effects might include sparing Mrs. X. the pain of knowing about a terminal illness and relieving her of many burdensome decisions.

The nurse would also consider the wishes of the physician and family members to spare Mrs. X. of pain. A nurse would also consider her own feelings in connection with her "caught in the middle" nursing role. In calculating her own desires to be open with Mrs. X. to maintain a trusting relationship a nurse could consider her desire and ability to help the patient and family in their experience with loss, grief, and the dying process.

The nurse would consider that Mrs. X.'s recent divorce might have created some painful and estranged relationships which Mrs. X. might wish to repair if she knew about her limited life expectancy. Mrs. X.'s former husband might also like to restore whatever fellowship was possible under the circumstances of an illness which was expected to result in death within a year.

The staff nurse might also wish to consider the consequences for the entire nursing profession if nurses were disciplined for informing patients about their terminal diagnosis against the wishes of physician and family. She would likewise consider the effects upon the nursing profession when nurses were denied the opportunity to be open and truthful with patients. The head nurse's attitude about the situation would also be considered by the staff nurse.

The long-range effect of deception upon the family would be a consideration for the staff nurse. The potential for family guilt feelings in the future might be one consequence of their deception. Their benevolent deception along with physician cooperation might disturb their future relationships with the physician. They might come to distrust him in future interactions and might terminate their relationship with him. They might prefer not to have him serve as their own physician because they might prefer a physician who would be open with them. It is also possible that they might value this physician greatly because he cared enough to spare their mother unnecessary pain and suffering.

An act utilitarian nurse would attempt to calculate the consequences of the specific action of telling patients about a terminal diagnosis. She would consider the long- and short-range effect on patient-professional relationships of deceiving patients who are dying. A nurse's values would determine the significance she would attach to whichever alternative she believed would reflect the greatest utility for all persons involved in the case. The nursing decision would also be influenced by her knowledge of her legal rights and perhaps liabilities in relation to the <u>Yarling</u> case.

An act utilitarian nurse would consider the consequences of a specific physician-nurse conflict upon future work relationships within the hospital. She would consider whether such a conflict might result in litigation against her which might endanger her nursing license, her staff nurse hospital position, and her financial resources to pay legal fees. Some nurses would consider their health status to determine whether or not they could maintain their health during a stressful litigation.

A nurse who determined that the principle of greatest utility for the most people who were involved in <u>Yarling</u> supported nurse disclosure would tell the patient both her diagnosis and prognosis. Another nurse who concluded that the price she would have to pay was so great that it would create more disutility (unhappiness) than utility (happiness) would not disclose the diagnosis or prognosis to the patient.

The Yarling analysis illustrated some of the problems for utilitarianism as an ethical theory. Some philosophers question utility as the ultimate principle by which actions should be judged. It is also both difficult and time-consuming to compute the consequences of actions or rules that require actions. Based upon the major consequences that happened to Tuma because she discussed alternative treatment information with a dying patient, one can only speculate that such major consequences might or might not occur in a Yarling incident. If major negative consequences occurred to the staff nurse in Yarling because she disclosed a terminal diagnosis and prognosis to a competent adult against the wishes of the physician and family, one might also question whether or not a nurse should be required to pay so great a price for doing the "right" thing. Nurses, as well as society, need to determine if nurses should be required to pay such a great price for doing that which produces the greatest good for the greatest number.

Summary of Yarling Issues and Research Questions

Legal Responsibilities

The <u>Yarling</u> analysis established data in areas regarding the legal, professional, and ethical responsibilities of professional nurses for the disclosure of prognostic information to dying adults. The first area involved legal responsibilities of nurses for the disclosure of prognostic information to dying adults. Legal responsibilities were identified in <u>Yarling</u> for due process, unprofessional conduct, and the definition of professional nursing.

<u>Due process.</u> The <u>Tuma</u> analysis established that nurses must be provided with due process if their professional functions are legally challenged. If the staff nurse functioning in <u>Yarling</u> were to be accused of wrongdoing for disclosing a terminal diagnosis and prognosis to a patient contrary to family and

physician wishes, the nurse must be provided with due process. Both a board of nursing and the court system would be required to exercise due process to protect the nurse from unfair procedures.

In response to the research question concerning the responsibilities of professional nurses for the disclosure of information to dying adults, it has been determined that nurses must be provided with due process if they are accused of infractions. Nurses are entitled to due process procedures to protect their nursing license as a valuable property.

