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SOCIALIZATION AND IDEAL EXPECTATIONS FOR
THE HEALTH PROFESSIONAL ROLE IN THE
PROVISION OF QUALITY TERMINAL CARE
FOR THE URBAN ELDERLY

by

Margaret Beth Neal

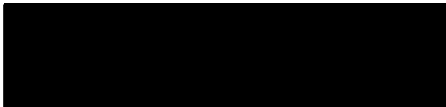
A dissertation submitted in partial fulfillment of the
requirements for the degree of

DOCTOR OF PHILOSOPHY
in
URBAN STUDIES

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TO THE OFFICE OF GRADUATE STUDIES AND RESEARCH:

The members of the Committee approve the dissertation
of Margaret Beth Neal presented November 27, 1985.

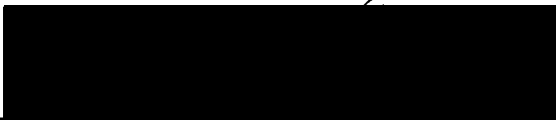

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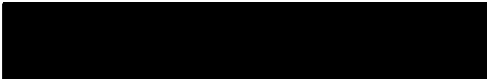

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AN ABSTRACT OF THE DISSERTATION OF Margaret Beth Neal for
the Doctor of Philosophy in Urban Studies presented November
27, 1985.

Title: Socialization and Ideal Expectations for the Health
Professional Role in the Provision of Quality
Terminal Care for the Urban Elderly.


APPROVED BY MEMBERS OF THE DISSERTATION COMMITTEE:



Leonard D. Cain, Chairperson



Nancy J. Chapman



Sheldon M. Edner



Clyde R. Pope

This study investigates socialization and ideal
expectations for the health professional role in the
provision of quality terminal care. Guiding the research

are role theory, socialization theory, and Talcott Parsons' (1951) pattern variables.

The research was conducted in three phases. The first phase involved development of an analytical framework elaborating upon Parsons' five pattern variables, which were first conceptualized as dimensions describing the ways in which roles could vary. Specific indicators for each of the pattern variables were developed. Typologies characterizing (1) the medical, or conventional, model and (2) the holistic model (specifically, the hospice model) for the provision of health care based on these indicators then were developed.

Using the analytical framework, the second and third phases consisted of: (1) a content analysis of the physician and nurse socialization literature to determine the role prescriptions learned by these health professionals; and (2) a content analysis of open-ended interviews with a group (N=94) of terminally ill elderly patients (n=17), family members (n=38), and health professionals (n=39) from 10 urban health care programs (five conventional and five hospice) to identify ideal role expectations for the health professional.

Major findings were that: (1) Parsons' pattern variables, with elaboration, can provide a useful framework for role analysis; (2) physicians and nurses appear to be socialized to a number of role prescriptions consistent with

the medical model, although there is evidence of conflicting socialization (to both models) for some role prescriptions; (3) respondents' expectations generally were consistent with those prescribed by the hospice model with some notable exceptions; (4) the role expectations of the three groups of respondents were more congruent than was expected, although subgroups' (conventional versus hospice) expectations tended to differ.

Implications of the findings for: (1) role analysis; (2) socialization of health professionals to minimize role strain and conflict with patients and families; (3) continued implementation of conventional and hospice models for the provision of quality terminal care; (4) assessment of the quality of terminal care are explored; and (5) further research are explored.

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CHAPTER I

INTRODUCTION

Statement_Of_The_Problem

The quality of the care provided to individuals who are terminally ill has become in recent years a matter of increasing concern. This concern centers around alleged inadequacies in conventional care for meeting the needs of people suffering from a disease from which recovery is no longer possible. Among the numerous specific criticisms are the emphasis placed in the training and practice of health professionals on acute and curative care, providers' failure to control patients' pain and symptoms, the impersonal nature of care, and the lack of attention to patients' and families' psychosocial needs.

Issues surrounding the quality of terminal care have particular relevance for the elderly: being old, being sick, and being near death are characteristics frequently viewed as synonymous. Scientific advances have led to an increase in life expectancy, with an attendant rise in the incidence of chronic and terminal illnesses such as cancer and heart disease. As a result, a substantial proportion of those who are terminally ill are elderly.

The provision of quality terminal care is essentially an urban problem. Ours is an urban society. With specialization and advances in technology have come the hospital and other medical facilities for the delivery of health care services. Whereas in the past in rural America, people usually died at home, in today's urban setting death occurs primarily in these specialized, urban health care institutions.

