A Qualitative Investigation of the Relationship between Social Loss and Nurses' Response to Terminally Ill Hospital-Based Clients

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LOYOLA UNIVERSITY CHICAGO

A QUALITATIVE INVESTIGATION OF THE RELATIONSHIP BETWEEN
SOCIAL LOSS AND NURSES' RESPONSE TO TERMINALLY
ILL HOSPITAL-BASED CLIENTS

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY
DEPARTMENT OF EDUCATIONAL LEADERSHIP AND POLICY STUDIES

BY

SANDRA MARIE WEBB

CHICAGO, ILLINOIS
JANUARY 1996
DEDICATION

To James, Eura, and Lillian

This dissertation is dedicated to the loving memories of my father, James Webb, my grandmother, Eura Gipson, and my aunt Lillian Gipson-Ezell. They have been ideal role models who have given me much inspiration and courage throughout the years.

Reflections of my late father and aunt have been helpful in assisting me to gain additional insights of the "social loss" concept.
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I would moreover like to acknowledge and express my appreciation to the nurses participating in this study, their nursing supervisors and fellow co-workers for assisting me in identifying perspective nurse subjects for this investigation.
ABSTRACT

Social loss is a feeling of actual/impending void experienced by family members, significant others, persons in the work place and society in general whenever a contributing member of society approaches or succumbs to death. Social characteristics such as education, family and occupation serve as some of the determiners of social loss.

High social loss persons make significant contributions to family, significant others, the work place and society. These individuals create feelings of grief and ineptness within nurses caring for them; thereby lowering nurses' professionalism. While low social loss persons make minimal to no contributions to family, significant others, the work place and society, their impending loss does not decrease nurses' professionalism.

The purpose of this qualitative study was to provide an understanding of the impact that social loss has on nurses presently caring for terminally ill hospitalized clients in young to middle adulthood, with non-malignant disease entities.
Sixteen nurses, working on two clinical units within a private hospital, were surveyed using a semi-structured interview schedule consisting of questions pertaining to social loss, social values and social characteristics.

Ethnographic observations were made of subjects while at work. Data gained from these observations focused on the unit's climate, staff contacts with known terminally ill clients, and staff comments about terminally ill clients' social characteristics, social values, prognoses and nursing care.

Descriptive statistics were used to analyze numerical social loss values and social characteristic rankings assigned by nurses. Constant comparative methodology was used to identify major themes among the data. Finally, triangulation strategies assisted in establishing validity and reliability of the data gained from observations and interviews.

Findings from the study can be used in designing standardized death education curricula for schools of nursing, staff development and long term care facilities.
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS........................................ iii

ABSTRACT....................................................... iv

LIST OF ILLUSTRATIONS...................................... viii

LIST OF TABLES................................................ ix

Chapter

I. INTRODUCTION ............................................. 1
   Background ................................................. 8
   Purpose of the Study ...................................... 10
   Conceptual Framework ..................................... 11
   Need for Study ............................................ 14
   Definitions of Terms ...................................... 15
   Organization of the Study ................................ 16

II. REVIEW OF THE LITERATURE ................................. 18
   Social Loss .................................................. 18
   Nurses and Families of Terminally Ill Clients .......... 38
   Nurses and Death Education ................................. 42

III. METHODS .................................................. 53
   Research Design ............................................ 53
   Setting ..................................................... 54
   Sample ..................................................... 55
   Data Collection Procedure ................................ 55
   Instrumentation ............................................ 59
   Data Analysis .............................................. 61
   Reliability and Validity ................................... 62
   Protection of Human Subjects ............................... 64

IV. RESULTS .................................................. 66
   Background Characteristics ................................ 67
      Clinical Characteristics of Terminally Ill Clients .. 69
   Research Question 1 ....................................... 70
   Research Question 2 ....................................... 74
   Research Question 3 ....................................... 76
   Research Question 4 ....................................... 78
   Research Question 5 ....................................... 79
   Research Question 6 ....................................... 81
<table>
<thead>
<tr>
<th>Figure</th>
<th>Illustration</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Social Loss Model</td>
<td>12</td>
</tr>
<tr>
<td>2.</td>
<td>Refined Model of Social Loss</td>
<td>106</td>
</tr>
<tr>
<td>3.</td>
<td>Modified Cantril's Self Anchoring Scale</td>
<td>118</td>
</tr>
</tbody>
</table>
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Background Characteristics of Subjects</td>
<td>68</td>
</tr>
<tr>
<td>2.</td>
<td>Nurses Mean Social Characteristics Rank Orders</td>
<td>83</td>
</tr>
<tr>
<td>3.</td>
<td>Correlations Between Nurses' Social Values</td>
<td>84</td>
</tr>
<tr>
<td>4.</td>
<td>Intercorrelations Among Nurse Subjects</td>
<td>85</td>
</tr>
<tr>
<td>5.</td>
<td>Nurses Mean Social Characteristics Rank Orders For Their Terminally Ill Clients</td>
<td>86</td>
</tr>
<tr>
<td>6.</td>
<td>Correlations Between Nurses' Social Values For Their Terminally Ill Clients</td>
<td>87</td>
</tr>
<tr>
<td>7.</td>
<td>Intercorrelations Among Nurses' Terminally Ill Clients</td>
<td>88</td>
</tr>
</tbody>
</table>
CHAPTER I
INTRODUCTION

Statistics reporting significant increases in the number of homicide, suicide and murder victims within the United States for 1990 tend to suggest that the value of human life is depreciating (U.S. Bureau of the Census, 1993). Despite these alarming reports, most Americans today continue to value longevity and have quite understandable desires and expectations of living beyond age sixty-five. The outlook for an increased life expectancy looks promising. Recent projections predict that 13% of the United States population will be age 65 years or older by the year 2000; and by the year 2030, the number of persons aged 65 and older will increase to 22% of the entire U.S. population (Healthy America, 1991).

Enabling Americans to achieve their potential for full and active lives by increasing the span of healthy life is one of the broad goals for this nation (Healthy People 2000, 1991). Achievement of this goal depends upon quality of life improvements, which include reductions in unnecessary suffering, illness and disabilities from infections and chronic disabling diseases. It follows, therefore, that
increases in the span of healthy life are equivalent to
increases in the quality and quantity of life for Americans. Thus far, examinations of the relationship between unity and quantity of life reveal that the likelihood of developing a chronic, disabling disease increases with longevity (Lubkin, 1986). Examination of chronic diseases and their relationship to quality and quantity of life is important because many Americans aged sixty-five and older have been diagnosed with at least one chronic disease. The known outcome for most chronic diseases is terminal illness followed by death. Chronic illness, as a precursor to terminal illness, represents a process of prolonged dying because chronic diseases are long-term, progressive disorders that are associated with irreversible pathological and physiological changes, physical disabilities and social dependency (Prichard, Collard, Starr, Lockwood, Kutscher & Seeland, 1979). This indicates that an inverse relationship exists between quantity and quality of life, i.e. longevity is associated with an increase in chronic and terminal illnesses and, consequently, a decrease in the quality of life. Presently, the estimated number of people with chronic and significant disabilities ranges between 34 to 43 million (Healthy People 2000, 1991).

Concerns about the needs of chronic and terminally ill individuals have proliferated from the health care community
since the early sixties. These concerns are primarily related to improvements in quality of life. The goal of health care is the prevention of quality of life losses. These losses impact the physiological, physical, social and psychological status, as well as the role functioning of individuals (Kazis, 1990). Physiologic concerns for the well being of chronic and terminally ill clients focus on the need for professional health care services provided by hospitals, extended health care facilities, home health care agencies, and hospice organizations. Quality of life concerns also focus on the concomitant object losses associated with deteriorating disease processes, such as the loss of employment, financial status and the loss of tangible items (Engel, 1961). These losses are significant not only for the client, but also for the client's family and significant others. Carlson (1970) pointed out that the probability of experiencing significant losses (including physiological, physical, social, role and object losses) increases during illness. Furthermore, the scope of losses increase as the disease process worsens.

Health care professionals' perceptions of terminally ill clients as biologically alive but **socially dead** have been attributed to these losses (Glaser & Strauss, 1964; Kalish, 1966; Pine, 1972; Quint, 1966; and Sudnow, 1967). This may, in part, be responsible for much of the support
given in ridding the terminally ill of their physiological, physical and social losses by means of voluntary euthanasia and assisted suicide. Publications like The Final Exit, authored by Derek Humphry (April, 1991), were written as a suicide how-to guide for persons experiencing long term pain and suffering associated with terminal disease entities.

Cox (1991) has described the Final Exit, in the Wall Street Journal, as a resource guide for health care providers who advocate assisted suicide for rational, terminally ill clients. Assisted suicide refers to the act of helping someone to bring on his/her death; while voluntary euthanasia refers to the performance of a medical procedure that is responsible for causing death (Wanzer, Federman, Aldelstein, Cassell, Cassem, Cranford, Hook, Lo, Moertel, Safar, Stone & Van Eys, 1989). Both procedures are gaining increasing acceptance by members of the health professions. Wanzer et al. (1989) state that some physicians believe assisted suicide should be seen as the last act to be performed on the health care continuum. The authors report that acts of euthanasia (injection of a legal drug) occur somewhere between 5,000 to 10,000 times a year in the Netherlands. They believe, moreover, that with the advent of legislation in 38 states pertaining to advanced directives ("living wills"), the courts are currently closer to developing legislation supporting that all patients,
whether terminally ill or not, are entitled to be permitted to die.

Doctors and nurses recognize that any attempt by them to actively aid clients in dying may prove to be damaging to the patient care provider relationship because the health care system has been established as a benevolent system which fights diseases (Johnson & Weiler, 1990). Most health care workers, therefore, tend to work toward the prevention and cure of diseases despite scientific evidence suggesting significant disease pathology, and escalating support for voluntary euthanasia and assisted suicide. Cain, Stacy, Jusenius and Figge (1990) and Sudnow (1967) contend that most physicians focus on the cure of disease and seem to lack interest from a medical perspective in providing competent supportive and palliative care for terminally ill patients. Palliative care lacks the diagnostic "power" that physicians enjoy and is thereby seen as a treatment concern for nurses. Seldom do physicians offer palliative therapy, treatment aimed at the control of specific disease related symptoms like pain and nausea, as an initial form of treatment. Physicians in the Netherlands, according to Young, Volker, Rieger and Thorpe (1993), upon request by their terminally ill patients, can legally assist them in dying. However, this is not true in the United States. Assisted suicide is considered unethical and illegal in
thirty-seven states within the United States (Andreola & Sullivan, 1994). It is moreover highly unusual for members of the health care professions, like Michigan pathologist, Dr. Jack Kevorkian, to participate in assisted suicide. Dr. Kevorkian has, so far, assisted in the suicide of twenty patients suffering undue pain in association with chronic and terminal diseases since June, 1990 (Hilton, 1994).

Physicians, in general, focus on pathological alterations associated with their client's disease processes and the promotion of cures for presenting symptomatology. Thorton (1991) has noted the findings of one study which disclosed that several terminally ill clients had died complaining of symptoms such as pain, nausea and sleeplessness. According to Cayle and Cherny (1994) needless suffering is experienced by one-third of all metastatic cancer patients because of physician uncertainty, which has ended in ineffective or inappropriate care. Findings such as these have been responsible for the recent issuance of guidelines by the Federal government, urging doctors to be more aggressive in the treatment of cancer pain. Additionally, of those physicians utilizing aggressive treatment modalities, many are hesitant to make medical decisions to withdraw aggressive treatment from their terminally ill clients because of legal repercussions (Wanzer et al. 1989).
Nurses, the largest body of health care professionals, on the other hand tend to focus their attention on the subjective aspects of their client's health and well being (Lubkin, 1986). They assess the significance of the disease's impact on their individual clients, i.e. the effects the disease process has on the client's quality of life. It is not uncommon for nurses to verbalize feelings of discomfort when caring for clients diagnosed with terminal diseases. They frequently report feelings of helplessness, sadness, anxiety and fear when caring for their terminally ill clients (Davitz & Davitz, 1975; Frommelt, 1991; Quint, 1967; Thrush & Thrush, 1979). Feelings, such as the aforementioned, influence the nurse's response to terminally ill clients and can lead to either an over indulgence in care and attention or to indirect (closing the patient's curtain or door) and direct (refusing to answer the patient's call light) forms of client avoidance. These feelings are due to verbal as well as nonverbal expressions of hopelessness by either the client, the client's physician or family members. Terminal clients can moreover have a profound effect on nurses because many of them are actively involved in making decisions related to their care, which includes switching from aggressive curative care to palliative care.
The apparent disparity between professional values of doctors and nurses, according to Cayle and Cherny (1994), is due to a conflict in values associated with the preservation of life and the alleviation of pain and suffering. Given this disparity, terminally ill patients are more likely to be shunned by both professionals. Doctors shun them because they are not medically challenging and nurses shun them because they are emotionally challenging. The reasons for the wide variations in the response of health care practitioners, particularly professional nurses, to their terminally ill clients are not clearly understood. One explanation for the extreme variation in behavior exhibited by professional nurses toward their terminally ill clients may reside in the professional nurse's estimate of the client's social loss value or overall worth to society.

**Background**

Moral neutrality is a desirable outcome of professional medical, nursing and social welfare training, but is not always a final product (Parsons, 1951). Judgments about a client's moral status and the quality of professional health care services that is offered to the client are sometimes based on the professional's perception of the client's social worth. Judgments about the social worth of patients are being made daily by doctors, nurses and social workers (Roth, 1972).
Members of the "helping professions" use the social attributes possessed by terminally ill clients in establishing the client's degree of social loss. The cumulative total of all social attributes associated with the dying patient indicates the client's loss to family, occupation and society; it moreover serves to impact the emotional status and bedside care rendered by professional nurses caring for terminally ill clients (Glaser & Strauss, 1964).