<u>Unprofessional conduct</u>. Important facts about unprofessional conduct derived from <u>Yarling</u> included several considerations. Unprofessional conduct is so ill-defined in many nurse practice acts that the term is essentially useless in forewarning nurses of prohibited actions except for crimes such as murder, arson, robbery, or rape. Courts have determined that the distortion of records regarding drug administration, personal use of drugs, and repeated acts of negligence were examples of unprofessional conduct even if those actions had not been specifically identified in practice acts. Unprofessional conduct cannot be defined on a case-by-case ex post facto basis. A nursing board cannot revoke a nurse's license for unprofessional conduct unless the nurse is forewarned regarding prohibited actions. It is not necessary for a statute to identify every course of conduct that might constitute unprofessional conduct but sufficient examples are necessary to aid nurses who must make judgments about disputed incidents.

None of the cited examples of unprofessional conduct apply to the <u>Yarling</u> incident if the staff nurse did decide to disclose the terminal diagnosis and prognosis to the patient. In fact, the Rosoff study (1981) revealed that some physicians permitted nurses to disclose a diagnosis and prognosis to dying adults.

Such actions indicated that at least some physicians and nurses do not think that such discussions by nurses constitute unprofessional conduct.

In response to the research question concerning the responsibilities of professional nurses for the disclosure of prognostic information to dying adults, the <u>Yarling</u> facts on unprofessional conduct reveal that inadequate nurse practice act definitions of unprofessional conduct make it almost impossible for nurses to be successfully prosecuted for unprofessional conduct when they discuss prognostic information with patients. Nurses and others such as legislators must decide whether or not they wish to prohibit such actions by nurses; if so, those actions should be clearly specified as examples of unprofessional conduct.

<u>Professional nursing</u>. Various legal definitions of nursing permit professional nurses to help patients achieve a dignified death. Most definitions require nurses to teach and counsel patients to achieve quality nursing care.

Some states allow patients to have open access to medical records. Such a practice would permit nurses to discuss freely the contents of a chart with a patient, including the diagnosis and prognosis.

Some legal definitions of professional nursing warn that a nurse can be prosecuted if she willfully acts in a manner inconsistent with the health and safety of persons entrusted to her care. If the staff nurse in <u>Yarling</u> disclosed the diagnosis and prognosis so that the health and safety of Mrs. X. were compromised, the nurse might be prosecuted for her action. The key factor in such an incident would be determined by the manner in which Mrs. X. responded to the news of her illness.

In response to the research question concerning the responsibilities of professional nurses for the disclosure of prognostic information to dying adults, the <u>Yarling</u> facts on the definition of professional nursing indicated that some

definitions of professional nursing permit nurses to discuss a terminal diagnosis or prognosis as one aspect of the nurse's responsibility to educate the patient. Because of disagreement in interpreting various definitions of professional nursing, some nursing boards have failed to support nurses who practiced nursing according to the legal definition as interpreted by other nurses, attorneys, and courts.

Professional Responsibilities

Relationships. Relevant factors about provider-consumer relationships derived from Yarling included the following considerations. Role perceptions between physicians and nurses varied. Nurses most often described themselves as colleagues of physicians; physicians, however, described themselves most often as employers of nurses. Relationships among nurses were sometimes less supportive of nurses than was desirable.

A basic relationship problem for nurses involved determining their responsibilities to physicians who wrote orders or made requests for nursing services that nurses considered morally wrong. An example was withholding pertinent diagnostic and prognostic information from a competent adult.

A Presidential Commission for the Study of Ethical Problems in Medicine (1982) recommended that decision making be shared among professionals and patients. Such a recommendation supports that a patient be informed about a diagnosis and prognosis in order to participate in effective health decisions.

In response to the research question concerning the responsibilities of professional nurses for the disclosure of information to dying adults, the <u>Yarling</u> analysis revealed that nurses place high priority on patient and family communications. When nurses communicate prognostic information to patients they may not be supported by other nurses. Physicians may wish to control the

communication of nurses because they view themselves as the employers of nurses. Nurses simultaneously view themselves as equal partners in the provider relationship who should not be subjected to physician supervision unless requested. The Presidential Commission recommended shared decision making as an essential factor in provider-patient relationships.

Rights. The Yarling analysis revealed some important considerations in relation to provider-patient rights. It was determined that some physicians were sensitive to and resented the term patient rights. They preferred the term patient needs. Nevertheless, it was established that patients have rights to information and access to medical records in some instances. Patients have the right to receive information about diagnosis, prognosis, and treatment from the physician. The rights of terminal patients to the truth about diagnosis, to privacy, and to confidentiality were compromised to some extent because of their terminal status. It was considered by some authors to be a violation of a patient's right to privacy whenever his providers shared his diagnosis with the family prior to or instead of first informing the patient. Physicians, however, have the right to utilize therapeutic privilege in medical practice.

It was also determined that nurses have rights to refuse to participate in situations which conflict with their beliefs, competencies, or preparation. Within legal limits, nurses also have the right to control the professional practice of nursing.