In response to perceived deficiencies in care of the terminally ill, an alternative concept of terminal care has been proposed: the hospice philosophy of care. With the proliferation of hospice proponents, the issue of the efficacy of this model of care as an alternative to conventional care for the terminally ill takes on increasing significance. Federal and state governments already have implemented rules and regulations governing licensure and reimbursement of the burgeoning number of hospice programs throughout the country.

Yet, even among hospice supporters, the proliferation of hospice programs has given rise to a number of concerns and questions regarding the viability of the hospice concept in America. Can hospice meet the needs of the dying, and how well can it meet these needs? How acceptable is the hospice concept to consumers and providers of care? Hospice care was conceived and developed in Britain; can hospice principles be implemented and feasibly administered in the

U.S.? Can hospice become integrated into the traditional health care system? If so, can its integrity be preserved? As the number of hospices increases, and as the shortage of key health personnel such as nurses continues, can current training programs produce professionals with the characteristics and qualifications necessary to provide hospice care?

The problem addressed in this research is the adequacy of the socialization of physicians and nurses for the provision of quality terminal care, as "quality" is defined by consumers and providers alike. Specifically, the normative role prescriptions of two groups of health professionals, physicians and nurses, as conveyed through professional and workplace socialization, are identified and analyzed with emphasis on the conventional and the hospice models of care. These role prescriptions then are compared with the expectations for the ideal provider of terminal care that are held by a group (N=94) of terminally ill patients (n=17), family members of terminally ill patients (n=38), and health professionals who themselves provide terminal care (n=39). The ultimate aim of the research is to identify ways in which the quality of terminal care may be improved.

This research is approached from a perspective that is primarily structural-functional. The theoretical framework

guiding the research is derived from role theory, specifically as it relates to socialization for professional roles. Parsons' (1951) pattern variables of role expectations are operationalized and used to classify, first, the various normative role expectations to which physicians and nurses are socialized and, second, the expectations for the ideal provider of terminal care held by the patients, family members and currently practicing health professionals who were interviewed.

The research is both basic and applied in nature. It contributes to knowledge about the nature of the health provider role with respect to the provision of terminal care, examining the definition of a "professional." An analytical framework comprised of indicators of expectations for the health professional role is developed, operationalizing and elaborating upon Parsons' pattern variable framework. This research tests the adequacy of the pattern variables for role analysis, particularly for (a) differentiating between the role of the health professional under the medical model of care and this role under the holistic model, (b) differentiating between two professional roles (physicians and nurses), and (c) differentiating among the role expectations of the occupants of various roles within the role set (patients, family members, and health professionals).

The findings of the research have a number of practical implications. The specific indicators of role expectations developed based on Parsons' pattern variables provide a broad framework from which to view the role expectations associated with the health professional's role in the provision of terminal care. This framework can be used in the development of instrumentation for assessing the quality of terminal care and, following further refinement, for recruiting and selecting health professionals for the provision of quality terminal care.

The illumination of consistencies and inconsistencies in professional and workplace socialization of physicians and nurses enables the identification of sources of role strain such as inconsistent patterning of the pattern variables or socialization of professionals to both models of care. Areas where modifications in education may be called for to minimize these inconsistencies can then be determined.

The findings from the comparison of patients', family members', and health professionals' perceptions of attitudes and behaviors of health professionals that contribute to the provision of quality terminal care point to arenas of potential conflict among these groups and also have implications both for role theory and for socialization theory. The research, therefore, has implications both for

professional socialization and for patient and family education.

Finally, the findings from the comparison of patients', families', and providers' descriptions of their ideal provider of terminal care with the principles of care embodied in the medical and the holistic models aid in ascertaining the desirability and long-term viability of these two models for the provision of quality terminal care.

Overview

The remaining chapters of the dissertation further introduce the topic, review relevant literature, describe the methodology used for implementing the research, detail the findings, and discuss the implications of the findings.

Chapter II reviews three areas of pertinent literature. Included are the literatures describing (1) the models of health care provision in America, (2) the state of the art relative to care of the dying in America, and (3) the definition and assessment of quality care.

Chapter III outlines the conceptual tools used in the research and includes an overview of issues in the conceptualization of role and role theory and socialization theory.