Social attributes possessed by the terminally ill client, along with the client's contributions to family, significant others, occupation and society, constitute the criteria for social loss determinations (Glaser, 1966; Glaser & Strauss, 1964; Hale, Schmitt & Leonard, 1984; Quint, 1967; Roth, 1972; and Sudnow, 1967). Appraisals of social loss take into consideration social characteristics such as age, education, occupation, family status, social class status, personality, talents and accomplishments. Other variables such as language (word usage and accent), mode of dress, insurance protection, religion and race are also considered.

These social characteristics, in addition to the client's contributions, are collectively calculated and an overall social loss value of high, low or average is assigned by the client's nurse. The assigned social loss
value represents the extent to which the client's death is perceived as a loss to society. Glaser (1965) found that a positive correlation existed between social loss and patient care. For example, low social loss clients (geriatric patients) receive less than routine bedside nursing care while high social loss clients (young and middle aged adults) receive greater than routine care. Hence, low social loss clients are less likely to receive the same resuscitative measures (the depth and extent of resuscitative efforts) as high social loss clients.

All aged clients are not, however, considered low social loss clients. Generally, aged clients who are not retired and remain actively involved in social organizations, as well as continue to practice in their profession until hospitalization, are exempt from a low social loss rating. Additionally, aged clients whose family members express significant concern and interest in their medical care and treatment and who also visit frequently are exempt from a low social loss value (Glaser, 1966). Hence, social characteristics take on different meanings based on the frame of reference.

**Purpose of the Study**

The purpose of this investigation is to explore and examine the impact of social loss on the behavior of professional nurses caring for terminally ill hospitalized
clients with non-malignant disease entities in young to middle adulthood. The specific aims of this research are to address the following questions:

1. Do nurses estimate the degree of "social loss" in their terminally ill clients?
2. If yes, what influence does the estimate of social loss have on nurses' perceptions of terminally ill clients?
3. Is there a relationship between the estimate of social loss and the nurse's clinical behaviors in the area of physical care and psychosocial interactions?

Conceptual Framework

The framework for this study arose out of the qualitative investigations exploring death and dying in medical institutions in the early nineteen sixties. Social loss was identified by several investigators as a psychosocial concept influencing the behavior of professional nurses, i.e. their reactions and responses toward as well as delivery of patient care to terminally ill clients. Glaser (1965) found a positive correlation between social loss and patient care by nurses. Kastenbaum (1986) emphasized that differences in patient care were based on perceived social value. All investigators felt that social
TERMINAL CLIENT

The client's social characteristics, contributions to family, friends, job and society.

Fig. 1. Social Loss Model
characteristics served as the criteria for social value and social loss determinations. Examples of social characteristics influencing social loss determinations included age, education, occupation, family status and personality.

Appraisals of social loss are purely subjective and reflect the social "worlds" of nurses assigning the value. Significant variations may occur in social loss appraisals if nurses from differing social backgrounds are used to rate the same client. Hence, social loss estimates are based on the respective nurse's life long experiences, interactions and values. The value assigned by the nurse performing the client rating not only reflects the nurse's response to the dying client but significantly impacts the nurse-patient relationship and the nurse's delivery of psychosocial and physical care. Figure 1 schematically depicts this relationship.

The terminal client, the client's social characteristics, contributions, family and significant others, are the inputs to (aspects and dimensions confronting nurses, using a systems' model) nursing care in Figure 1. The nurse is the throughput to patient care (individual responsible for rendering patient care), but the nurse is also a societal member who reflects the values of the world surrounding him/her. Nurses, like most societal
members, are constantly interacting with their surrounding world and all of the variables within their world. Some of the variables within the nurse's world which influence the nurse's assessment of terminally ill clients include the hospital setting, the nurse's clinical unit of assignment within the hospital, the nurse's culture, social values and social relationships. These variables are a part of the nurse and thereby influence the nurse's estimate of the client's social loss. Estimates of the client's social loss by nurses ultimately impact the delivery of nursing care to the client.

**Need for the Study**

Most of the research in the area of social loss has focused on terminally ill cancer clients or geriatric clients (Benoliel, 1970; Denton & Wisenbaker, 1977; Glaser, 1965; Glaser & Strauss, 1964; Hale et al. 1984; Kastenbaum, 1986; Keck & Walther, 1977; Popoff, 1975; Quint, 1967; Roth, 1972; Stoller, 1980; Strauss, 1969; Strauss & Glaser, 1970; Sudnow, 1967; Wegman, 1979; Yeaworth, Kapp & Winget, 1974). Little research has been conducted on terminally ill clients in young to middle adulthood with non-malignant diagnoses. Thus, a study which explores the relationship between "social loss" and nurses' response to terminally ill non-malignant, hospital-based clients from early to middle adulthood is both needed and appropriate.
Findings from this investigation can be used as a basis for designing standardized death education curricula for schools of nursing, staff development departments, long term care facilities and community settings. The findings can also be used in determining those variables which have the greatest impact on the emotional status of professional nurses and their clinical nursing behaviors. Meaningful information can additionally be gained regarding measures that may minimize the overall impact that social loss has on professional nurses caring for terminally ill clients.

**Definitions of Terms**

For the purpose of this study, the following operational definitions will be employed:

**Professional nurse** - any graduate of an associate, diploma or bachelor's of science nursing program who is licensed to practice nursing.

**Social value** - the overall worth or importance to society that an individual possesses while still alive. Social value determinations are based on social characteristics possessed by the individual and contributions made by the individual to family, occupation and society.

**Social loss** - an actual or impending void which is associated with death. Social loss estimates or social
loss values are based on one's past social characteristics and contributions to family, occupation and society. Social loss estimates are made by members of the health care professions, particularly nurses. The social loss value/estimate, for the purpose of this investigation, will represent a numerical value between 1 and 10.

*Terminal illness* - an end stage medical condition or disease which leads to the cessation of life within six months to one year.

*Clinical behaviors* - refers to the delivery of nursing care i.e. physical care and psychosocial interactions.

**Organization of the Study**

Chapter I has presented the introduction to the study, conceptual framework, definitions of terms, background and need for the study as well as the purpose of the study.

Chapter II will present a review of the relevant literature pertaining to social loss, nurses and the needs of the terminally ill client's family members and nurses and death education.

Chapter III will discuss the methods, research design, setting, sample, data collection procedures,
instrumentation, data analysis and protection of human subjects.

Chapter IV will provide the analysis of the data and a discussion of the results.

Chapter V will offer a summary of the major findings, the conclusions, limitations and implications for future research.
CHAPTER II
REVIEW OF RELATED LITERATURE

This chapter provides a review of the relevant literature pertaining to social loss, nurses and families of terminally ill clients and nurses and death education.

Social Loss

Every society has values. Values are embedded in a society's habits, customs and traditions in an effort to promote their continuation. They are basic to a society's way of life because they provide the standards for judging social behavior and maintaining group order. Social life, particularly the functioning of social systems, would be impossible without values (Rosser, 1971).

Values are categorized according to their level of significance. Values of great importance provide direction for life, promote the making of choices, and facilitate decision making within a society (Davis & Aroskar, 1991). Social and cultural values are important in determining the manner in which people conduct themselves when exposed to death and dying (Pine, 1972; Sorokin, 1968). The dying are generally avoided and the degree of avoidance, sometimes
referred to as social distance, has been speculated to be dependent upon the life value, social value or social relevancy of the dying person.

Death creates a "social vacuum" that disrupts the equilibrium of social life (Blauner, 1966). This vacuum is manifested whenever the loss of a societal member results in a gap within the functioning of social institutions. The extent of the vacuum depends on the depth to which the deceased has been engaged in society and societal groups. Another name for "social vacuum" is "social loss", a term coined by Glaser, Strauss and Quint in the early 1960's.

Social loss, according to Hale et al. (1984), is a function of perceived societal values. Societal values are those values which are based on social characteristics and are assigned by a society to its members. Societal members are esteemed to the degree that society has placed values on their social characteristics. Social values assigned by a society to its members can be either "high", "low" or "average". Determinations of high, low or average social value ratings are dependent, in turn, upon a multitude of social characteristics like race, religion, occupation, age, gender, social class and morality (Glaser, 1965; Glaser & Strauss, 1964, 1968; Sudnow, 1967). The assigned social value is also a reflection of the individual's contributions to family, occupation and society (Glaser & Strauss, 1964).
Social characteristics may therefore be used to measure a person's life value, social value or social relevancy. They are often included in the appraisal done by members of a hospital's medical staff when assessing the impending loss that is to be incurred by the death of a hospitalized patient (Charmaz, 1980). This finding suggests that members of the health care professions not only bring societal values into the hospital setting, but they also use societal values in assessing their clients. Glaser & Strauss, (1964) assert, "In our society we value people more or less on the basis of various social characteristics: for example, age, skin color, ethnicity, education, occupation, family status, social class, beauty, personality, talent and accomplishments..." (p. 119).

Nurses, in general, respond to patients based on the client's computed social loss value (high, low, or average). This "calculation" is based on the cumulative total of social characteristics possessed by their clients (Glaser, 1966; Glaser & Strauss, 1968; Quint, 1967). Nurses as well as doctors also use social characteristics as a means of classifying dying patients according to their (patients) perceived societal value, i.e. the extent to which a dying patient is perceived as a loss to society (Quint, 1967).

The lives of patients are sometimes placed in competition with other patients during times of limited
resources. For example, patients needing donor organs or the services of a dialysis machine for survival during times of scarce resources are placed in competition with each other based on their social value (Glaser & Strauss, 1968). This finding has also been corroborated by numerous investigators. For instance, Roth (1972) observed that emergency room staff members from six different hospitals were not uniformly dispensing medical services to every patient needing them. Judgements made by these staff members about the patient's worthiness and appropriateness of demands were taken into account when performing medical services. Sudnow's (1967) research as a non-participant observer in two hospitals, one in the Midwest and the other on the West Coast, is in agreement with this finding. Sudnow discovered that a direct correlation existed between the intensity and time interval of an ambulance siren and the social value of the person being transported. Hence, paramedics would ring their ambulance siren at a large volume for greater periods of time if they were transporting a high social loss client. Sudnow (1967) further pointed out that "Two persons in similar physical condition may be differentially designated dead or not dead" (p. 10).

Kalish (1965) acknowledged that factors such as age, race, sex, finances and personality are used in making decisions regarding who lives and who dies. He furthermore
argued that higher mortality rates among African-Americans can in part be attributed to the differential treatment they receive from members of the health care system. Other factors influencing which clients are saved as well as when they are saved include social class status, marital status, parenthood, occupation and physical condition (Glaser & Strauss, 1968). Preference, however, is given to persons who are members of the upper class social strata, married, parents of young children, healthy and employed in jobs that are vitally essential to the workings of society. Simpson (1976) reminded us that social status not only influences medical care but may also be responsible for prolongations in the pronouncement of "death". Such was the case with President John F. Kennedy, when he was shot in Dallas, Texas. An emergency room physician caring for President Kennedy was quoted in the New York Times (1963) as saying: "Medically, it was apparent that the President was not alive when he was brought in... Technically, however, by using vigorous resuscitation, intravenous tubes and..., we were able to raise the semblance of a heart beat" (p. 2). Much time and effort was expended before he was pronounced dead.

Other characteristics assessed by hospital medical staffs when determining a client's social loss value include the client's mode of dress, medical insurance, language (accents and words used) and mannerisms displayed when
interacting with staff members (Roth, 1972). According to Simpson (1976) and Sudnow (1967) the perceived moral character of a patient is also used in determining the amount of effort that is to be made when the patient is clinically dead.

Of all the social characteristics cited, the single most important characteristic used in assessing a dying person's social loss and length of resuscitative efforts is "age" (Simpson, 1976). Age is a criterion of one's actual and future potential (Glaser & Strauss, 1964). Age and social situation are key criteria of the impact associated with mortality (Blauner, 1966). Hale et al. (1984) maintain there is an inverse relationship between age of the dying patient and the perception of loss in nurses. This relationship was moreover supported by Popoff in his investigation of 15,430 nurses. Popoff's (1975) findings revealed that, with the exception of newborn babies, the younger the patient the greater the sense of discomfort experienced by nurses caring for terminally ill clients. Newborns were felt to generate less discomfort because they were not old enough to know they were dying. Given this, the lives of children are valued highly and dying children, represent a loss to the future society. Whereas the social loss of the aged can in no way compare to that of children, because the aged have lived their lives and have had an
opportunity to make contributions to family, job and society (Glaser & Strauss, 1964).

Explanations using social loss in rationalizing the deaths of children are however not used because their lives and abilities to contribute to society have been short lived. Social loss explanations are instead used in discussing the deaths of contributing societal members like young and middle aged adults (Glaser, 1966; and Hale et al. 1984). According to Glaser & Strauss (1964), "Americans put a high value on having a full life" (p. 119).

The death of a young or middle aged person is disturbing for American families because these individuals are perceived as being vital to the workings of society. Their lives are deserving of more time and expense when compared to the elderly because they carry a greater social value (Benoliel, 1971; Blauner, 1966; Glaser & Strauss, 1964; Kalish, 1965; Kastenbaum, 1986; Pine, 1972; Quint, 1967; Roth, 1972). Support for the expression of strong emotions for the death of young adults by nurses are documented in investigations by Hale et al. (1984), Lerea and LiMauro (1982) and Vanden Bergh (1966). Results from the study conducted by Hale et al. (1984) on the impact of age of the dying person on the reactions of nurses revealed that 67 out of 81 nurses studied perceived a greater loss when a younger, rather than an older, person died.
Forty-seven percent of the 67 nurses verbalized that the loss of a young person was devastating because young people are not expected to die. According to Glaser and Strauss (1964), the greatest loss occurs with the terminally ill middle aged patient because this individual is in the midst of living a full life and is depended upon the most by family and significant others as compared to young adults and the elderly. Blauner (1966) adds, however, that families and work groups are usually affected more by the loss of persons in the middle years of life. Support for viewing young and middle age adults as important to the workings of society is also documented in the developmental psychology literature. Young adults are individuals between the ages of 18 and 40 years of age, approximately. Erickson has labeled young adulthood as a period of intimacy or isolation (Dworetzky, 1985). Developmental tasks associated with this stage include independence from parents, pursuit of a career and adulthood. Other developmental tasks, as well as events associated with this period, include marriage, parenthood, establishing friendships, and social and civic responsibilities.