In response to the research question concerning the duties of professional nurses for the disclosure of information to dying adults, the <u>Yarling</u> analysis of rights revealed that patients have rights to receive prognostic information from physicians. Some assert that nurses have the right to disclose prognostic information whenever physicians do not reveal such information to competent adults. Nurses have the right to refuse to participate in situations which conflict

with their beliefs. For example, if a physician withholds the prognosis from an inquisitive terminal patient a nurse who disagrees with that decision because it conflicts with her belief about truthfulness may refuse to participate in the situation.

<u>Yarling</u> included several considerations. The case established that nurses were responsible for various aspects of patient education, for influencing policy decisions, and for providing quality nursing care to individuals, families, and groups. Nurses were responsible for protecting patients and the public when health care and safety were endangered. Some nurse practice acts stated that in compromised situations nurses were responsible for informing the attending physician and if the physician failed to act the nurse was then required to advise hospital authorities for appropriate action to be taken. Nurses were also responsible for helping patients to implement their rights when they were hospitalized. When substandard hospital practices occurred nurses were responsible for charting and for following administrative channels.

Some ANA nurse practice guidelines required nurses to provide care to patients and families who experienced loss, grief, anxiety, and depression. Nurses were responsible for involving patients in planning their own nursing care.

In response to the research question concerning the responsibilities of professional nurses for the disclosure of information to dying adults, the <u>Yarling</u> analysis established that nurses are sometimes responsible for notifying physicians when nursing care is compromised; they are sometimes responsible for following administrative procedures; and they are sometimes responsible for providing direct information to educate patients. At times when physicians fail to inform patients of a terminal prognosis, a nurse may decide that such instances compromise the quality of nursing care the patient can receive. In

those instances a nurse may decide that her responsibility to provide patient education permits her to provide the information directly. In some states the nurse may think that she has fulfilled her responsibilities when she informs attending physicians and hospital administrators.

Conflicts. Relevant facts about conflicts were derived from the Yarling situation. The analysis established that nurses have obligations to execute physician orders and to meet patient needs. When a conflict existed in those two areas, a nurse was obligated to place higher priority upon meeting patient needs than upon executing physician orders. Nurses sometimes disagreed about nurse functions and failed to support nurse colleagues when conflicts arose. Courts protected nurses on some conflict occasions from disciplinary action when they refused duty assignments for valid professional reasons.

Curtin and Flaherty (1982) suggested that physicians should not be allowed to control access of patients to such important information as a terminal illness. Veatch (1982) suggested that a trend existed to limit severely the physician's use of therapeutic privilege as an attempt to control a patient's access to information about his illness.

In response to the research question about the professional responsibilities of nurses for disclosure of prognostic information to dying adults, the <u>Yarling</u> analysis established that nurses have higher obligations to patients than they do to physicians when conflicts occur. Nurse colleagues may not support nurses who reveal prognostic information to an inquisitive patient but courts may support such nursing actions.

Informed consent. Relevant facts about informed consent were established in Yarling. Informed consent is required prior to surgery or a risky diagnostic or treatment procedure. Emergencies provide exemptions from informed consent. Yarling raises the question of whether or not informed consent would be required

if no additional surgery or therapeutic measures are contemplated. A strict interpretation of informed consent could indicate that it is not required, but the general spirit of informed consent includes that the option for no treatment be discussed as one alternative whenever other treatment options are discussed.

Diagnosis and prognosis are considered essential aspects of most informed consent issues. It is difficult to comprehend why informed consent should not apply merely because a diagnosis involves cancer with a limited prognosis for which no effective curative therapy exists.

Free access to medical records by patients could facilitate informed consent practices. With free access to medical records informed consent information could be more easily shared between professionals and patients.

Veatch (1982) identified that informed consent practices had shifted recently. Formerly, informed consent involved a professional standard whereby elements of informed consent were decided by practices that commonly occurred among professionals, primarily physicians. The present informed consent standard is often determined by a reasonable person standard. That standard involves the information a reasonable person would need to know in order to participate in effective decisions regarding one's health care. Indications are that most people desire to know their diagnoses and prognoses.

In response to the research question concerning the responsibilities of professional nurses for the disclosure of prognostic information to dying adults, the <u>Yarling</u> analysis established that nurses might be responsible for providing prognostic information to patients. Some state statutes hold both nurses and physicians responsible for providing treatment information to patients. Recent informed consent standards have shifted in the direction of providing patients with the information reasonable persons need to know in order to make health care decisions.

<u>Disclosure</u>. The <u>Yarling</u> analysis definitely involves disclosure issues even if one were able to assert effectively that informed consent standards were not applicable. Arguments for and against disclosure of a terminal diagnosis and prognosis were established in <u>Yarling</u>. The decision on disclosure often reduced to a fundamental disagreement between those who support patient autonomy which includes disclosure and those who support paternalism which could involve non-disclosure.