Chapter IV applies the conceptual tools discussed in the previous chapter in its description of the research. In particular, the conceptual framework underlying the study is presented, and the specific research questions are detailed.

Chapter V outlines the research design and methods. This research was conducted and is described in three phases. The first phase involved the development of an analytical model, based on Parsons' pattern variables, for use in classifying the role expectations of health professionals. In the second phase, a systematic review of literature was conducted for the purpose of identifying the role prescriptions and expectations to which physicians and nurses in training are professionally socialized. The strategy employed for identifying the role prescriptions and expectations to which physicians and nurses are socialized is described here. The third phase consisted of reanalysis of data gathered in the earlier exploratory study described above. These data were used to determine patients', families', and health providers' role expectations for the provider of quality terminal care. The procedures for selecting respondents, the interview schedules used, and the quality and limitations of the data are discussed.

Chapter VI presents the analytical model developed in the first phase of the research, as described in Chapter V. Chapter VII details the results of the study, using the analytical model. In this chapter, each of the research questions is dealt with separately. The final chapter, Chapter VIII, summarizes the findings and discusses their theoretical and practical implications.

CHAPTER II

REVIEW OF THE LITERATURE

Three literatures relevant to this dissertation will be reviewed here: (1) literature concerning the models of health care provision in America today; (2) literature regarding the care of the dying in America today; and (3) literature relating to the definition and assessment of the quality of health care.

MODELS OF HEALTH CARE PROVISION IN AMERICA TODAY

Description Of The Major Models

Hardy (1978) states that there is no one prevailing paradigm, or model, that is used by health professionals. Two models, however, appear to dominate American health care: the medical model and the holistic model. These two competing models are described in this section.

The medical model. The first major model of health care provision in America has been variously referred to as the "medical intervention pattern," the "disease model," or the "biomedical model" (Freidson, 1970a); the "classical hospital care model" (Wessen, 1966, cited in Rosenthal et al., 1980); the "medical teaching model" (Coombs and Powers, 1975); and the "traditional pattern" (Germain, 1980). This

first model will be referred to here either as the medical model or as conventional care.

Freidson (1970a) characterizes the medical model as having the features of:

- (1) physician dominance, with staff's work organized by physician orders;
- (2) consideration of the patient as incapable of judging what is needed and expecting him/her to submit passively to the judgment and treatment of staff;
- (3) impersonal interaction between patients and staff, since staff serve mainly as the physician's agents in dealing with the patient; and
- (4) interaction among various staff members ordered by professional chain of command because of the physician's dominance.

Germain (1980:46), too, portrays the "traditional pattern" as one of "medical dominance and bureaucratic constraints" in health care institutions.

Professional authority, then, is the first critical element in the medical model. In this model, the physician's role is characterized by dominance over the patient as well as over other health care professionals. Parsons (1951), whose theories exemplify the medical model and whose work in this area will be described in subsequent sections in considerable detail, conceptualizes the patient, who occupies the "sick role," as being temporarily in a deviant

status and in need of expert help to end his or her deviancy. Under this model, the assumption is made that the instructions of medical authority must be accepted in order for the patient to get well (Haug, 1979).

Initiation of the medical model in medical education began from 1830 to 1910 (Bloom, 1979:5), when:

a revolution in the content and structure of American medical education occurred. What had been for well over a century a frontier-oriented system, characterized by the methods of apprenticeship and a proprietary type of organization, was replaced by a combination of extended academic training within the laboratories and classrooms of the university graduate school and bedside clinical teaching in university hospitals. Until today, over more than a half-century later, this general form has persisted, producing an elite corps of highly trained medical specialists who are prepared to practice a science-based, technologically complex type of medicine.

Bloom's (1979) description demonstrates the second critical characteristic of the medical model: the importance of sophisticated technology and technical expertise, including specialization. Coombs and Powers (1975:260) view this feature as the primary one distinguishing the medical model, stating that the medical model "glorifies the science of medicine (a thorough knowledge of disease processes and a ready command of clinical technique)..."

The third characteristic of the medical model is impersonal interaction, or the lack of expression of affect or concern on the part of the professional (including the nurse and the physician) toward the patient. As pointed out

by Bloom (1979), a dichotomy typically is drawn between skills and knowledge, on the one hand, and concern for the patient on the other hand.