Middle adulthood, on the other hand, covers the age span between 40 and 65 years of age, approximately. Most individuals during this period experience peaks in their income, social status and responsibility. Erickson calls
middle adulthood the period of self absorption or
generativity (Dworetzky, 1985). Developmentally, numerous
physical and emotional changes take place during this stage.
Both sexes suffer declines in their reproductive capacities
and become keenly aware that they have less time to live.
Middle aged men, in particular, experience a mid-life crisis
or a period of readjustment, while middle aged women
experience menopausal symptoms and the "empty nest" syndrome
due to the exodus of adult children from the home.

Age is therefore seen as an important variable,
especially when appraising young adults, because it is
equated with the actual potential or developing potential of
the young adult. Age, however, is not a reliable indicator
of a middle aged person's actual or developing potential.
Education takes over as the primary social characteristic
used in determining the social loss for dying middle aged
adult clients because it gives a better perspective of how
the client has spent past years in preparing for the present
Education outweighs age because it reflects the middle aged
person's actual, present and future potential. Besides age
and education, no other priorities have been established in
assessing the remaining social characteristics influencing
social loss.
Thus, the younger the client, the higher the social loss estimate assigned by nurses. Whereas for middle aged clients, the greater the number of degrees, certificates and years of formal education, the higher the nurse's social loss estimate. However, the combination of a series of high social loss factors usually carries more weight than any one single factor (Quint, 1967). Low social loss values, on the other hand, are frequently assigned to elderly clients and clients with minimal to no family input and formal education.

Calculations of social loss are based on the composite of all social characteristics possessed by the dying client, whether they be apparent characteristics such as ethnicity, language and beauty or learned characteristics such as education, talents and occupation. Glaser and Strauss (1964) state that "the total of the valued social characteristics which the dying patient embodies indicates the social loss to family, occupation, and society on his death..." (p. 119). "The degree of abandonment, isolation, and loneliness" (Kneisl, 1968, p. 551) experienced by terminally ill clients is influenced by the patient's social loss value. Calculations are not fixed but are adjusted each time new information is learned about the client. These adjustments ensure the accuracy of the nurse's social loss appraisal. Recalculated scores reflect the most
up-to-date information about the client and the depth of the client's loss to family, occupation and society also.

In general, the greater the value assigned to individual social characteristics possessed by the client, the greater the impact the patient's terminal status has on the nurse. "The greater the number of social loss factors the patient embodies, the greater the impact the client's death has on members of the nursing staff" (Glaser & Strauss, 1964, p. 121). Social loss has its principal impact on the emotional status of professional nurses. High social loss clients produce feelings of grief, sadness, distress, regret, ineptness and loss in professional nurses. The expression of these emotions is felt to be related to the nurse's humanism. These feelings are not associated with professional training or mannerisms.

The secondary impact of social loss on nurses is in the area of patient care delivery. Feelings such as grief and distress can lead to variations in client care, i.e. too much care, routine care or client avoidance because physical contact with the client threatens the emotional status of nurses. Feelings of grief and distress are believed to be responsible for lowering a nurse's professionalism (composure and nursing care). Nurses caring for low social loss clients do not experience these emotions. Deteriorations in the health status of low social loss
clients essentially go unnoticed. These clients are
oftentimes forgotten during medical emergencies (Glaser,
1966).

Time and its multidimensional aspects appear to be the
major variables influencing changes in social loss values.
As the length of time for nurse-patient interactions
increases, information learned about the client increases as
well. As the client's data base expands, the nurse
gathering client information eventually develops a "social
loss story". This story reflects important historical
information gained about the patient, i.e. the patient's
life, life style, contributions and social characteristics.
This story is usually repeated whenever information is
sought or concerns about the client are verbalized.
Listening to the social loss story can be disheartening as
well as therapeutic for nurses. The story creates feelings
of sadness and discomfort for nurses; yet, repeated
listening can offer nurses some assistance in rationalizing
the client's approaching death while reducing the impact or
trauma associated with the client's expected death. Nurses
caring for high social loss clients uniformly reach the
conclusion, considering the client's past history of
significant contributions and the client's inability to
perform at this past level, that the client is socially
worthless to family, job and society and is better off dead than alive (Glaser, 1965).

Time also influences the intensity of the nurse's response to the terminally ill client. Nurses caring for high social loss clients that have been hospitalized on the same unit for long periods of time are extremely vulnerable to emotional upsets. Whereas, nurses caring for hospitalized terminally ill high social loss clients for brief periods of time are desensitized from emotional upsets. Time, additionally, influences the number and frequency of deaths repeatedly witnessed by nurses caring for terminal patients. Nurses caring for clients with the same degree of social loss, i.e. all clients are perceived as high social loss patients, are also desensitized to emotional upsets.

Additional variables influencing social loss values include type of hospital (private versus public), type of patient unit (oncology versus obstetrics), social relationships among staff members (close friendly relationships versus distant and unfriendly relationships), nurse patient relationships (therapeutic versus non-therapeutic relationships) and work demands (heavy versus light patient assignments), i.e. number of patients cared for, patient dependency level and amount of required care,
as well as length of duty, i.e. eight hours versus twelve hours versus sixteen hour shifts.

Private hospitals as opposed to public hospitals are believed to be the most likely facilities where high social loss clients seek medical care. It is also believed that the death of a terminally ill obstetric (pregnant) client or a terminally ill psychiatric client is likely to generate strong emotions within nursing personnel that resemble those associated with high social loss clients. Deaths on units such as these (obstetrics and psychiatric) are highly unusual and are perceived as a travesty regardless of their causation, be it an end stage disease or not. It is furthermore likely that news about a client's death on a psychiatric or obstetrical ward, whether it is due to a terminal ailment or not, is likely to be heard in most areas of the hospital. Whereas deaths on specialty care units such as oncology/hematology (cancer), intensive care (ICUs) or acquired immune deficiency disease (AIDS) wards are expected occurrences and news about these deaths are usually contained within the respective specialty area and adjacent wards. Pine (1972) affirmed that different social organizations (including subdivisions within an institution, e.g. the ICU, emergency room (ER) and oncology/hematology units) engender different reactions to death related phenomena. Deaths in the ICU lack the same impact as deaths
in the ER, and deaths in the ICU and ER lack the same impact as deaths in oncology/hematology (Stoller, 1980b).

Social relationships among staff members, as well as those between patients and staff, also influence the degree of social loss. Each health care setting has an established social order (Stoller, 1980b). Formal organizational rules, as well as informal agreements pertaining to behavioral norms for staff members, make up the social order while establishing group cohesion. All members of the setting (whether it be ambulatory, home, or institutional) are socialized to adhere to the established social order. For example, staff members in nursing homes are felt to have a lower prevalence of bereavement than hospital staff members because staff members in nursing homes readily accept the consequences of physical deteriorations and patient losses associated with their population of clients (Lerea & LiMauro, 1982). The ward environment also influences how nurses communicate with their clients. Nurses employed in general hospitals that encourage autonomy, independent decision making and an open environment were more facilitative of patient communication (i.e. these nurses allowed their clients to discuss their problems). Whereas nurses working in specialty cancer hospitals who had a strong fear of dying significantly blocked patient communication (Wilkinson, 1991).
The quality of the nurse patient relationship has an impact on the degree of social loss. Units whose nurses develop close ties with their patients typically have greater perceptions of high social loss deaths. The experience of high social loss emotions by staff members other than those directly involved in the patient's care are likely to occur on these units if staff members adhere to the established social order. Nurses who establish therapeutic (i.e., helpful, cooperative and trusting) relationships with their terminally ill clients are also more vulnerable to the experience of grief and helplessness than nurses who have established non-therapeutic relationships. The quality of the nurse-patient relationship is significantly influenced by work demand. Nurses working on units with heavy patient load responsibilities (large numbers of dependent clients who require significant amounts of physical and technical care) are least likely to psychosocially interact with their clients. These nurses are least likely to establish quality relationships with their patients because of the time demands and are therefore less likely to experience social loss when their clients die.

It is the opinion of Davies and Oberle (1990) that nurses assume a more dominant role than physicians in the care of dying clients whenever the treatment regimen is
changed from aggressive to palliative care (emphasis is placed on the promotion of comfort measures, particularly pain relief). Hence, with an increase frequency of close contacts with dying clients, nurses can be expected to experience some degree of emotional involvement with their dying clients (Thrush et al. 1979). This tendency subjects nurses to more client losses, thereby creating an even greater need for them to protect themselves from such losses than physicians (Vanden Bergh, 1966). It is the belief of McWilliam, Burdock and Wamsley (1993) that the preservation of nurses' integrity is essential to their maintenance of feelings of self-esteem and self-worth as well as their ability to function effectively. Efforts by nurses to protect their emotional integrity and well-being leads to the utilization of numerous defensive strategies (Quint, 1966; Wegmann, 1979).

Defensive strategies by nurses incorporate physical and verbal avoidance techniques which help in maintaining social and emotional distance from dying clients. Examples of verbal avoidance strategies include referring the client to his/her physician, changing topics and/or offering false reassurance for recovery whenever discussions about the client's prognosis or impending death surface (Schoenberg, Carr, Peretz & Kutscher, 1972; Simmons & Givens, 1972; Wegmann, 1979); while physical avoidance strategies include
closing doors and bedside curtains so the patient's view of hospital personnel and activities is obstructed. These examples support Benoliel's (1970) belief that nurses, for the most part, are ill-prepared to deal with the psychosocial difficulties encountered when interacting with dying clients.

Ironically, nurses caring for terminally ill clients, on the average, spend more time with these clients than they do with non terminally ill clients (Keck & Walther, 1977; Wegmann, 1979). Their care, however, often takes on a "task orientation" (focus on objects, equipments, and duties) as a means of maintaining composure (Glaser, 1965; Schoenberg et al. 1972; Simmons et al. 1972; Thorton, 1991; and Wegmann, 1979). These nurses refuse to become attached or personally involved with their terminal clients. Physical and verbal avoidance tactics, in addition to an equipment centered focus to nursing care, symbolize a form of "premortem dying", (Vanden Bergh, 1966, p.73). A study examining the perceptions of 36 terminally ill patients (average age of 56) and their nurses revealed that most patients perceive a lack of "expressive behaviors" (psychosocial factors, e.g. communications) and not "instrumental behaviors" (goal specific behaviors, e.g. administering a treatment or pain medication) as constituting the most distressing aspects of their illness (Keith & Castles, 1979).
Instrumental behaviors accompanied with physical and verbal avoidance strategies may be helpful in reducing nurses' vulnerability to feelings of fear and grief, but they also place severe limitations on nurse-patient relationships. Refusals by nurses to become personally involved with dying clients is quite understandable, according to Quint (1970), considering the opposition among clinical nursing goals they must face. Confrontation with clinical goals which promote comfort and the relief from suffering are conflictual for members of the nursing profession because they are sometimes in direct opposition to those clinical goals which prolong and protect human life.

Reimer, Davies and Martens (1991) assert that much research on nursing behaviors fails to focus on the nurse as a person and the impact the nurse's characteristics have on client care. The vast majority of the research instead seems to focus on the nurse as a professional, i.e. the nurse's ability to provide physical care and supportive care for terminally ill clients. Research by McWilliam et al. (1993) points out that a nurse's ability to function as an effective care provider is strongly influenced by the nurse's ability to preserve his/her own integrity. McWilliams et al. (1993) furthermore declared that nurses preserve their own integrity through maintaining their
feelings of self-worth and self-esteem. Studies by Denton et al. (1977), Frommelt (1991), Glaser (1965), and Stoller (1980a) suggest that professional registered nurses (R.N.'s) may be less prepared emotionally to deal with terminally ill patients than licensed practical nurses (L.P.N.'s) or nursing assistants (N.A.'s). Stated differently, positive attitudes toward death and dying may be inversely correlated with greater amounts of nursing education and clinical nursing experience. Stoller (1980a) concluded that R.N.'s with an average of 11.5 years of clinical nursing experience had greater feelings of uneasiness toward their terminally ill clients. L.P.N.'s in this same study, with an average of 5.5 years of nursing experience, demonstrated a greater ability to cope with dying clients. This finding is partly consistent with Lester, Getty and Kneisl's (1974) investigation which demonstrated that first year graduate nursing students experienced greater fears of death and dying than senior level undergraduate nursing students. It furthermore revealed that an increase in education can generally be associated with a decrease in fears of death and dying for nursing students enrolled in undergraduate nursing programs. However, upon completion of undergraduate nursing programs, fears of death and dying tend to escalate with an increase in clinical contact with terminally ill patients. These findings by Lester et al. (1974) and
Stoller (1980a) point out that education and clinical experience cannot be used as reliable indicators of one's emotional stability.

**Nurses and Families of Terminally Ill Clients**

Life threatening illnesses and death-related losses affect a wide arena of persons, according to Coolican, Stark, Doka and Corr (1994), which include family members, healthcare professionals and the society at large. Gulla (1992) insists that the health care system often fails to consider the relationship/connection between terminally ill patients and their family members and significant others who are invested in the patient. Family members, according to Gulla (1992), begin to mourn the loss of their loved ones before the loss actually occurs.

Hull (1989) states that families of terminally ill clients consider nurses as the healthcare providers primarily responsible for their relative's care. Hull (1989) furthermore alleges that the type of relationship with the dying family member affects the entire experience from diagnosis until death and during bereavement. Hence, if nurses are to be supportive resources for family members, then their nursing care must include the families of terminally ill clients (Kleinpel & Powers, 1992). Knowledge of the importance of the terminally ill client's family system and the various roles and functions
within that system is needed by nurses to assist them in meeting the needs of the client and the client's family.