Data support the argument that most patients want to know about their terminal illness. Recent information indicated a trend toward the willingness of more physicians to discuss terminal illness with patients. Law and ethics most often supported patient autonomy which included disclosure of significant information.

In response to the research question concerning the responsibilities of professional nurses for the disclosure of prognostic information to dying adults, the <u>Yarling</u> analysis established that physicians were more likely to discuss a terminal illness with family members than with patients. Such a practice creates a difficult situation for nurses who must deal with questions from patients. When nurses know that nursing definitions and statutes allow them to disclose prognostic information to patients they may do so. Other nurses may refuse to discuss such information with patients because they believe nurses are not permitted by law to disclose such information to patients. Recent trends indicated a greater tendency for physicians to discuss a terminal illness with a patient. Such a trend might decrease the need for nurses to disclose such information.

<u>Confidentiality</u>. Pertinent considerations about confidentiality were established by <u>Yarling</u>. The basic principles upon which confidentiality was established supported patient autonomy regarding the control of information. The

Yarling analysis revealed that it was a fairly common practice for physicians to discuss a diagnosis of cancer with family members prior to discussing it with patients. Even though such a procedure was viewed as a standard health care practice, it was considered by Annas (1974) to be a violation of a patient's right to privacy or confidentiality. Bok (1982) considered that such a procedure would violate all the principles for which confidentiality had been established.

In response to the research question about the professional responsibilities of nurses for disclosure of information to dying adults, the analysis of <u>Yarling</u> indicated that physicians may violate confidential relationships when they discuss a terminal diagnosis with family members prior to or instead of discussing it with a patient. It is unclear whether or not society desires that nurses discuss terminal prognoses with patients. Future legislation may be needed to support nurses for such actions. The degree of harm to patients seems, at present, to be the determinant factor that there probably is not a legal responsibility for nurses to warn patients about their impending death, but there are both ethical and professional responsibilities for doing so.

<u>Deception</u>. Relevant facts were also derived from the <u>Yarling</u> incident regarding deception. It was determined that dying patients are sometimes deceived about their illnesses. Such deception has led to an erosion of the public's trust in health care professionals. Nurses' attitudes toward openness with dying adults correlated with the desires of patients for openness about terminal illness. Deception most often left patients alone to face their terminal illnesses.

To respond to the research question about the responsibilities of professional nurses for disclosure of prognostic information to dying adults, the <u>Yarling</u> incident established that dying patients should be treated just as other patients are treated. That would mean that nurses should discuss prognostic information

with dying adults. Unless nurses wish to leave patients alone to face terminal illnesses, nurses should discuss prognostic information openly with those dying adults who wish to discuss their situations with health care providers. The public trust can be preserved whenever deception of patients generally does not occur.

Ethical Responsibilities

Kantianism

Important factors related to Kantianism and the ethical responsibilities of professional nurses for the disclosure of prognostic information to dying adults were derived from an analysis of <u>Yarling</u>. Kantianism would question whether withholding information from a patient or deceiving her would be the right thing to do even if such deception prevented harm, such as suffering. For Kant, deception violated a universal principle — never to lie or deceive. The duty of being truthful is unconditional in Kantianism.

Health care providers were responsible not to deceive the patient; thus, they were required to provide the patient with diagnostic and prognostic information. The physician was unwilling to provide information to the patient who needed to know about her condition. The nurse possessed the information and the nurse had a sufficient relationship with the patient which allowed her to communicate in an effective manner.

Rule Utilitarianism

Important factors related to rule utilitarianism and the ethical responsibilities of professional nurses for the disclosure of prognostic information to dying adults were also determined by the <u>Yarling</u> analysis. A general rule which was determined to produce the greatest good for the greatest number included that a rule of telling the truth about diagnosis and prognosis to dying patients

produced the greatest good. Another rule that can be generalized is that when one qualified health care professional for invalid reasons, that are established by critical analysis, fails to disclose a diagnosis and prognosis to a dying, competent adult, another qualified health care professional is justified in providing the information.

A nurse would be responsible for communicating relevant information to a physician. A physician is responsible for communicating a diagnosis and prognosis to a dying adult. A nurse would also be responsible for disclosing a terminal diagnosis and prognosis to a competent adult when the physician for invalid reasons, as determined by critical analysis, failed to provide the needed or requested information. Rules about active lying or passive deception cannot be justified by rule utilitarianism.