Donabedian (1980) makes a similar distinction in his discussion of the way in which quality of care assessment research typically divides the care given into two domains: the technical and the interpersonal. Technical care is "the application of the science and technology of medicine, and of the other health sciences, to the management of a personal health problem" (Donabedian, 1980:4). Interpersonal care is "the management of the social and psychological interaction between client and practitioner" (Donabedian, 1980:4).

Likewise, Freidson (1961) refers to "competence" on the one hand and "personal interest" on the other hand. In the medical model, emphasis is placed on the technical aspects of care, on the competence side; emotional and psychosocial problems are defined as out the realm of medical competence or responsibility (Robinson, 1974).

The holistic model. The second major model of health care provision in America is that of "holistic" or "comprehensive" care (Bloom, 1979; Field, 1953; Freidson, 1970a; Merton, 1957b; Rosenthal et al., 1980). Bloom (1979:11) refers to this second model as the "new humanism" (i.e., of medical ethics):

The intent is to assure the patient a type of medical care that, in addition to the best scientific

techniques, would include concern about the emotional and social factors in the patient's illness.

Furthermore, according to Freidson (1970a:134), this model maintains "the view that ailments should not be managed discretely, separately from each other by individual specialists."

Field (1953) is one proponent of this model or philosophy of "total medical care" and its concept of "patients as people." She (Field, 1953) advocates a broadened concept of illness, particularly prolonged illness, as both a medical and a social problem. Also, she advises an emphasis on the intrinsic worth of the patient as a person, with interest centered not merely on the disease process, but on the patient as a person and on his or her social background as well.

In describing this concept of comprehensive, or holistic, medical care, Field (1953) outlines the need for: (1) attention to the social and emotional factors; (2) care of the family as a unit of treatment; (3) rehabilitation as a part of total medical care (including self care and sheltered workshops); and (4) inclusion of social service (specifically, the establishment of a social service department) as a part of total medical care. With regard to the second feature (inclusion of the family in the care), Field (1953:219) asserts, "Experience has demonstrated that

the illness of one member of the family has its repercussions on the entire group, affecting their health and well being." Rehabilitation (the third feature) has a role in the provision of terminal care insofar as rehabilitation therapy is aimed at promoting quality of life.

Merton (1957b) also has described this holistic model of health care provision. In his review of the history of medical education, he notes the recent advances in psychosomatic medicine and the "renewed emphasis, within medicine, upon the concept of [the patient as a whole person.]" (Merton, 1957b:25). An advocate of this "social medicine," Merton (1957) cites many physicians who feel as he does.

Paradigms Of The Doctor-Patient Relationship Within The Medical And The Holistic Models

There are several paradigms of the doctor-patient relationship that fit generally within either the medical model or the holistic model of health care provision. These paradigms focus on two related features which differentiate the medical and the holistic models of care: (1) physician authority and patient participation, and (2) communication, particularly physician disclosure of the diagnosis and prognosis.

Physician Authority And Patient Participation. One of the principal differences between the medical and the

holistic model concerns the amount of authority the physician has. In the medical model, as noted above, the patient is expected to defer to the physician's authority and expertise. In the holistic model, the patient participates in his or her own care and is involved in treatment decisions. Several authors have described models of "the doctor-patient relationship" which address the extent of physician authority in this relationship.

Particularly illustrative and salient is Talcott Parsons' (1937, cited in Bloom and Summey, 1976) model of the doctor-patient relationship as a social system. Parsons' model includes the following premises, as described by Bloom and Summey (1976:21-22):

1. The problem of health is intimately involved in the functional prerequisites of the social system. Too low a general level of health, too high an incidence of illness, is dysfunctional.
2. Sickness and health are, because of their importance, part of the culture.
3. Health care is a social role relationship between a helping agent and a person needing help.
4. The social roles of the health care relationship are a patterned sector of culture and are thus learned sequences of behavior.

Quoting Parsons (1951), Bloom and Summey (1976:24) point out that the premise of the Parsonian model of the doctor-patient system is one of functional specificity: "Modern medicine is organized about the application of scientific knowledge to the problems of illness and health and to the control of disease."