Research by Kleinpel and Powers, (1992); Reimer et al. (1991) and Waltman (1990) has identified that family members of terminally ill clients, regardless of the setting (hospice, hospital or the client's home), have a tremendous need for information regarding their terminal family member. Some of the needs for information by families include: having their questions answered honestly; being phoned at home about changes in their loved one's status; knowing the client's treatment; having knowledge of the client's progress, and what was done for the client. Nurses in the Kleinpel and Powers (1992) investigation were able to accurately identify two of the five major needs of family members for information, i.e. having questions answered honestly and knowing what was done for the client. However, nurses' perceptions of the three remaining major needs for information differed from those of family members in that nurses felt family members of terminally ill clients had a greater need for explanations, e.g. to know their loved one's prognosis and to know that caring hospital personnel were rendering service for their family member.

Hull (1989) maintained in her investigation that relatives of hospitalized terminally ill clients need to be close to their dying family members because it assists
family members in maintaining their sense of security, self
worth and emotional integrity. Hull (1989) also
acknowledged that families undertaking home care for their
terminally ill family member need information on how to
perform specific nursing skills. Most family members
overwhelmingly wanted nurses to give patient-centered
nursing care as opposed to family-centered care. They also
felt that behaviors which encouraged their expression of
personal and emotional needs were least important to them.

Considering the aforementioned data, Gulla (1991)
asserts that nurses need to borrow from hospice the
practice of conducting assessments of family dynamics when
admitting terminally ill clients. Information from family
level assessments could be used to facilitate improved
communications and relationships between nurses, family
members and terminally ill clients. Reimer et al. (1991)
are strong advocates for strategies and methodologies which
improve communication among nurses, terminally ill patients
and their families. It is their belief that improvements in
communications will eventually lead to improvements in
terminal care.

Several additional factors have been found to influence
the quality of care for terminally ill clients, particularly
their nursing care. Waltman (1990) purports that the
behavioral intentions of nurses toward the dying (attitudes
and subjective feelings regarding verbal and nonverbal activities which meet the physical, emotional, spiritual and social needs) are highly predictive of their actual behaviors toward dying clients and their families. Frommelt's (1991) investigation offers some support for Waltman's theory. According to Frommelt (1991), nursing care given to terminally ill patients and their families is directly related to the nurse's attitude toward giving this type of care.

Even though factors such as "attitudes and one's feelings" affect the quality of nursing care rendered to terminally ill clients, Trygstad (1986) alleges that the relationship between the nurse and the nurse's patient must always remain "professional, goal oriented and patient-centered". Nursing behaviors, identified as critical to the care of dying clients, include notifying family members when death is imminent, providing physical comfort measures, showing empathy and respect when patients and their family members express anger, identifying a family member to serve as liaison between the family and staff, focusing on the patient's quality of life even though the client is dying, providing emotional support and feedback to nursing colleagues, and defining the nurses role and allowing for personal growth (Degner, Gow & Thompson, 1991, p. 248).
In addition to the aforementioned seven critical behaviors in the care of terminally ill clients, several other dimensions of the nurse's role in palliative care have been cited. These dimensions have been listed by Davies and Oberle (1990) and include getting to know the client and the client's family (which involves gaining knowledge of their thoughts and feelings), assisting the client in meeting his/her needs, giving encouragement and sharing information pertaining to treatments and changes in the client's status. There are times, however, when the nurse-patient relationship goes beyond the typical professional, goal oriented and patient-centered relationship to become a personal relationship. When this occurs, the nurse takes on the role of "professional friend". Nurses who assume this additional role have made a conscientious decision to develop a socially meaningful relationship with the terminally ill client.

**Nurses and Death Education**

Historically, the training of doctors and nurses in the care of terminally ill patients has been problematic for the health professions educator to handle both professionally and personally (Coolican et al. 1994; Dickinson, Sumner & Durand, 1987; Schoenberg et al. 1972). The professional difficulties experienced by health professions educators primarily stem from investments by members of the health
care professions in the promotion of cures and prevention of death. Personal difficulties stem from prior as well as present socialization toward death and dying (Quint, 1967). Surveys of nursing schools have specifically revealed that instructions of nursing students in the care of terminally ill clients have been presented in a variety of ways by a variety of instructors.

Content pertinent to terminal illness has been presented as elective courses, required courses or curriculum strands that are integrated in several courses at various levels of the nursing program. Each approach has included didactic content but not clinical practicums (Degner & Gow, 1988; Thrush et al. 1979). Each course has assigned readings from professional death and dying literature, but this information has been inconsistently tested on written examinations. Examination content emphasizes physiological and technical aspects of death and dying and not psychosocial components (Strauss, 1969).

It has also been noted, in a study by Quint and Strauss (1964), that nursing instructors seem uncomfortable or ill prepared emotionally to discuss death. Feelings of uncomfortableness when death becomes a conversational topic, particularly by a patient, is an indication of unresolved fears regarding death, according to Popoff (1975). The investigation by Quint and Strauss (1964) further revealed
that some graduate nurses experienced minimal to no encounters with terminally ill clients because their instructors failed to carefully plan their clinical assignments of patients. It therefore seems likely that fears of death by nursing instructors may be responsible for the failure to consider the care of terminally ill clients as an important aspect of clinical nursing education.

Documented support for this speculation can be found in Thrush et al. (1979) survey of 240 nursing students in baccalaureate and associate degree nursing programs showing that 60 percent of these students had never witnessed a patient's death. Findings cited in Kastenbaum and Aisenberg's (1972) text have revealed that nurses experienced difficulties in responding to the needs of dying clients. Kastenbaum and Aisenburg (1972) note that in an experiment by Le Shan, it took significantly greater periods of time for nurses, when clocked with stop watches, to respond to the call lights of terminally ill patients as compared to patients with less severe illnesses.

The death of a client frequently represents the irretrievable loss of someone meaningful. The meanings attached to patient deaths are numerous and varied. Hence, the repeated occurrences of irretrievable losses is upsetting to nurses caring for terminally ill clients. Besides classifying a client's death as a social loss,
nurses may also classify them as a personal loss and/or a work loss (Glaser & Strauss, 1964).

Personal losses of clients to nurses symbolize friendly and close nurse-patient relationships, whereas patients representing work losses to nurses symbolize the expenditure of much effort in the preservation of the patient's life. These categories of losses (personal, work and social) are not mutually exclusive, and it is highly probable that for some nurses a combination of all three types may be experienced following the death of single client.

The repeated experience of loss frequently leads to anxiety, stress, grief and burnout in nurses (Eakes, 1990; Folta, 1965; Gray-Toft & Anderson, 1986; McElroy, 1982; Quint, 1967; 1983; Reimer et al. 1991; Wegmann, 1979). Feelings such as anxiety and discomfort are generally experienced by younger nurses as opposed to older nurses (Popoff, 1975). Older nurses usually experience relief after a patient dies. Popoff (1975) and Hoggatt and Spilka (1978) discovered that most terminally ill clients are cared for by younger nurses aged 28 years and less and not by older nurses aged 40 years and older. This finding led Lester et al. (1974) to hypothesize that fears of death and dying influenced nurses' selection of areas of clinical nursing practice. This hypothesis moreover suggests that
older nurses choose clinical practice units in which the death of a client is less likely to occur. The experience of stress by nurses can be associated with meeting the demands for care by dying clients and their significant others. This frequently leads to withdrawal, isolation and avoidance of terminally ill patients by nurses. In other words, stress, particularly unresolved stress, contributes to nursing burnout and staff turnovers. Grief, on the other hand, attempts to minimize the suffering that accompanies the loss associated with death (Cowles & Rodgers, 1991; Eakes, 1990; and Lerea & LiMauro, 1982). Grieving that is normal fosters emotional healing. It also prevents the emotional stagnation of nurses and allows them to move out of a state of helplessness. This in turn promotes the continuous delivery of nursing care to terminally ill clients, thereby permitting the effective provision of care for other terminally ill individuals. According to Kubler-Ross (1969), it is a paramount necessity that nurses deal with their emotions and attitudes toward death before they can effectively administer care to terminally ill patients, families and significant others. Yet, grieving in the presence of patients and their significant others conflicts with professional nursing behaviors and expectations because it results in a lack of composure and control of emotions (Eakes, 1990). It seems as though deficits in the provision
of death and dying instruction to nursing students and other health professions students, in general, has led to deficits in the health care practitioner's ability to deliver holistic (comprehensive) health care for the terminally ill (Degner et al. 1991). Thus, upon completion of nursing school, graduate nurses learn to deliver patient care in areas where they lack knowledge, like death and dying, according to the manner that is approved and practiced by experienced nurses. Nurses, especially those who feel as though they were inadequately prepared to deal with terminally ill clients, often abide by these "accepted" practices even if they include the avoidance of terminally ill clients (Degner et al. 1991; Frommelt, 1991; Quint, 1967; Yeaworth et al. 1974). Hence, nursing instructors are not solely responsible for the deficiencies in nursing care for the terminally ill. The avoidance of contact with dying clients could, according to Quint (1967), be curtailed if nurses were given systematic educational support by their employers.

Nurses fears are a reflection of "societal values" (Quint, 1966 p. 229 and Schoenberg et al. 1972, p. 9). Nursing as a profession has supported society's values. Society in general is fearful of death and so are society's nurse members. Society values life and the heroic preservation of life and devalues dying, palliation and
death. Traditionally, the nursing profession has had much more esteem for intensive care and emergency care nurses over nurses working in specialty areas such as palliative care and oncology/hematology because much of their time and skill is spent in preserving life.

Society's values, however, are in the midst of change. Persons living during the 19th century and before were exposed to more sickness and death, primarily due to acute infections. Terminally ill persons were cared for and interacted with family members and friends during the entire disease process within the context of their homes as opposed to health care settings. Health care for the terminally ill did not begin to change until sometime after World War II when the public demanded improvements in the delivery of health care (Benoliel, 1970, 1983; and Schoenberg et al. 1972). The public's outcry, coupled with technological advances and disease treatments, impacted health care delivery for the terminally ill tremendously. Terminal illness care shifted from the home to the hospital.

The demand for health care services by the terminally ill is gaining serious attention because present day American society has not been socialized in dealing with death and dying in a manner similar to past societies (pre World War II). Americans today have had limited personal experiences, especially within the home, to witness the
death of a loved one. Institutions, as opposed to residential homes, are perceived as the setting of choice for death to occur. However, even this attitude is changing, and more terminally ill patients and their family members are seeking services from agencies such as hospices, which support the care of dying clients within the home. This is due to the increasing denial rate for hospital admissions and limitations posed on the length of stay for terminally ill clients.

Credit for many of these changes in the care of the terminally ill, as well as in death education for the health professions, needs to be given to Dr. Elisabeth Kubler-Ross and Dr. Cicely Saunders. These pioneers, in the early 1960's, reported on the neglect dying patients encountered by medical staff members. Their findings are also responsible for the emergence of many nurse researchers in the field of death and dying. However, it was Quint's (1966) discovery and Eakes (1990) affirmation that empirically demonstrated that nursing students were not adequately prepared to responsibly assume care for the dying. Quint attributed these limitations in nursing students' abilities to care for dying clients to be directly related to feelings of uncomfortableness and the lack of preparation by nursing instructors to deal with terminally ill clients beyond the realms of physical care.
regimens. Nurses, in general, agree that their professional education in death and dying has been less than adequate (Hoggatt & Spilka, 1978; Vachon, Lyall & Freeman, 1978). It appears as though "personalized nursing care is the exception and not the rule of practice when it comes to the terminally ill" (Schoenberg et al. 1972, p. 149).

The conclusions listed above have been drawn based on the aforementioned review of the literature, which reveals a dearth of information related to social loss. This scarcity of information is responsible for this researcher's investigation of social loss and social loss estimates of terminally ill young to middle aged clients by hospital based nurses.

Social loss is a purely subjective psychosocial concept which impacts the quality of the nurse-client relationship, i.e. clinical behaviors and emotional status. There are numerous explanations why this occurs. One explanation states that nurses have a high frequency of contact with dying clients because they are considered the primary health care providers for terminally ill clients. As the frequency of contacts with dying clients escalates, nurses experience anxiety, stress, grief and burnout. In an effort to protect their integrity and emotional involvement with terminally ill clients, nurses begin to utilize defensive strategies such as physical and verbal avoidance.
Communication among terminally ill patients, their family members and nurses suffers during the interim because social loss also impacts family members of terminally ill patients. Family members begin to mourn the loss of their loved one prior to their impending death. Nurses can better assist family members of terminally ill clients by getting to know the client, the client's family, the various roles played by the client within the client's family system, and by sharing information with family members having a vested interest in the client.

The differences in the quality of nursing care can be attributed to nurses' attitudes, feelings and the client's social value as determined by the nurse. Nurses' attitudes and feelings regarding the physical, emotional, spiritual, and social needs of terminally ill clients are highly predictive of their actual behaviors. However, L.P.N.'s and nurses aides seem to be better prepared from an emotional perspective to care for terminally ill clients than R.N.'s.

Age and education are two of the most important social characteristics used in making social loss determinations. Additional variables influencing social loss determinations include type of social organization (i.e. hospital, patient unit), work demands and social relationships among staff members and among staff members and their patients.
The methods used to explore the various relationships between the aforementioned variables and social loss will be discussed in the next chapter.
CHAPTER III
METHODS

This chapter describes the methods used to explore the relationship between social loss and nurses' responses to terminally ill clients. The following are described in this chapter: research design, setting, sample, instrumentation, data collection procedures, data analysis, and protection of human subjects.