Act Utilitarianism

Important facts about act utilitarianism were examined in <u>Yarling</u>. Facts were examined regarding the potential decision and action by the nurse. One fact involved determining if an action of telling the truth created the greatest good for the greatest number. Another fact involved examining whether or not the staff nurse's decision to disclose the diagnosis and prognosis to an inquisitive patient created the greatest good for the greatest number. Both generalized and individualized consequences were examined. Some of those consequences included public distrust, negative or positive influence upon the nursing profession, broken or restored relationships, conflicts, potential legal fees and litigation, pain, depression, and acceptance.

It was determined that nurses might vary in the way they computed the consequences of their actions. A nurse who determined that the greatest utility for the most people concerned in <u>Yarling</u> supported nurse disclosure of the

terminal diagnosis and prognosis would tell the patient. By contrast, another nurse who determined that disclosure would create more disutility than utility would not tell the patient.

CHAPTER V

SUMMARY, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Summary of the Study

A literature search revealed that many registered nurses were sometimes hampered in their decisions and nursing actions by a secretiveness associated with dying adults. In those situations where important prognostic information was kept secret from a patient, some nurses were faced with a decision regarding their desire to respond to a patient's request for information and the nursing obligation to abide by a plan of care prescribed by the physician.

The purpose of this study was to determine through case study analysis the responsibilities of registered nurses as they make decisions about the disclosure of prognostic information to dying adults. Research questions were used to examine the legal, professional, and ethical responsibilities of registered nurses as they made decisions about their disclosure of prognostic information to dying adults.

A case study design with a descriptive approach was used to investigate the research questions. Two cases, <u>Tuma</u> and <u>Yarling</u>, were analyzed. The particular cases were selected based upon their relevance to the research questions. <u>Tuma v. Idaho Board of Nursing</u> (1979) involved an actual case in which a nurse was charged with unprofessional conduct for discussing Laetrile and reflexology with a dying adult who questioned the nurse about alternatives to chemotherapy as a treatment for leukemia. Tuma informed the patient about

treatment alternatives and her nursing license was suspended for six months. The <u>Yarling</u> incident involved a theoretical case found in the literature in which a postoperative female adult patient questioned the nurse about her prognosis. Surgery had established a prognosis of less than one year of life. The physician and adult daughters wanted to withhold knowledge of the diagnosis and prognosis from the patient because they wanted to protect her from the trauma of learning that she had a terminal illness. The nurse believed the patient should be informed about her prognosis.

Literature sources used to examine the cases included the <u>Idaho Nurse</u>

<u>Practice Act 1974</u>, the ANA <u>Code for Nurses</u>, the AHA <u>Patient's Bill of Rights</u>,
and the ANA <u>Nursing Practice Act: Suggested State Legislation</u>. In addition,
more than 300 journal articles and 50 books were examined to analyze further
the issues involved in the two cases.

Content analysis of issues and sub-issues was used as the research methodology. Issues and sub-issues were chosen based upon their relevance to the <u>Tuma</u> and <u>Yarling</u> cases and the frequency of their occurrence in nursing, medical, legal, and philosophic literature. Issues included due process, unprofessional conduct, definition of professional nursing, health care provider-consumer relationships, informed consent, and disclosure. Sub-issues included rights, responsibilities, conflict, confidentiality, and deception in terminal illness. Issues and sub-issues were validated by the researcher and two doctorally prepared nurse experts. Two legal consultants were used to provide advice on legal issues.

Kantianism and utilitarianism provided the theoretical perspective for the study. Those theories were selected because experts in both nursing and philosophy had asserted in the literature that those theories were used most often in nursing.

To address the purpose of this study the following research question about legal responsibilities was explored: What are the legal responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults? Content issues of due process, unprofessional conduct, and the definition of professional nursing were analyzed in both the Tuma and Yarling cases to determine responses to the legal research question.

To address the purpose of this study the following research question about professional responsibilities was explored: What are the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults? Content issues of health care provider-consumer relationships, informed consent, and disclosure were used to analyze both the <u>Tuma</u> and <u>Yarling</u> cases. Sub-issues of rights, responsibilities, conflict, confidentiality, and deception in terminal illness were also used to analyze both cases to determine the responses to the professional research question.

To further address the purpose of the study the following research question on ethical responsibilities was explored: Based upon Kantianism and utilitarianism, what are the ethical responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults? The Tuma and Yarling cases were analyzed according to principles of both ethical theories to determine the responses to the ethical research question.

Summary of the Findings

The research question regarding the legal responsibilities of registered nurses focused on those duties that are performed in relation to established standards of human conduct and enforced through the governmental authority of an organized society. Data sources that were examined to determine responses to the research question about legal responsibilities of nurses for their disclosure

of prognostic information to dying adults included the <u>Idaho Nurse Practice Act</u>

1974, the ANA <u>Nursing Practice Act: Suggested State Legislation</u>, attorney briefs, and relevant legal cases from the literature.