Derived from these premises are Parsons' ideal types of sick and professional roles (Bloom and Summey, 1976). The sick role is characterized as an involuntary, temporary form of undesirable and disruptive social deviance, which "must be controlled to prevent abuses by persons who gain psychological rewards as a result of the legitimized dependency of illness" (Bloom and Summey, 1976:23). The individual who occupies the sick role has certain obligations: "to be motivated to get well;" "to seek technically competent help;" and "to trust the doctor; or, to accept the competence gap (the asymmetry of the relationship)" (Bloom and Summey, 1976:24, citing Parsons, 1951). The occupant of the sick role has privileges as well, including exemption from "performance of normal social obligations" and from "responsibility for one's own state" (Bloom and Summey, 1976:24, citing Parsons, 1951).

The doctor, who occupies the professional role, is obligated to "act for the welfare of the patient;" to "be guided by the rules of professional behavior;" to "apply high degree of achieved skill and knowledge to problems of illness;" and to "be objective and emotionally detached" (Bloom and Summey, 1976:24, citing Parsons, 1951). The privileges of the professional role include: "access to physical and personal intimacy" (i.e., in examination of the patient's body); "autonomy;" and "professional dominance" (Bloom and Summey, 1976:24, citing Parsons, 1951).

Szasz and Hollender (1956) extended the Parsonian model by positing a three-fold typology of the doctor-patient relationship which incorporated the implications for this relationship of various types of illness. This typology includes: (1) activity-passivity; (2) guidance-cooperation; and (3) mutual participation. The first two of these types are essentially synonymous with the medical model. The third parallels the holistic model.

Szasz and Hollender's (1956:586) first type of doctor-patient relationship (activity-passivity) is "the oldest conceptual model." Here, the physician does something to the patient. Szasz and Hollender (1956) state that this model's orientation originated in and is appropriate for treatment of emergencies. This type "gratifies physicians' needs for mastery and contributes to feelings of superiority...it requires that the physician disidentify with the patient as a person" (Szasz and Hollender, 1956).

The second type (guidance-cooperation) is that which Szasz and Hollender (1956:586) assert "underlies much of medical practice." This type of relationship is employed in non-emergency situations. While the patient is acutely ill, he or she "is conscious and has feelings and aspirations of his or her own." The patient seeks the physician's help, is willing to cooperate, and transfers power to the physician due to the physician's knowledge of medicine. In this type of relationship, the patient is expected to look up to,

obey, and not question the physician. While similar to the first type of relationship, in this second type there is less disidentification with the patient on the part of the physician (Szasz and Hollender, 1956).

The third type of relationship (mutual participation) "is predicated on the postulate that equality among human beings is desirable" (Szasz and Hollender, 1956:587). For an interaction of this type, participants must have approximately equal power, must be interdependent, and must engage in mutually satisfactory behavior.

This third type of relationship, while "essentially foreign to medicine," (Szasz and Hollender, 1956:588) is most appropriate and necessary the greater the intellectual, educational, and general experiential similarity between the physician and the patient (Szasz and Hollender, 1956). It "may also be [realistic] and necessary, as, for example, in the management of most chronic illnesses," where the "patient's own experiences provide reliable and important clues for therapy" (Szasz and Hollender, 1956:587). The same would be true for the management of terminal illness.

Szasz and Hollender (1956:588) note that this third type of doctor-patient relationship is "characterized by a high degree of empathy" and "has elements often associated with the notions of friendship and partnership and the imparting of expert advice." The physician helps the patient help himself (Szasz and Hollender, 1956). Instead

of deriving satisfaction from power over someone else, the physician's satisfactions stem from "more abstract, less understood kinds of mastery" (Szasz and Hollender, 1956: 588). Szasz and Hollender (1956) point out that the physician must undergo a process of change as he or she strives to alter the patient's state if the patient's emergent needs are to be complemented. Otherwise, the physician "foists upon the patient the same role of helpless passivity from which he (allegedly) tried to rescue him in the first place" (Szasz and Hollender, 1956:588).

Szasz and Hollender (1956) argue that each of the three types of therapeutic relationships is appropriate under certain circumstances. When there is a change, such as in the patient's symptoms or in the way he or she wishes to relate to the physician, they state that the physician must change. In the situation of a patient with a disease that has progressed to become incurable, it may be inferred that the physician, in his or her powerlessness to cure, must change his or her attitude.

Bloom and Summey (1976:23) point out that in the Szasz and Hollender typology, as in the Parsonian model, "dependence-independence is the behavioral quality which is most significant." The extent of physician dominance, or patient passivity or dependence, required in this role was posited to depend on the nature of the patient's illness. Szasz and Hollender's typology of the doctor-patient relationship has

implications for the professional socialization of physicians:

If, therefore, the doctor learns to act as a dominant, controlling figure, essentially authoritarian, and uses this style under all conditions, he is bound to fail when he enters a situation with a patient in which mutual participation and not the active-passive interaction is required (Bloom and Summey, 1976:25).