Research Design

A descriptive field study approach, which incorporated concepts from grounded theory, was used for several reasons. The research used qualitative methods because the study attempted to provide an understanding of social phenomena (Dempsey & Dempsey, 1992; Miller & Fredericks, 1987; 1988). The focus of the study was to describe the present relationship existing between social loss and nurses responses to terminally ill clients. Both qualitative and quantitative measures were used to gather data from the viewpoint of the nurse-subjects. Grounded theory is generally used whenever little is known about a problem, (Glaser & Strauss, 1975; Miles & Huberman, 1984). Such was the case with social loss; hence, concepts from grounded
theory such as constant comparative methodology and triangulation were used to facilitate the emergence of a plausible theoretical framework for the social loss concept. Constant comparative methodology permitted simultaneous processes such as data collection and data analysis in addition to the comparing and contrasting of the data. Triangulation was used to support the reliability and validity of the research findings.

**Setting**

The study was conducted on two 24-bed medical units within a private not-for-profit university-affiliated medical center located within the Midwest. Both medical units cared for adult clients with non-malignant terminal illnesses and clients between the ages of twenty to sixty-four years of age. The average daily census for these 24-bed units ranged from 21 to 22 patients per day. The facility had more than 650 licensed patient beds and employed more than 1,000 nurses. It was felt that nurses working in a tertiary care institution, such as the one used for this study, would have greater exposure to the care of terminally ill clients than those nurses working in small community hospitals because of the advanced technologies used in the delivery of health care and because of the advances in health care research.
Sample

Subjects for this investigation consisted of a convenience sample of all licensed registered nurses (R.N.'s) from two clinical units meeting the researcher's eligibility criteria. All nurse-subjects eligible for inclusion in the study had to meet the following criteria: possess a minimum of six months clinical experience on their respective clinical unit; work an average of twenty hours per week minimally; provide client care to terminally ill clients between the ages of 20 to 64 years of age on at least two occasions, with the last day of patient care occurring within 7 days of the interview with the researcher; and express a willingness to participate in the study. Licensed practical nurses (L.P.N.'s) were not included in the study because R.N.'s, according to Denton et al., (1977); Frommelt, (1991); Lester et al., (1974), and Stoller (1980a), experienced more difficulty caring for terminally ill clients than L.P.N.'s and because the researcher wanted to minimize the variability among the subjects.

Data Collection Procedure

The researcher, a professional nurse, made visits to the hospital to meet with the Director of Nursing Research, one Clinical Manager, and one Assistant Clinical Manager
prior to the onset of data collection. The purpose of these visits was to discuss the intent of the study and determine which units were most likely to care for terminally ill clients with non-malignant diseases. Initially, only two medical units were identified during this pre-data collection phase, but the study was expanded two weeks after initiation of the data collection phase to include two additional units. One 24-bed neurological medical unit, and one 32-bed medical/surgical cardiac unit, for a total of four units included in the investigation. After monitoring the patient census for a period of two months on these latter two units, it was found that no nurses met the researcher's criteria for participation in the study because no terminally ill clients were admitted to these units during this period. Consequently, these latter two units were eventually excluded from the study.

The researcher assumed the role of a non-participant observer, spending a minimum of three to four hours a day, three days each week for a period of two weeks on each shift for each nursing unit included in the study, prior to conducting scheduled interviews. Ethnographic observations were begun on each clinical unit the day following the researcher's introduction to the staff assigned to the respective unit. All introductory staff meetings were conducted by the researcher in conjunction with the unit's
manager or assistant manager. These meetings began in July, 1992, and were scheduled one week apart. This approach permitted a gradual expansion of the number of units participating in the study. It also represented an increase in the scope of the study by including nurses caring for clients with a variety of terminal illnesses.

Observations on all units were made of the various health care personnel, i.e. nurses, physicians and ancillary health care personnel providing chest related services on the various shifts for each unit. These naturalistic observations initially focused on the types of interactions between and among health care personnel and their clients. Attempts were made to record the frequency and length of staff contacts with clients while in the unit's corridor, nurses station and nurses conference room. Observations were additionally made to assess the overall climate of the unit as perceived by the researcher and corroborated by the subjects, which included the identification of any underlying climate variables that might impinge on the study. This was the original plan of observations. This plan was eventually modified because of the difficulty experienced by the researcher in trying to accurately record the frequency and length of staff contacts with patients. This aspect of the observations was deleted, and observations of the hospital's staff activities on the
clinical units was expanded to incorporate the taking of field notes and memos on staff members' comments about their unit, its atmosphere, including personnel relationships, client population, client prognoses, client social values/characteristics and nursing care. (These comments were verbalized in the nurses station and nurses conference room during change of shift reports, medical rounds and coffee breaks.) Comments expressed by staff members about patients were expressed either preceding or following client contact. Field notations were also made of any observed patterns associated with client contacts such as the performance of certain behaviors or mannerisms before responding to a patient's call-light or a question/concern by a patient's family member.

Sixteen nurses working on two medical clinical units were interviewed. Eight nurses working on each unit participated in the study. All subjects were contacted by the researcher and all interviews took place within the hospital setting with the exception of one and were researcher-administered. Interviews were scheduled by appointment and were conducted, on scheduled workdays, pre and post shift or during lunch and dinner breaks. The interview varied in length from 30 to 60 minutes.

All R.N.s working on Unit A cared for terminally ill clients assigned to their unit and qualified as potential
participants for the study. These nurses willingly offered to participate in the study, if determined eligible, with the exception of two nurses (one full-time nurse who had recently returned to work after being on an extended sick leave and one part-time nurse whose work schedule varied from 16 to 24 hours per week). Only eight nurses employed on Unit B actually cared for terminally ill clients and therefore qualified as potential participants for the study. All eligible nurses employed on Unit B willingly offered to be in the study. (Unit B, unlike Unit A, was very selective in assigning nurses, particularly on the 7:00 - 3:00 and 3:00 - 11:00 shifts to care for terminally ill clients.)

The interviewer read a cover letter to all subjects to reintroduce the researcher and the purpose of the study (refer to Appendix A) and a consent script which requested their verbal permission to participate in the study and tape the interview (refer to Appendix B).

**Instrumentation**

All data were collected using a semi-structured interview schedule developed by the researcher, which required a one time face-to-face audiotaped interview (see Appendix C-- Interview Script). Questions in this schedule asked subjects to rank order ten social values (characteristics) twice. The first rank ordering of social characteristics by the nurses was based on the nurse's
professional life. While the second rank ordering by nurses was based on the nurse's knowledge and perceptions of a specific terminally ill client cared for by the nurse, the specific client's social characteristics and the significance of these characteristics to the client. Nurse-subjects were requested to select one client that the nurse was either presently providing care for or had cared for within the past seven days for two or more shifts. The nurse was asked to use the information gained from interactions with the client, the client's family and significant others in rank ordering the ten social characteristics. The nurse was also requested not to disclose the client's identity, thereby maintaining the client's anonymity. After rank ordering the social characteristics, nurses were then asked to assign numerical estimates (ranging from one to ten) which represented the client's social loss to family, occupation and society using a modified version of the Cantril Self Anchoring Scale (see Appendix D).

After assigning numerical estimates, nurses were then asked to share their rationales for each numerical score assigned and to discuss whether they felt the clients' social characteristics and potential losses to family occupation and society influenced the nursing care (physical and psychosocial care) rendered to this client. Before
concluding the interview, all nurse-subjects were requested to respond to a series of demographic questions pertaining to their age, ethnicity, religion, nursing education and nursing experience. Questions on the interview schedule were developed based on a review of the literature in the area of social loss and the pilot study conducted two months prior to the investigation.

**Data Analysis**

Data analysis began upon completion of the first interview and became an ongoing process until the study's completion. Responses to each item on the instrument were individually evaluated and descriptive statistics (i.e. mean, median and mode), in addition to Q sort and grounded theory methodology (i.e. constant comparative methodology and triangulation), were used to analyze numerical estimates of social loss, social characteristic/value rankings, and demographic data. Constant comparative methodology which included memoing and coding of data was used to identify the major themes among the various data sets with the goal of generating a plausible theory of social loss. Finally, triangulation strategies were used to assist in establishing the reliability and validity of the research findings (Denzin, 1970). Triangulation among data sources was used to examine and compare the data from ethnographic observations, the review of the literature and the semi-
structured interview. Triangulation within and among the
data was used in determining the reliability and validity of
the data gained from the semi-structured interviews
(numerical social loss scores and the rationales supporting
the assignment of social loss scores).

**Reliability and Validity**

Content validity of the structured interview schedule
developed by the researcher was established by a panel of
four nurse experts: one hospice nurse-coordinator with
greater than 20 years of nursing experience, one certified
oncology head nurse with 12 years of oncology nursing
experience, one oncology nurse researcher with 17 years of
oncology nursing experience and one nurse educator/clinician
specializing in the care of chronically ill clients with 16
years of clinical experience.

The structured interview schedule was also piloted with
four staff nurses employed by government and public
hospitals two months prior to data collection. Each of
these nurses had 10 - 15 years of experience as staff
nurses. The comments by the panel of nurse experts, along
with those of the four staff nurses in the pilot study, were
incorporated in the final form of the research instrument.
The collective comments of theses nurses necessitated only
minor revisions in the research questions in order to
enhance their clarity. The researcher also decided to do
face-to-face interviews with the nurse subjects to further ensure uniformity in interpreting research questions.

Ethnographic field notations were used to assist the researcher in validating the findings gained from the structured interview schedule, as well as validating the findings cited in the literature. Another function of the field notes was to assist the researcher in establishing and describing unit climate variables. Data gained from interviews and observations were used to establish validity and reliability through triangulating research strategies.

The Cantril (1965) Self Anchoring Scale has been used to obtain overall measures of the "reality world" that people live in, as expressed by people in their own terms. According to Cantril (1965, p. 15), people are what their loyalties are: loyalties to a family, class, neighborhood, religion or, more realistically, a combination of many of these and others help to form the individuals' reality world. Cantril believed that an accurate appraisal of one's reality world could not be assessed by forcing an individual to make choices between categories, alternatives, symbols or situations and, therefore, devised the Self Anchoring Scale. This scale serves as a means for tapping the unique reality worlds of individuals and learning the commonalities shared by individuals. The assigned ratings are rooted in the subject's reality world. The rating process entailed the
discovery of the spectrum of values the subject had as well as the means by which the subject evaluated his\her life.

Data from interviews using this tool have been collected on approximately 20,000 people from more than 13 countries, including the United States, over a 6 year period. Cantril (1965, p. 27) reports an interrater reliability among coders of 95 per cent. Prior to conducting international studies, Cantril determined the validity of his instrument by interviewing 3,000 subjects from around the world. He strongly emphasizes that the ratings assigned by subjects are entirely subjective. A rating of 5 given by one subject does not necessarily indicate the same thing/things as a rating of 5 given by another subject. All ratings are anchored within an individual's own reality world and the anchoring points are entirely personal. Cantril has divided the ratings into three groups, low (Steps 0,1,2,3); middle (Steps 4,5,6); and high (Steps 7,8,9,10) [see Appendix E].

**Protection of Human Subjects**

The study was approved by the Institutional Review Board of Loyola University of Chicago prior to its initiation. Approval for this study, involving human subjects, was also obtained from the university affiliated hospital's Nursing Research Committee and Institutional Review Board.
All subjects were informed that their participation in the study was strictly voluntary and that they could withdraw without consequences at any time. They were also told that no risks or injuries were associated with the study and that they had the right not to answer any questions that may seem problematic or difficult to them. All respondents were also informed that confidentiality and anonymity would be maintained throughout the investigation and that all taped interviews would be erased at the conclusion of the study. Finally, after reading the informed consent, each subject was asked to verbally consent to participation in the study.
CHAPTER IV

RESULTS

This chapter analyzes the study's data. Several tests were used to determine the possible significance of the data from the 16 nurses interviewed. Spearman's rank order correlations were used to ascertain the relationships between the various social characteristics based on the Q sort values assigned by nurses first for themselves and, secondly, for their terminally ill patients. Pearson product moment correlations were also used to determine the relationships between nurse subjects first and their terminally ill clients, secondly, based on Q sort values assigned by nurses. Descriptive statistics and constant comparative methodology were used, additionally, to analyze the rank orderings of social values and numerical estimates of "social loss". Descriptive statistics and constant comparative methodology were, moreover, used to identify major themes within the study.

A description of the subject's background (demographic) characteristics will be presented first, followed by a description of their terminally ill clients' clinical characteristics. Then, findings related to each research question will be presented.
**Background Characteristics of Nurse Subjects**

The background characteristics of the nurse subjects included demographic variables which are given in Table I. All sixteen nurse-subjects were female with a mean of 8.2 years of professional nursing experience (nursing experience ranged from 8 months to 35 years) and a standard deviation (SD) of 5.07 years. Seven nurses (44%) had bachelor's of science degrees in nursing (BSN); five (31%) had associate degrees in nursing (ADN); while four (25%) had diplomas in nursing.

The ages of the nurse subjects ranged from 26 to 57 years, with a mean age of 37.4 years (SD = 9.6 years). The mean ages of nurse subjects by nursing degrees was as follows: BSN's ages ranged from 26 to 48 years with a mean age of 35 years (SD = 9.2 years); the ages of ADN's ranged from 29 to 43 years with a mean age of 38 years (SD = 5 years) and the mean age of diploma nurses was 42 years (SD = 12.09 years) with ages ranging from 28 to 57 years.

Sixty percent (3 out of 5) of the nurses in the 37 - 47 year age range had previous nursing experience as licensed practical nurses (LPN's) ranging from 6 to 18 years before becoming registered professional nurses (RN's). All subjects in the 47 - 57 year age range had prior nursing experience as diploma nurses; only 1 nurse out of 3 had returned to school to obtain a B. S. N. The average years
of nursing experience by nursing degrees was 19.7 years for diploma nurses, 5.55 years for BSN's and 2.86 years for ADN's.

The majority of the nurses (56%) were single; 38% were married, while only 1 nurse-subject was divorced. The ethnicity of the nurses can be described as predominantly African-American (81%) and 19% other (1 Filipino, 1 Caucasian and 1 Haitian). All subjects reported affiliations with a religious faith.