Legal

Nurses are responsible for knowing the legal constraints and dimensions within which they function. Specifically they are responsible for:

- 1. Knowing that due process protects them from unfair disciplinary procedures. Nurses are entitled to due process whenever they are accused of infractions regarding the improper disclosure of information. Boards of nursing and court systems are required to exercise due process to protect nurses from unfair procedures.
- 2. Knowing that inadequate legal definitions of unprofessional conduct make it almost impossible for nurses to be successfully prosecuted for disclosing alternative treatment or prognostic information to dying patients.
- 3. Knowing that some legal definitions of professional nursing have been interpreted as allowing nurses to discuss alternative treatments with dying adults.
- 4. Being aware that some legal definitions of professional nursing may be interpreted to permit nurses to disclose a terminal prognosis as one aspect of the nurse's responsibility for patient education and for involving the patient in nursing care planning.
- 5. Understanding that legal definitions of professional nursing have received different interpretations. Some boards of nursing have failed to support nurses who practiced according to the legal definition of nursing as interpreted by other nurses, attorneys, and courts.

- 6. Practicing nursing in accord with the state legal statute which defines professional nursing.
- 7. Practicing nursing in such a manner as to avoid charges of unprofessional conduct.

Professional

A summary of the research findings regarding the professional responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults must be viewed in relation to legal precedents and ethical theories. Even though the areas were analyzed separately for the purposes of this study, it was recognized that legal, professional, and ethical responsibilities of nurses cannot be treated as discrete entities. Data sources used in the professional area included the ANA <u>Code for Nurses</u>, the AHA <u>Patient's Bill of Rights</u>, and the literature.

- 1. Nurses are responsible for communicating alternative therapeutic information when asked by patients or as part of the nursing care plan.
- 2. Nurses are responsible for various aspects of patient and family communication which include such topics as loss and grief.
- 3. Nurses are responsible for participating in shared decision making in the professional-patient relationship, thereby supporting patients' access to diagnostic and prognostic information.
- 4. Nurses are responsible for assisting patients to retain their rights, especially when they are hospitalized. In some states patients have the right to access to their medical or health care records. The literature supports that patients have the right to receive prognostic information from physicians. Patients may be assisted by nurses to identify and clarify their questions to physicians about prognostic information. Nurses have the right to refuse to

participate in situations that conflict with their beliefs, such as when a physician refuses to tell a dying patient his prognosis. There is evidence in the literature that some writers believe that nurses have the right to disclose prognostic information to dying adults whenever physicians do not.

- 5. According to some nurse practice acts, nurses are responsible for notifying physicians when nursing care is compromised, such as when dying patients are not informed about their diagnosis or prognosis. According to other nurse practice acts, nurses are responsible for following administrative procedures. In some states, nurses are responsible for providing treatment information directly to patients as one aspect of the nurse's duty to teach patients.
- 6. Both nurses and physicians are responsible for providing treatment information to patients. Nursing and medical alternatives overlap, and guidance regarding disclosure of information is unclear. Some legal experts advise nurses to disclose a terminal diagnosis to patients even if the legal system does not provide support for such actions. A reasonable standard for informed consent is based upon the premise that most reasonable persons want to be informed about a fatal illness. Several research studies validate this assertion.
- 7. When conflicts occur between a nurse's responsibility to execute a physician's order or to provide effective nursing care to a patient, a nurse is responsible for placing higher priority upon providing effective nursing care to the patient.
- 8. Nurses at the present time may not be legally required to forewarn a patient about impending death. However, professional and ethical reasons exist to support such a forewarning.
- 9. Violations of a patient's privacy and confidentiality occur whenever a family is informed about a patient's fatal illness prior to or instead of informing

the patient. There is greater societal support for physician-patient confidentiality than for nurse-patient confidentiality.

- 10. Nurses are responsible for obtaining informed consent from dying adults who participate in nursing research procedures. If dying patients are required to know what happens to them in research, it seems logical to assume that they should be informed about what happens to them in the course of treatment for their illness.
- 11. If nurses are responsible for contributing to the maintenance of the public's trust in health care professionals, then nurses are also responsible for not deceiving dying patients about their prognosis.

Ethical

In summary of the responses to the research question regarding the ethical responsibilities of registered nurses as they make decisions about their disclosure of prognostic information to dying adults, theoretical principles based upon Kantianism and utilitarianism were used to determine responses to the research question.

Kantianism

- 1. The responsibility of truthfulness is unconditional in Kantianism.

 Deception violates a universal Kantian principle never to lie or deceive.
- 2. A nurse is responsible for not deceiving a patient about treatment information and not withholding relevant information from health professionals such as physicians.
- 3. Nurses and physicians are responsible for communicating relevant information to patients and each other.