With regard to these models of the doctor-patient relationship proposed by Szasz and Hollender (1956), Freidson (cited by Robinson, 1974) argues that logically, there should be two additional models: one in which the patient guides and the doctor cooperates, and another in which the patient is active and the doctor is passive. Both of these additional models would fall under the umbrella of holistic care.

Haug (1979) is another scholar who has addressed the issue of the authority of physicians in the doctor-patient relationship. Her work has focused specifically on physicians' relationships with elderly patients. She notes that physician authority is legitimated and is a "taken-for-granted phenomenon," based on the notion that only physicians have the necessary expertise to deal with patients' problems. Citing Freidson (1970a; 1970b) and Parsons (1975), Haug (1979) argues that it is this power relationship, or "competence gap," that distinguishes professionals from nonprofessionals.

Haug (1979) asserts that this "authority model" of the doctor-patient relationship increasingly has been challenged since the mid-1960's. The unwillingness to accept professional authority without question on the part of clients has been characterized as "consumerism" (Reeder, 1972, cited in Haug, 1979). According to Haug (1979), evidence of this trend toward increased consumerism is found in the demand for accountability and consumer quality assessment (Reeder, 1972), the various self care movements (Levin et al., 1976), and the popularity of do-it-yourself books (Sehnert and Eisenberg, 1976) (all cited in Haug, 1979).

To test the question of whether the elderly, too, are challenging physician authority, Haug (1979) conducted an interview survey of 640 randomly sampled persons in a mid-western state. She found that the 153 respondents aged 60 and over were more likely to accept physician authority, both in terms of attitudes and behaviors, than were younger groups (25% of the younger groups, compared to only 8% of the persons aged 60 or older had high scores on a measure of willingness to challenge physician authority). Haug (1979: 859) concludes:

Because future cohorts of the elderly are likely to be better educated and thus more medically knowledgeable, and carry over current tendencies rejecting authority, it is suggested that physicians will need to exercise their powers of persuasion, and depend less on their traditional authority in encounters with patients.

Veatch and Tai (1980) also note the "new" moral norms of (1) patient autonomy and (2) patient self-determination, or at least consent to medical treatment, and argue that there is a perceptible shift toward these norms. The standard for disclosure based on the consensus of one's colleagues has been gradually abandoned, they assert, in favor of the "reasonable person standard," in which the physician is required to disclose what a reasonable person would find relevant for making a decision to participate in the therapy (Veatch and Tai, 1980).

Physician Communication (Disclosure) With Patients.

Communication by the physician with the patient, or with the patient and the family, is one way in which the extent of the physician's authority and of the patient's participation in the care may be manifest. The following paragraphs describe some of the literature with regard to this area.

In a study specifically of physicians' preferences for revealing or not revealing diagnosis of a fatal illness to patients and their families, Harman (1971) posits two distinct models. The first, the "psychiatric (semi-Freudian) model," parallels the medical model. This psychiatric model is derived from Wahl's work (1965, cited in Harman, 1971) and addresses whether to tell, and how much to tell, patients and their families.

The assumptions of this "psychiatric" model are that: (1) fear, denial, and repression of death are natural, and

that confrontation of the fact that one is dying is dangerous to the stability of one's mind; (2) such a stressful communication must be made only on the basis of a deep personal knowledge of the patient; (3) there is a medical decision model (Freidson, 1971, cited in Harman, 1971) that favors diagnosing sickness rather than health, and this leads to assuming damage is likely to occur when a patient is confronted with fatal illness; thus, (4) it is safer for patients' mental health to interpret their questions as needing denial and reassurance rather than to guide patients to "acceptance of dying and death" (Harman, 1971:67-68).

The second model posited by Harman (1971) for revealing fatal illness is the "social-psychological model." This model parallels the holistic model, and derives from the work of Glaser and Strauss (1965, 1968), Weisman and Hackett (1965, cited in Harman, 1971), and Verwoerd (1966, cited in Harman, 1971). Only the question of how to tell patients of their prognosis is addressed; this model assumes that most patients should be told.