Table 1

Background Characteristics of Subjects

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>(n=8)</th>
<th>(n=5)</th>
<th>(n=3)</th>
<th>TOTAL</th>
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<td></td>
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</tr>
<tr>
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<td>6</td>
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<td>Divorced</td>
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<td>0</td>
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<td>1</td>
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<tr>
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<td>0</td>
<td>2</td>
<td>4</td>
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<td>3</td>
<td>0</td>
<td>5</td>
</tr>
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<td>7</td>
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<td>Range</td>
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<td>12 - 144</td>
<td>144 - 420</td>
<td>8 - 420</td>
</tr>
</tbody>
</table>

The mean number of years employed on their present units (units A and B) was 4.8 years and the mean years caring for
terminally ill clients was 9.09 years. Eight nurses predominantly worked the day shift (7 a.m.- 3:30 p.m.); six nurses worked the afternoon shift (3 p.m.- 11:30 p.m.); and two nurses worked permanent nights (11 p.m. - 7 a.m.).

**Clinical Characteristics of Terminally-Ill Clients**

The ages of the sixteen terminally-ill clients ranged from 28 to 63 years with an average age of 42.2 years (SD = 10.32 years). Seven clients were seropositive for the human immunodeficiency virus (HIV+). HIV is a member of the sub-family of retroviruses that cause chronic slow developing infections which attack the nervous system (Greene, 1991). HIV, according to the Center for Disease Control, is becoming a chronic condition (Center for Disease Control and Prevention, 1994).

Seven clients had end stage renal failure (ESRD). ESRD is a chronic condition which is associated with the toxic accumulation of nitrogenous waste products within the body due to kidney failure (Diseases, 1993). Five of the 7 clients had primary diagnoses of renal disease; while two of these clients had primary diagnoses of systemic lupus erythematosus. Systemic lupus is a chronic inflammatory connective tissue disorder that affects multiple organ systems (Diseases, 1993).

One client had a history of chronic asthma prior to receiving a terminal prognosis because of anoxic
encephalopathy which is responsible for an inadequate oxygen supply to the brain (Diseases, 1993). While the last client had a history of chronic alcoholism which led to the client's terminal diagnosis/prognosis of hepatic encephalopathy (a chronic liver condition associated with ammonia intoxication of the brain and coma). Nurse-subjects minimally cared for the aforementioned terminally-ill clients 2 days (16 hours); however, the mean length of time of providing nursing care was 5 days (40 hours). Some nurses reported caring for these clients off and on for as many as 3 years.

**Research Question 1**

When you think about your own professional life, how would you prioritize these ten social characteristics (religion, social class status [social economic status], family status [biologic family], race/ethnicity, talents [i.e. singing and dancing], accomplishments [achievements], education, occupation, personality [friendly and open versus cold and distant] and insurance protection?

The nurses' mean rank orders for the 10 social characteristics from most to least important revealed the following sequence of importance for the social characteristics: education, personality, religion, occupation, family, accomplishment, race, insurance, talents
and social class. The mean scores and standard deviations for all social characteristics are given in Table II.

It is interesting to note that only 31% (5 out of 16) nurses rated "education" as either the first or second most important social characteristic; while 50% (8 out of 16) of the nurse-subjects rated "religion" as either the first or second most important social characteristic, and 43% (7 out of 16) of the nurses rated "family" as either the first or second most important social characteristic.

No subjects rated "education" as being least important. Rank order assignments for "education" ranged between 1 and 6; whereas rank order assignments for "family" ranged between 1 and 10; and those for "religion" ranged between 1 and 8. Constant comparison of nurses' responses point out that 3 out of 4 nurses choosing "religion" as the most important social characteristic were assigned to unit A; while 4 out of the 5 nurses choosing "family" as the most important social characteristic were assigned to unit B. Spearman's rank correlation coefficients for the nurses Q sort values concluded that statistically significant relationships existed between rank order assignments given by nurses for the following combinations of social characteristics: "race and talents", "race and accomplishments", "race and insurance", "race and family", "social class and insurance", "talents and insurance", "...
"accomplishment and insurance", "accomplishment and education", "personality and occupation", "personality and family" and "family and religion" (refer to Table III).

It is important to note that the majority of the social characteristics (6 out of 10) demonstrated multiple statistically significant correlations; while only one single statically significant relationship could be found for 4 social characteristics (social class, occupation, education and religion). It should furthermore be noted that all correlations among the various social characteristics were positive, and they ranged from 0.35 - 0.90 (see Table III).

Q sort rank order correlations for the 10 social characteristics by nurses are listed in Table III. Intercorrelations among nurse-subjects based on their individual rank orderings for the 10 social values using Pearson's product moment correlation coefficient demonstrated statistically significant relationships (8 degrees of freedom [d.f.], probability [p]=0.01) among 12 nurse-pairs. The majority of the relationships, 8 out of the 12 nurse-pairs (67%), existed among nurse subjects assigned to the same unit. Among nurses working on the same unit, 3 nurse-pairs (37.5%) were permanently assigned to work the same nursing shift while the remaining 5 nurse-pairs (62.5%) occasionally worked the same shift (nurses
assigned to the 7 - 3:30 shift periodically rotate to the 3 - 11:30 and 11 - 7 shifts). This finding suggests that social relationships on clinical units may significantly impact the beliefs and behaviors of nurses. Triangulation of the aforementioned finding with the review of the literature serves to confirm the validity of the impact social relationships have upon the beliefs and behaviors among nurses working on the same clinical unit (Lerea & LiMauro, 1982; Pine, 1972; Stoller, 1980a).

Significant correlations were also found to exist between foreign-born nurses and nurses completing their nursing education outside of the United States. Intercorrelations also existed for 4 nurse-pairs assigned to opposite units (one nurse member worked on unit A while the other nurse member worked on unit B). Comparisons between each individual nurse member making up the 4 nurse-pairs, revealed a history of recent employment on their respective units which ranged between 8 and 15 months. This may suggest that time, particularly the length of time it takes to establish social relationships, also impacts the cohesiveness of nurses' beliefs and behaviors. Pearson's product moment correlations for the various nurse-pairs ranged between -0.60 and 0.94. The majority of Pearson's correlations were positive (66%); negative correlations were primarily found to exist between nurses employed on opposite
Research Question 2

How would you prioritize these same 10 social characteristics for a client you're presently caring for, between the ages of 20 - 60, who has a terminal (end stage) non-cancerous life threatening condition that's not expected to live beyond 6 to 12 months?

Ninety-three percent (15 out of 16) nurse-subjects responded to this question. One nurse felt her knowledge of the client and the client's social characteristics was insufficient to respond to this question. The mean rank orders of the 10 social characteristics by the 15 nurses for their terminally ill clients, from most to least important, revealed the following sequence of importance for the social characteristics: family, personality, religion, race, accomplishment, social class, occupation, education, talents and insurance. The mean scores and standard deviations for the 10 client social characteristics are listed in Table V.

Comparisons of the nurses' responses for their terminally ill clients revealed that clients on unit A, based on the perception of their nurses, had no dominant preference for any of the 10 social characteristics. Rank orders for 6 out of 8 nurses on unit A were evenly dispersed between 3 social characteristics (family, religion and
personality). While comparisons of unit B nurses' rank orders for their clients revealed that 5 out of 7 nurses rated "family" as the client's most important social characteristic.

Spearman's rank correlation coefficient for the 15 Q sort values, by nurses for their clients, concluded that statistically significant relationships (8 d.f., p=0.01) existed for the following pairs of social characteristics: "race and social class", "race and personality", "race and religion", "social class and talent", "social class and accomplishment", "social class and insurance", "social class and occupation", "social class and personality", "accomplishment and insurance", "accomplishment and occupation", "accomplishment and education", "accomplishment and religion", "insurance and education", "insurance and religion", "occupation and education", "occupation and religion", "personality and family", "personality and religion", "education and religion", "family and religion". It is important to note that each of the 10 social characteristics positively correlated with at least 2 other social characteristics (refer to Table VI). This finding, when compared to the Q sort values for nurses, reveals that the perception of the population of terminally ill clients on units A and B are more diverse than the nursing staff caring for them.
Intercorrelations among the nurses rank orders for terminally ill clients using Pearson's product moment correlation coefficient demonstrated statistically significant relationships (14 d.f., p=0.01) for clients cared for by 2 nurse-pairs. Nurse members making up these 2 nurse-pairs were employed on opposite units. Nurse members making up 1 nurse-pair had recently cared for terminally ill HIV+ clients. While nurse members in the second nurse-pair had recently cared for terminally ill clients with dissimilar diagnoses (end stage renal disease and HIV). This finding further attests to the diversity of the terminally ill patients cared for by nurses on both units (only 4 patients out of 16 had Q sort values that demonstrated significant correlations, refer to Table VII). Pearson's correlations ranged from -0.82 to 0.84. The majority (75%) of the correlations between terminally ill clients were positive. Negative correlations were primarily found to exist between clients on opposite units.

**Research Question 3**

When you consider all of the potential losses associated with this client, what numerical value between 1 and 10, if one represents the lowest value that could be assigned and ten represents the highest value, would you assign to this client based on the client's potential losses to family and significant others, job related contributions
to society, and non-job related civic/social contributions to society?

Numerical scores assigned by nurses based on their client's potential losses to family and significant others ranged from 4 - 10. Eleven out of the 16 responses were placed on the uppermost rung of the Cantril's ladder (steps 8, 9, and 10); indicating significant losses to family and significant others. The remaining 5 responses were in the middle rungs of the Cantril's ladder (steps 4, 5, 6, and 7); indicating moderate losses to family and significant others. No potential client losses were placed on the lower rungs of the ladder (steps 3, 2, or 1). Hence, none of the clients potentially represented minimal losses to family and significant others.

It is important to note that in every instance where nurses deemed their clients represented significant losses (scores 8 - 10), they stated their client was either a sibling, parent or child; their decision was based on the volume of phone calls, cards, flowers, visits by family members and significant others, and conversations with the client and/or the client's family. Nurses assigning moderate numerical loss values (between 4 - 7) to their clients verbalized they had minimal to no familial contact with their client's family. They perceived, in several instances, that the client's family and significant others
took advantage of the client (i.e. financially or physically, because of the assistance offered by the client in the care of small children).

Only 31% (5 out of 16) nurses were aware of the job related contributions made by their clients. Numerical values based on the client's job related potential loss ranged from 5 - 9. Three clients were assigned significant loss scores (8 - 10); these clients worked as a nurse, hair stylist and political pollster. Clients with numerical job related loss scores in the moderate range (between 5 - 7), included one minister and one patient who held several odd jobs as a painter and automotive repairman.

Only 18% (3 out of 16) of the nurses were knowledgeable of their client's non-job related/civic contributions. All numerical loss scores given for clients based on civic activities were within the moderate loss range between 4 - 6.

**Research Question 4**

Tell me some of the potential losses associated with this client?

Responses given by nurses to this question can be divided into two categories: potential losses to family and significant others, and potential losses to the client. Some of the potential losses to family and significant others cited by nurse-subjects included the loss of parents,
siblings, family members, good friends, supportive and helpful individuals, and experts within a profession. Potential losses associated with the respective client included the client's eventual loss of finances, control over one's life and one's environment.

**Research Question 5**

Describe the client's nursing care, i.e. physical and psychosocial?

Forty-three percent (7 of 16) of the nurses stated their clients required complete nursing care; in other words, these client were totally dependent upon nurses for their physical care and well being. Thirty-seven percent (6 of 16) of the nurses stated their clients required assistance; stated differently, these clients partially participated in their self care regimens by bathing, feeding, dressing and ambulating themselves. While 18% (3 of 16) nurses were assigned to clients who independently performed their care regimens.

Psychosocially, clients receiving complete nursing care were perceived as withdrawn, depressed and non-responsive; pain control was considered a major client problem. Nurses caring for these patients often gave their family members emotional support. Clients who were able to assist with their care regimens were perceived as withdrawn, suicidal, demanding, defensive, distrusting, helpless and unmotivated.
These clients were considered to be very time consuming because of their experience of pain, weakness, loss of self esteem and anger over the loss of control over their lives, bodily functions and environment (several needed blood and body fluids or protective isolation which required use of protective garments such as gown, gloves and mask).

It is interesting to note that most nurses verbalized several distinctions between male and female terminally ill clients. Female clients were considered helpless, suicidal, not energetic, unmotivated and withdrawn. Nurses felt that females needed frequent and much encouragement; whereas male clients were considered demanding, defensive, distrusting and occasionally withdrawn. Nurses felt most of their time was spent providing emotional support for male clients as opposed to providing physical care because their male clients desired complete control over their activities of daily living while hospitalized. Nurses caring for the self care terminally ill clients also stated they required much psychosocial care because of protective isolation and frequent episodes of nausea and vomiting. Nurses additionally, perceived these clients as being depressed, defensive, non-compliant, manipulative and verbally abusive. Nurses also stated they feared these clients.
Overall, clients requiring complete care were considered physically demanding because of their debilitated states, and nurses felt compelled to offer emotional support to their family members. Whereas clients who either required assistance with their care or were independent in administering self care were not seen as physically demanding, but were instead viewed as psychosocially demanding. Nurses offered these clients, as opposed to their family members, much support and encouragement. Recurrent themes for these clients were protective isolation, depression and non-compliance.

Research Question 6

Considering the scores you have assigned to this client, based on the client's meaning to family and significant others, job related and non-job related contributions to society, how has the client's nursing care been influenced by these scores?

Eighty-one percent of the nurses (13 of 16) stated that the client's numerical social loss score had no influence on the client's nursing care. Four of the 13 nurses also added that alterations in the client's care were made because of the client's family. Overall, these 13 nurses felt that alterations in their nursing care were based on patient diagnoses, treatments, needs, assessments and the patient's knowledge of the terminal disease entity and its treatment.
These nurses, moreover, stated that they sometimes gave their terminally ill clients special or additional care and attention if they felt these measures would make their clients "happy" or as an outward show of their "religious beliefs".