4. Nurses are responsible for informing physicians whenever they decide that they must disclose a prognosis to a dying patient contrary to the physician's directives or orders.

Utilitarianism

- 1. A nurse is responsible for determining the greatest good for the greatest number. Both utilitarian rules and actions which achieve truthfulness produce the greatest good for the greatest number in most situations.
- 2. Nurses are responsible for communicating to patients those aspects of treatment information which produce the greatest good for the greatest number. It is not justifiable for nurses to lie to patients or to deceive them whenever a physician advocates deception as a means of protecting a patient from potentially painful information.
- 3. Nurses are not justified in disclosing a terminal prognosis to a patient without also informing the physician of the nurse's decision to disclose the prognosis to the patient.

Conclusions

Findings from the study led to conclusions in relation to the three research questions regarding legal, professional, and ethical responsibilities of registered nurses for the disclosure of prognostic information to dying adults. None of the findings, however, can specifically answer the question for the nurse regarding the decision she should make. In fact, the legal, professional, and ethical considerations must interact so that individual nurses can determine their own decisions.

Legal

Due process rights guarantee legal protection for nurses. Ambiguity in the definitions of unprofessional conduct and professional nursing creates unclear consequences for nurses regarding the disclosure of alternative treatment or prognostic information to competent dying adults. Off-duty status does not provide nurses with immunity from the consequences of their professional decisions regarding the disclosure of alternative treatment information. According to current nurse practice acts, nurses are not legally required to forewarn patients about impending death.

Professional

Different nurse practice acts identify varying responsibilities of nurses for the disclosure of prognostic information to dying adults. A nurse's responsibility to teach a patient can include the discussion of alternative treatment information or prognostic information with competent adults. Nurses are responsible for assisting hospitalized patients to obtain information about any risks of death, serious harm, or complications that could occur to them.

Varying sources of authority exist to resolve conflicts between a nurse's responsibility to provide nursing care to a patient or to follow a physician's order which is questionable. Nurses are directed by the ANA <u>Code for Nurses</u> to piace highest priority upon their responsibilities to patients whenever conflicts occur. Professional codes do not have legal status, however, and they may vary widely in the extent of their influence upon registered nurses.

A nurse's values regarding the importance placed upon professional, legal, or ethical guidelines for decision making will ultimately be the force for the decision made regarding disclosure of information to patients. Informed consent practices are influenced by professional and legal guidelines which are relatively

dynamic and by ethical guidelines which are relatively static. Informed consent standards are based upon a principle that responsible persons should be informed about their conditions and that they have a right to such information. Health care workers, including registered nurses, are obligated to provide such information.

The rights of dying patients to truthful information about diagnosis and prognosis, to privacy, and to confidentiality are compromised, to some extent, because of their terminal status. A recent trend by some physicians toward open discussions with patients affects access to health care information.

Ethical

According to Kantianism, the nurse must always tell the truth. In utilitarianism, the nurse must evaluate a situation from the standpoint of the greatest good for the greatest number. Decisions must be made about what constitutes the greatest good and about the greatest good for whom.

Decisions in both <u>Tuma</u> and <u>Yarling</u> might differ if other ethical theories were used as theoretical frameworks for the case analyses. Ethics and law most often support patient autonomy which includes the disclosure of significant information, such as a diagnosis or prognosis, to a patient. Society is harmed whenever deception results in a lack of trust toward others.

Implications

Several implications have been derived from the examination of nurse responsibilities for disclosure of prognostic information to dying adults. These implications are grouped according to nursing practice and nursing education. Within each area implications are stated for legal, professional, and ethical categories.

Nursing Practice

Findings in this study support that an increased awareness of due process rights for nurses could allay some anxiety within registered nurses about legal sanctions in relation to their nursing actions. Legal bulletins could be used to inform nurses about due process.

Knowledge of due process would help to assure nurses that decisions which result in disciplinary actions are subjected to a fair and rational process. As a procedure, due process serves as a right to those who need it and as a duty to those who should provide it for others. State boards should ascertain that registered nurses receive due process whenever indicated.

Increased attention to legal definitions of unprofessional conduct and professional nursing can provide some clarity for nursing actions as well as some of the legal consequences of such actions. Journal articles could inform nurses about legal definitions of unprofessional conduct and professional nursing.

Increased awareness among nurses that there is no off-duty immunity regarding their nursing actions can aid nurses to recognize and to accept more responsibility for their nursing actions and decisions. Discussion of precedent-setting legal cases in nursing could inform practicing nurses of this responsibility.

Findings in this study support that practicing nurses should become more aware of situations that require disclosure of information to dying adults. An increased sensitivity among nurses to the informational needs of dying adults could assist in improving nursing care.

If it is beneficial to society for nurses to disclose a prognosis to a dying adult whenever the physician fails to do so, then society should provide greater support through legislative activities for nurses to perform such responsibilities.

Laws which involve professional nursing and unprofessional conduct could be clarified by both nurses and legislators.

Increased clarity about the responsibility of nurses for patient education could provide direction for nurses as they strive to meet informational requests of patients. Nurses, physicians, and patients could be interviewed to determine their opinions about what information nurses should teach patients.

Determining if nurses are deterred from providing prognostic information to dying patients based upon fear of legal repercussions, or upon fear of conflicts and power struggles with physicians, could be helpful in ascertaining the attitudes of nurses in this area of nursing practice. A questionnaire to nurses could be used to identify reasons why nurses discuss or refrain from discussing terminal prognoses with patients.

Additional attention to informed consent practices and requirements could clarify the responsibilities of nurses for ascertaining that patients have been adequately informed. Nurses could identify incidents that directly involve informed consent practices. Team conferences and planned workshops could help to expand their knowledge in the area of informed consent.

Findings from this study could be used to improve relationships among health care providers and patients. Additional attention to role relationships between nurses and physicians, especially in the communication of information to dying patients, could result in efforts to improve care to those patients.

Increased information about ethical theories such as Kantianism and utilitarianism could aid nurses in clarifying options for decision making. Clinical seminars could be used to examine the use of theories for decision making.

Increased emphasis upon the use of ethical theories in decision making could result in a more rational approach to nursing actions. Workshops on the

use of ethical theories for decision making could be conducted for practicing nurses.

Nursing Education

The findings from this study revealed that a lack of clarity exists in the definitions of professional nursing and unprofessional conduct. Educators and others need to discuss those terms in order to arrive at more satisfactory definitions which could then be disseminated to all members of the nursing profession.

Students should be guided in understanding the various components of due process. Such knowledge could aid nursing students to become more aware of the legal factors which influence nursing practice.

Students should become more knowledgeable about informed consent and the role of nurses in informed consent practices. Such information could assist students and practitioners to guide patients as they seek informed consent information. An examination of informed consent incidents that involve nurses could aid in clarifying some aspects of the nurse's role in informed consent.

Clarity about role responsibilities for patient education could decrease conflicts among health care providers. Patients might be better informed if health care providers knew the requirements that are necessary for patients to obtain access to their health care records. Dissemination of information about which states provide patients access to health care records could aid health care professionals to provide patients with this information.

Nursing curricula should incorporate more attention to ethical theories.

Kantianism and utilitarianism illustrate two theories that are commonly used in nursing. Most nursing students should become knowledgeable about both theories

in order to better understand important factors that influence ethical decisions in nursing.

Recommendations for Future Study

Based upon the findings of this study, the following recommendations are made for future study:

- 1. A legal analysis of all nursing cases which have involved unprofessional conduct could aid in more clearly defining unprofessional conduct.
- 2. An analysis of the definitions of professional nursing contained in all nurse practice acts could provide some clarity to state boards of nursing and legislators who debate and revise nurse practice acts.
- 3. Findings in this study reveal that further clarity should occur between nursing and medicine about disclosure of health care information to patients. Further research is suggested regarding shared aspects of communication, especially in areas such as informed consent, disclosure, and health teaching.
- 4. A study of those nursing incidents whereby colleagues failed to support other nurses who were involved in debatable but acceptable nursing practices is recommended to support nurses and to strengthen the concept that nurses are innocent until proven guilty by due process procedures.
- 5. An analysis of ethical incidents in nursing can provide guidance about ethical theories and issues which commonly occur. Such an analysis can provide direction for nurses involved in no code situations for which orders have not been written, in situations involving the care of defective newborns, in situations where newly dead bodies are used for educational purposes without specific consent of the person or family, in situations where the use of placebos are considered justified, in nursing situations whereby lying or deception could be

justified, and in situations whereby nurses could justifiably violate patient confidentiality.

- 6. A study should be conducted of nursing ethical incidents in which the nurse is the primary decision maker. Such a study could identify the ethical decisions which registered nurses make and it could help to differentiate nursing decisions from those ethical decisions which are routinely made by physicians.
- 7. An examination of methods conducive to strengthening the ability of nurses in critical and ethical analyses should be conducted in order to aid nurses to articulate reasoned arguments for issues, topics, and positions with which they disagree.
- 8. A study is suggested to determine the influence of the fear of legal processes, or the fear of power struggles and conflicts with physicians, as variables that affect nursing decisions in situations where a terminal prognosis is withheld from a competent dying adult.
- 9. Content analysis of issues is recommended for the investigation of a variety of ethical problems in nursing. Content analysis can provide methodological assistance to researchers who seek methods for studying ethical nursing problems.

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