The remaining 3 nurses responding to this question stated their numerical scores were influenced by the client's personality and the client's family, particularly the family's involvement in the client's care, frequency of visits and degree of closeness to the client. Overall, it can be concluded from these responses that patient care alterations were based on the client's family, personality, education, (i.e. knowledge of the client's terminal disease entity and its treatment) and nurses' religious beliefs.
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TAL = TALENT      ED = EDUCATION
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INS = INSURANCE   REL = RELIGION
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Intercorrelations Among Nurse Subjects

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df = 14  *p = 0.01
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Nurses Mean Social Characteristics Rank Orders for Their Terminally Ill Clients

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TAL = TALENT  
ACC = ACCOMPLISHMENT  
INS = INSURANCE  
OCC = OCCUPATION  
PER = PERSONALITY  
ED = EDUCATION  
FAM = FAMILY  
REL = RELIGION

df = 8  
*p = 0.01
Table 7

Intercorrelations Among Nurses' Terminally Ill Clients

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CHAPTER V
DISCUSSION

This chapter includes a summary of the major findings, a discussion of the results, limitations, and implications for nursing with suggestions for future research.

Summary of Major Findings

The purpose of this investigation was to explore and examine the impact of social loss on the behavior of professional nurses caring for terminally ill hospitalized clients with non-malignant disease entities in young to middle adulthood.

All nurses willingly assigned numerical social loss values to their clients. High numerical social loss scores, between 8 to 10, were assigned by 69% of the nurse-subjects; while 31% of the nurse-subjects assigned middle (average) range scores between 4 and 7. No clients were assigned low numerical social loss scores. Nurses' justifications for the assignment of numerical social loss scores always incorporated the client's family. Their scores were influenced by visits and phone calls from family and significant others as well as tangible evidence of familial
support within the patient's hospital environment such as cards, flowers, pictures and posters.

Clients receiving complete nursing care were considered physically demanding by their nurses, while clients who were able to provide their own personal care independently were viewed as psychosocially taxing. Distinct differences between terminally ill male and female clients were reported by their nurses. Male clients were perceived as more demanding in their mannerisms; while female clients were viewed as helpless and unmotivated.

It is significant to note that all dependent clients (n=7) were recipients of complete nursing care, had frequent close contact with family members, and were assigned high social loss scores. In contrast, all independent clients rendering self care (n=3) received middle range social loss scores. Independent clients had minimal familial closeness (contact) based on visitations and phone calls from family members and significant others when compared to dependent clients.

Thirty-seven percent (n=6) of the clients received assistance with their personal care from nurses. Of these clients, 4 received high social loss scores. Consistent themes expressed by nurses regarding these clients were "helplessness, disability and frequent close familial contact". Nurses perceived these clients as helpless
because of partial loss of sight (i.e. blind in one eye), inability to walk or inability to talk. The two remaining partially dependent clients were given social loss ratings in the middle range category (indicating average or moderate social loss). Nurses perceived these clients as either "suicidal" or "unmotivated". Nurses verbalized that the family members of these clients were rarely seen by nurses.

Ninety-four percent (n=15) of the nurses felt they knew their clients well enough to prioritize the 10 social characteristics. Q sorts of the 10 social characteristics, using Spearman's correlation, revealed that nurses rated "education" as the most important social characteristic for themselves, while "family" was the most important social characteristic by nurses' for their terminally ill clients.

Q sorts of the 10 social characteristics assigned by each of the 16 nurse subjects for themselves revealed significant correlations between nurses employed on the same clinical units, especially among nurses working on the same shift. Significant correlations were also found to exist between foreign-born nurses and nurses completing their professional nursing education outside of the United States. This finding tends to suggest the existence and profound impact of outside sociocultural forces.

All clients experienced problems in the areas of communications, symptom control, and treatment modalities.
Communication problems ranged from non-responsiveness to verbal abusiveness. Complete care clients were more likely to be non-communicative while independent clients were more likely to be perceived as verbally abusive.

Patients additionally experienced problems with symptoms such as pain, nausea and vomiting and treatments which included protective isolation. Nurses also reported that knowledge of the client's job-related contributions and non-job related civic contributions influenced the voluntary performance of services by nurses such as watering plants, arranging cards and flowers, special nail and hair care.

**Discussion**

These findings suggest that physically taxing dependent clients with frequent familial contact are more likely to receive higher social loss scores than psychosocially taxing clients who lack frequent familial contact. These findings, moreover, indicate that only 5 out of 16 clients (31%) were known to be employed by their nurses; while only 3 out of 16 nurses (18%) were knowledgeable of their clients civic activities. It's interesting to note that most nurses felt that the majority of their terminally ill clients were unemployed and lacked any involvement with civic organizations because of their longstanding disabilities associated with their chronic disease. However, the study's
findings did point out that nurses willingly performed volunteer activities for clients with recent histories (within the past year) of employment or civic activities. Variables cited in the literature such as nurse-patient relationships, the social organization of the hospital, particularly patient care units, and the client's age (Pine, 1972; Stoller, 1980b; Lerea & LiMauro, 1982 and Wilkinson, 1991) were also found to significantly influence the assignment of social loss scores on the nurses' emotional status in this investigation.

**Family Status and Expressive Behaviors**

Given the aforementioned, familial contact and expressive behaviors were the primary influencers in the interpretation of social loss in this study. The data support the existence of a positive correlation between clients, who were both psychosocially impaired (non-communicative) and partially to totally dependent upon nurses with frequent close familial support, and the assignment of high social loss ratings. Clients assigned high social loss scores were, in several instances, no closer to death than those clients assigned moderate social loss ratings. Nurses assigning high social loss scores to their clients additionally admitted to altering the delivery
of their nursing care to either include or exclude the client's family based on the family's preference.

Additionally, a negative correlation was found to exist between the assignment of high social loss scores and clients who were independent with their personal care, with minimal to no familial contact. The data, moreover, suggest that nurses experience difficulties in "expressive behaviors" or psychosocial communications with their independent terminally ill clients, particularly those experiencing frustration, disappointment and anger which results in the patient's lack of adherence to their prescribed treatment regimen.

It is interesting to note that "non-communicative patients" with terminal conditions 20 years ago, according to Glaser and Strauss (1964), Kalish (1966), Pine (1972), Quint (1966), and Sudnow (1967), were perceived and labeled as "socially dead" by medical personnel. This finding, however, was not supported by this research. The findings of this study suggest that terminally ill, non-communicative clients would have been labeled "socially dead" and perceived as having little to no social significance to society, if the present study had been conducted 20 years ago. This finding furthermore suggests that a positive relationship may exist between the interpretation of social values and health care values. Additionally, the findings
indicate that the relationship between nurse providers and their patients is a complex one that leads to a series of other questions. An example of one such question pertains to the relationship between nurses' skills and their assignments of social loss values. Do nurses assign higher ratings of social loss to terminally ill non-communicative and partially to totally dependent clients because they feel more proficient when it comes to "instrumental behaviors" or "task oriented skills" as opposed to "expressive behaviors" or "psychosocial skills"? This investigation was unable to answer this question; hence, further exploration is needed. Traditionally, nursing education and nursing practice has placed greater emphasis on the development and skillful execution of psychomotor skills more so than psychosocial communication skills. Psychosocial communications, in general, is considered an integral component of nursing education, especially at the baccalaureate level, and nursing practice. However, psychosocial communications have in the past been perceived as an area associated with "non-accountability", according to Strauss, Glaser and Quint (1964). Members of the medical community, particularly physicians and nurses, assume accountability for their clients' response to medical procedures and therapies and reflect such by means of written documentation. However, they infrequently demonstrate this same level of
accountability for their psychosocial dialogues with patients, including patient education. Another question which can also be raised as a result of this research pertains to the quality and meaning of relationships established by nurses. Is the relationship between nurses and terminally ill clients of greater, equal or lesser importance than the relationship between nurses and the family members of terminally ill clients? If the relationship between nurses and the family members of terminally ill clients is of equal or greater importance when compared to relationships between nurses and terminally ill patients, then can it be said that the family, and not the patient, is the unit of care? If the family is the true unit of care, in terminal illness care, then Gulla's (1991) recommendation regarding the incorporation of family level assessments during the admission of terminally ill clients in health care facilities would be of benefit because emphasis would be placed on the assessment of family needs, instead of patient needs solely. The "client's family" should be perceived as an integral part of healthcare according to the Joint Commission on Accreditation of Healthcare Organization (JCAHO, 1994). According to JCAHO (1994), improvements in the health status of patients are enhanced when the patient, his/her family and natural
support system are included in the development and implementation of the patient's therapeutic care plan.

The review of the literature and the findings of this investigation also revealed that variables such as client's age, nurse-patient relationships and social organizations significantly influenced the assignment of patient social loss scores.

**Age**

Age at first did not appear to be a crucial variable, since all clients assigned social loss scores by their nurses were in young to middle adulthood. However, it is this researcher's observation that during face-to-face interviews with nurses, greater emotions were evoked when clients aged 47 or less were discussed in comparison to clients aged 50 and over. The researcher specifically observed more body language or physical changes in nurses' composure, such as the use of more hand and facial gestures as well as variations in their voice tones, when discussing clients aged 47 or less. The findings from Glaser's (1966) study revealed that aged clients were exempt from low social loss scores if their family members expressed significant concern and interest and visited frequently. Glaser, however, fails to mention the age range of the clients he refers to as "aged"; hence, this investigation is unable to
support or refute his finding. Thus, based on this investigation, Glaser's findings can be expanded to include young to middle aged non-communicative adults as being exempt from assignments of low social loss scores.

**Education**

Nurses rated education as the most important social characteristic for themselves. However, nurses did not rate education as the important social characteristic for their clients. Nurses, instead, rated "family" as the most important social characteristic for their terminally ill clients. Overall, nurses felt that the client's education was of importance if the client could express a significant breadth of knowledge regarding his/her terminal disease entity and their treatment. This fact served to impact the nurse's delivery of nursing care. In this instance, it seems as though nurses perceive the client's base of social support as more crucial to the client's well-being than education.

**Nurse Patient Relationships**

Several nurses verbalized personal biases against clients whose terminal status was associated with a history of alcohol and substance abuse, as well as sexual promiscuity and homosexuality. Examples of comments made by
these nurses were: "I am usually very negative when I think of people like this and how they have messed up their lives; it angers me initially and you don't want to care for the patient when you hear how the patient's life has been destroyed; persons like my client have contributed very little to society". These nurses, however, also verbalized that observations of the family's willingness to support their loved one or to assist nurses in caring for their relative somehow aided them in resolving or minimizing their negative perceptions toward the client.

Nurses, moreover, verbalized that terminally ill clients and their relatives looked to nurses for guidance, support and explanations, more so than physicians. The study further revealed that nurses served in various roles ranging from "professional care providers to professional friends" based on their patient relationships, specifically the degree of closeness to their patients. This finding supports that of Trygstad (1986) which states that some nurses serve in duo capacities as care providers and professional friends to clients they have special relationships with.

**Social Organization**

Naturalistic observations of both clinical units assisted the researcher in establishing several perceptions
about the social organization of each unit. Nurses on both units routinely assessed and evaluated their terminally ill clients because they felt these clients rarely used their call lights or made requests for help. Staff relations on Unit A appeared to be close and friendly on all three shifts while relations on Unit B seemed "cliquish". Divisions were perceived to exist among staff members. Personnel working evenings and nights on Unit B felt that personnel working days received preferential treatment and greater respect from nursing administration. Additionally, new nurses (those recently out of school with less than 2 years of professional experience whose primary shift was days, i.e. worked 2 months on day shift and 2 - 4 weeks on evening or night shifts), felt "isolated or left out" when rotated to evenings or nights on Unit B.

It is also worth noting that the review of the literature indicated differences in social loss ratings among nurses employed in private and public hospitals (Pine, 1972). This fact was consistent with the researcher's findings. Nurses participating in the pilot study were all employed in public hospitals and social loss scores assigned by them for their terminally ill clients ranged from 1 to 3 in the "low social loss" range; while nurses employed in the private hospital used for this investigation assigned social
loss scores in the middle to high social loss range (4 to 10). No clients were assigned low social loss scores.

**Limitations**

The limitations associated with this study are primarily conceptual and methodological in nature. The conceptual framework used for this study is limited because the number of studies on the topic of social loss is not extensive. Considering this limitation, the author's intent was to provide an appraisal of the existing framework by investigating the impact of social loss on the behavior of nurses caring for terminally ill hospitalized clients.

The methodological limitations are related to the use of a small non-probability sample of 16 subjects, the utilization of one hospital setting, and the lack of control over the variables impacting the data collection process. The data for this study were solely collected from a convenience sample of 16 nurses working within one hospital setting. Given these parameters, the study can in no way provide a complete understanding of the impact of social loss on nurses' responses to terminally ill hospitalized clients. The use of a convenience sample, however, should not be entirely viewed as a limitation. Instead, the use of a convenience sample should be viewed as a means of ensuring that the data obtained have been gained from subjects having
knowledge of the care of terminally ill clients. According to Dempsey and Dempsey (1992), the goal of qualitative research is to provide meaning about specific events, situations and relationships and not generalizations. Because "social loss" remains a difficult and elusive concept, the study is incapable of yielding a precise measure of this concept. However, researchers utilizing qualitative research methods such as coding, categorizing and triangulation in their examinations of value laden concepts like "social loss", can and do assist in demonstrating the similarities and differences associated with these concepts (Polit & Hungler, 1991).

Additional limitations associated with the inability to control variables impacting the study within the naturalistic environment of the hospital were also encountered. Environmental variables associated with the hospital in general impacted the study's subjects. These variables included factors such as inadequate parking facilities, visitations to the city and surrounding hospital community by President George Bush, the media, and rumors of staff reductions. These factors periodically created preoccupation with safety and security issues among the hospital's employees that oftentimes led to postponement and rescheduling of interviews. Other factors which impacted
the collection of data included the researcher's inability to determine the number, diagnoses, and health status of terminally ill clients hospitalized during the time of the investigation; the amount and types of information shared between nursing personnel during change of shift report; and the inability to interact with and identify all of the various health disciplines entering the client's room. Knowledge of the aforementioned could have assisted the researcher in determining the existence of other terminally ill clients hospitalized on other units.

Further potential limitations associated with the study included the various social characteristics of the subjects, i.e. age, sex, ethnicity, and nursing education in addition to their feelings, thoughts and perceptions about the care of terminally ill clients. It should also be noted that the researcher made the assumption that responses by nurse-subjects were true reflections of their beliefs and feelings about themselves and their terminally ill clients.

**Implications for Nursing Practice**

The results of this study have several implications for nursing practice and nursing education. Efforts to promote death education in health professions training, particularly nursing education, are needed. Nurse educators need to incorporate didactic content pertaining to nurse-client and
nurse-family relationships, as well as family dynamics, and the emotional aspects of health care particularly terminal illness care, throughout the entire nursing curriculum.

Nurse educators should ensure the provision of clinical opportunities for all nursing majors to care for terminally ill clients (i.e. direct hands-on experiences as opposed to simulated clinical exercises prior to program completion). They should also facilitate the integration of concepts, such as family dynamics in students' care plans for terminally ill clients. Staff development personnel should likewise provide opportunities during the orientation phase of employment for new employees to care for terminally ill clients, as well as verbally and physically abusive clients. They should periodically provide skills development and enrichment opportunities for staff nurses in the areas of depression, defense mechanisms and manipulative behaviors.

Nurse administrators need to recognize the impact that staff cohesiveness may have on staff members' perceptions and behaviors; they moreover should consider examining the mix of personalities among staff members and provide opportunities for staff members consistently exposed to numerous patient losses (be they work losses, personal losses or social losses) to grieve and therapeutically vent their feelings and ethical concerns related to this care.
Nurse administrators should moreover explore the need for expanded pastoral care services/interventions for nursing personnel working in high patient loss areas (death and dying areas). Additionally, nurse administrators should explore the need for psychiatric support teams to assist/advise nurses caring for emotionally taxing clients.

**Recommendations for Future Research**

1. Examinations of terminal illness care which incorporate the client and the client's family as the "unit of care".

2. Examinations of terminal illness care which assess nurse-family relationships.

3. Examinations of nursing personnel caring for terminally ill clients which assess the professional skills (i.e. clinical and psychosocial nursing skills) of staff members.

4. Examination of nurses' beliefs and practices in the area of grief and bereavement.

5. Exploration of nurses' ethical concerns regarding terminal illness care.

6. Examinations of the impact of sudden unexpected deaths of chronically ill clients upon nurses.
Terminal Client and Family of Terminal Clients

Their social characteristics, contributions, job, and society.

Fig. 2. Refined Model of Social Loss
APPENDIX A

COVER LETTER

My name is Sandra Webb, and I am a registered nurse and a graduate student working on my dissertation at Loyola University of Chicago - Department of Educational Leadership and Policy Studies. I am studying "responses to terminally ill clients". I am not employed with any hospital at this time, but have had previous experience caring for terminally ill clients as a staff nurse. I became interested in this topic as a result of my past nursing experience. I feel, that the information obtained from this study will contribute to existing knowledge and beliefs about terminally ill patients.

I have several questions, I would like to ask your honest opinion on. There are no right or wrong answers to these questions. There are no risks associated with this investigation. You have the right not to answer any questions that may seem too problematic for you. The interview will be taped and should take about 30 minutes to complete. All tapes will be erased upon completion of the study.
Participation in the study is voluntary and you have the right to withdraw from the study without consequence. All information given by you will be treated confidentially throughout the entire study. All data will be pooled for analysis and your name will not be used in any publication or presentation as a result of this study.
APPENDIX B

VERBAL CONSENT SCRIPT

I have been informed that participation in this study is voluntary and that I have the right to withdraw from the study without consequence. I am also aware that I have the right not to answer any question that is too problematic for me. I, further realize that all information given by me will be treated confidentially throughout the entire study and in any future publications and presentations.

I have been informed that there are no risks associated with this investigation. I am aware that the study involves an interview that will take about 30 minutes to complete. I, furthermore realize that the interview will be recorded and that the tapes will be erased upon completion of the study.

I understand what's required of me and hereby give my consent to participate in this study. (State your name, today's date and the time.)
APPENDIX C

SCRIPT

Every individual possesses a unique set of social characteristics. These characteristics can range from age to physical attractiveness to mode of dress and to language/word usage. Some social characteristics like race/ethnicity and family status are inherited at birth. Other social characteristics like education and occupation, are acquired later in life.

1. When you think about your own professional life, how would you prioritize these ten social characteristics. [Handing subject 10 index cards, each with one of the following social characteristic written on it i.e. religion, social class status (social economic status), family status (biologic family), race/ethnicity, talents (i.e. singing and dancing), accomplishments (achievements), education and occupation, personality (friendly and open versus cold and distant) and insurance protection]?

In other words, how important are these social characteristics to you when you think about your professional work life, as a registered professional nurse at this hospital, on your assigned clinical unit?

There are no right or wrong answers to this question. I only want your opinion only. Please arrange the cards in
order from least to most important, placing the card with the least important social characteristic on top and continuing in this manner till the most important social characteristic is on the bottom. You can lay the cards on the table whenever you're done.

OPTIONAL ***

I'd like for you to think about what's really important to you in your work life e.g. as a professional nurse working on a clinical unit within this hospital and to organize these cards so that they reflect such. [The rank order of the cards (characteristics) will be repeated out loud for accuracy and recording purposes]. Thank you.

Now, I'd like for you to reflect on one of your clients you're presently caring for. This client needs to be someone between the ages of 20 to 64 who has been diagnosed with a terminal/end stage condition that's non-cancer related, i.e. a condition that is not associated with any form of malignancy. **A TERMINAL/END STAGE ILLNESS IS ANY LIFE THREATENING MEDICAL CONDITION IN WHICH THE CLIENT IS NOT EXPECTED TO LIVE BEYOND THE NEXT 6 TO 12 MONTHS UNLESS SOME HEROIC LIFE PRESERVING MEASURE IS TAKEN.**

Examples of acceptable end stage/terminal diagnoses, for this study include: liver conditions due to cirrhosis,
kidney conditions due to acute or chronic renal failure, lung conditions due to emphysema, heart conditions due to failure or severe burn wounds which cover a large portion of the body surface area. I don't want you to reveal the clients' identity to me; it's to remain anonymous.

LET ME KNOW WHEN YOU HAVE A CLIENT IN MIND. (PAUSE)

2. TELL ME THE CLIENT'S AGE AND DIAGNOSIS.

3. HOW LONG HAVE YOU CARED FOR THIS CLIENT?

4. Prioritize these same 10 social characteristics based on your knowledge of this client's life and the significance of these social characteristics for this client?

Take your time. Remember, there are no right or wrong answers. You may place the cards on the table when completed. (The ordering of the cards will be verbalized out loud for accuracy and recording purposes). Thank you.

5. Continue thinking about this client, but now in terms of the clients' meaning to family and significant others; job-related contributions to on society and non-job related contributions to society, i.e. civic/social? When you consider all of the potential losses associated with this client, what numerical value between one and ten, if one represents the lowest value that could be assigned and ten represents the highest value, would you assign to this client (pointing to the modified Cantril's ladder, running
my index finger up and down the ladder) based on the clients' potential loss to family and significant others?

(PAUSE)

Based on the client's job-related contributions to society?

(PAUSE)

Now, based on the client's non-job related civic/social contributions to society?

6. Tell me some of the potential losses associated with his client?

7. Describe for me, the client's nursing care, i.e. physical and psychosocial?

8. Considering the scores you have assigned to this client, based on the client's meaning to family and significant others; job-related and non-job-related contributions to society, how has the client's nursing care been influenced by these perceptions?

9. Is there anything else you would like to share with me?

We're almost finish, I just need to ask you some questions about yourself. Tell me your...

Year of birth.
Religion.
Ethnic group.

Marital status.

Name all of your nursing degrees and give the dates of completion.

Years of professional nursing experience.

Length of time employed on this unit.

Length of time, as a professional nurse, working with terminally ill clients.

Nursing shift normally worked.

Thanks much for your time and willingness to participate in this study.
Fig. 3. Modified Cantril's Self Anchoring Scale
APPENDIX D

SAMPLE SCHEDULE OF OBSERVATION FOR UNIT X
## APPENDIX D

### SAMPLE SCHEDULE OF OBSERVATION FOR UNIT X

**June-July, 1992**

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Total of 72 hours of observations, within 18 days for a six week period, based on a maximum of four hours each day.
REFERENCES CITED


The author, Sandra Marie Webb (Booker), was born in Chicago, Illinois.

In September, 1973, Ms. Webb entered The University of Illinois at the Medical Center, College of Nursing, receiving the degree of Bachelor of Science in Nursing in June, 1976. In September, 1978, she accepted her first position as a professional staff nurse at the University of Chicago Hospitals and Clinics, for the Department of Surgery initially and later for Wylers' Emergency Room. In March, 1978, she accepted her first community health/teaching position as a Teacher-Nurse, for the Chicago Board of Education.

In September, 1978, she was granted a health professions traineeship to return to the University of Illinois at the Medical Center to pursue graduate studies in nursing. She received the degree of Master of Science in Medical Surgical Nursing, from the Graduate College of Nursing at the University of Illinois Medical Center with a subspecialization in Nephrology and a minor in Health Professions Education in 1980.
Prior to graduate school completion, Ms. Webb was employed as a visiting (part-time) nurse by the Visiting Nurses' Association of Chicago from January, 1980 till September, 1984. Upon graduation from the University of Illinois, Graduate College of Nursing, she accepted a full time position at Chicago State University, where she was appointed Assistant Professor of Nursing in the College of Nursing in September, 1980. In August, 1985 she was elected to the Board of Directors for the National Black Nurses Association and served a three year term. In April, 1986, she was promoted to the rank of Associated Professor of Nursing and given tenure, in the College of Nursing at Chicago State University. She was elected and later appointed Acting Chairperson, 1991-92 and Chairperson of the College of Nursing, Chicago State University, Chicago, Illinois, 1992-93. Webb, in October, 1993, took a leave from Chicago State University and is serving as the Coordinator of the Chicago Public Schools Practical Nursing Program.

Webb's career has included employment as a Research Assistant for the University of Illinois at the Medical Center, College of Nursing, Department of Medical-Surgical Nursing and for the Westside Veterans Administration Hospital at the Medical Center from 1987 till 1988. Webb's published research includes an article written in conjunction with Powers, M. J. entitled, "Evaluation of Life Satisfaction and
Sexual Function In Female Patients Post Renal Transplant in the *Journal of Dialysis and Transplantation* 11 (6), 799-801 in 1982. She has also authored an "EKG Student Workbook" in *ERIC*, ed 261-171 in 1984. Her unpublished research includes two scholarly papers "Perspectives of a Death Education Community Health Practicum for Senior Level BSN Student," 1990, and "Perspectives of a Death Education Community Health Practicum for R.N.'s In a BSN Completion Program" in 1991.

Ms. Webb's other experiences in the area of research and creativity entail services as a consulting editor for the Journal of National Black Nurses' Association (JNBNA) since September 19, 1987; coordinator of Maryland Avenue Baptist Church-Hypertension Program, since 1985; Co-chairperson of the International Society on Hypertension in Blacks, Committee to Assist the Medically Indigent in U.S.A., 1988; and chairperson of the program committee for the American Heart Association of Metropolitan Chicago (AHA-MC) Hypertension Consortium, 1990-1992.

She has provided volunteer services for Meridian Hospice of Chicago from 1982 till 1990, as a volunteer nurse caring for terminally ill homebound clients, then as a nurse-coordinator from 1986-88, and lastly as a Board of Directors member from May, 1988 till May, 1990.

Ms. Webb's military career began as a commissioned 1st Lieutenant in the United States Army Reserves (USAR), Army Nurse Corps in February, 1985, assigned to the 395th Combat Support Hospital, Gary Indiana. She was promoted to the rank of Captain February, 1987 and to Major in February, 1994. She has served as the Officer in Charge (OIC) of Physical Examination, HIV Education, Nursing Education and Staff Development (NESD), and the Surgical Intensive Care. A review of Major Webb's military education reveals completion of the Officer's Basic Course (OBC), Fort Sam Houston, San Antonio,

Militarily, she is credentialed as a medical-surgical nurse, 1985; intensive care nurse, 1994; community health nurse and nurse administrator, 1995. Tours of duty for Major Webb, reflect overseas assignments as: the OIC of the Medical Dispensary, Republic of Honduras, Central America, (Annual Training), 1987; Chief Nurse, Medical Dispensary Hanil Bank, Camp Humphries, South Korea (Annual Training), 1990 and staff nurse, Gorgus Army Hospital, Panama City, Panama, (Annual Training), 1991.

Honors for Webb are as follows: Paul and Emily Douglas Fellow, Chicago State University, College of Nursing, 1980-81; Outstanding Teacher of the Year, Chicago State University, College of Nursing, 1980-81; Listed in Who's Who Among Contemporary Nurses, 1983-84; Sigma Theta Tau, National Honor Society of Nursing - Alpha Lambda Chapter, Inducted May, 1987; Army Overseas Service Ribbon, May, 1988; Army Accommodation Medal, January 1989; Faculty Excellence Award, Chicago State University, College of Nursing, May, 1989; Army Overseas Pin, March, 1990; Army Achievement Medal, August, 1990; Recipient, Chicago Chapter National Black Nurses Association, Graduate

The dissertation submitted by Sandra Marie Webb has been read and approved by the following committee:

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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Ph.D.

November 20, 1995  
Date  

Director's Signature