The assumptions of Harman's (1971) "social-psychological model for revealing fatal illness" are: (1) most patients are stable and able to endure being told; (2) stressful information must be presented with tact and compassion; falsehoods and bluntness are to be avoided; when attainable, personal knowledge of patients and their likely response is of great assistance; (3) patients should be

"helped to achieve as appropriate a death as individually possible;" (4) a bias toward a health diagnosis rather than one of sickness is better for most patients; it should be assumed that telling is less damaging than not telling; (5) a patient's silence regarding dying and death should not be ascribed to lack of interest (Harman, 1971:69-70).

Veatch and Tai (1980) also call attention to the presence of two differing sets of "medical ethical norms" specifically with regard to disclosure of diagnosis and prognosis. They assert that "physicians traditionally have been committed to the ethical principle that their duty was to do what they thought would be beneficial to their patient." They note that sometimes this norm is expressed negatively: primum non nocere (first, do no harm). The "traditional" belief of medical professionals is that harm is caused by disclosure; this norm is a patient-protective, paternalistic norm (Veatch and Tai, 1980).

The "new" belief is that it is beneficial to disclose to the patient his or her diagnosis and/or prognosis, and that harm is caused by nondisclosure. Veatch and Tai (1980: 37) assert that "presently...not only has the belief about benefits and harms come unstuck, but the basic norm has as well."

The Context For Change Between Models

From the above descriptions of the medical and the holistic models for health care provision and the various specific submodels, a sense of cyclical movement between the two models is discerned. Rosenthal et al. (1980) describe the "traditional hospital pattern" and say that over the past few decades this model has been undergoing change toward one of comprehensive, or holistic, care.

Field (1953) points out, however, that the concept of the patient as a whole person is not "new;" that a sick organ cannot be separated from the person to whom it belongs is attested by the age-old adage that "the part can never be well unless the whole is well." Nor is the concept of the interrelationship between physical and emotional states new: Mens sana in corpore sano (mind healthy, body healthy) is possibly older than the Roman Empire (Field, 1953). Merton (1957:25) also argues that "the lineage of this idea is, of course, ancient--John Locke, Francis Weld Peabody..." (Merton, 1957:25). In other words, the concept of the holistic model of care preceded that of the medical model, and now there is some evidence of a return, at least theoretically, to this holistic model of care.

What, then, initially caused the idea of holistic, or comprehensive care to fall from favor? According to Bloom (1979:5), a key role was played by the famous Flexner

Report, which indicted the poor quality of medical education in the early 1900's. This report brought about a "revolution" in medical education (Bloom, 1979). Prior to this time, a "frontier-oriented," non-science-based, and technologically simple system existed. A new model of medical education, the medical model, evolved in response. The effect of this new educational model was a dramatic increase in medical specialization (Bloom, 1979).

Accompanying this increase in specialization was a dehumanization of medicine (Bloom, 1979). Furthermore, a change in the nature of the dominant or paradigm diseases also occurred (Veatch and Tai, 1980). Prior to the 1960's, "the paradigm disease was the aggressive, acute infection," and the expected outcomes were either rapid death or cure (Veatch and Tai, 1980:41). "As long as the model was acute illness with a passive, perhaps unconscious, patient, the authoritarian, rather paternalistic physician was understandable" (Veatch and Tai, 1980:41). However, by the 1960's, with technological developments such as hemodialysis; heart transplant; surgery, radiation, and chemotherapy for malignancies; and perfection of the respirator, the infectious diseases and the diseases of infancy were all but eliminated (Veatch and Tai, 1980). "Chronic disease suddenly became the socially dominant or paradigm disease" (Veatch and Tai, 1980:41).

With this shift in paradigm disease came a different type of patient: one who is ill and debilitated only intermittently, and who is much more capable of participating in his or her own care (Veatch and Tai, 1980). Robinson (1974), too, points to the distinguishing characteristics of long-term, chronic, or permanent illness that necessitate a model different from the Parsonian model of illness, where the patient is expected to desire to get well and to conform to other expectations that are based on the assumed temporariness of the condition.

Bloom (1979) also discusses the pressures for change from the medical model to the holistic model. He argues that these pressures began soon after World War II, and that changes in response were initiated at the medical school at Western Reserve. The changes initiated encompassed the key concepts of: (1) integration (both among academic disciplines, and between preclinical and clinical training); (2) human development; and (3) comprehensive care. The overall goal of these changes was the humanizing of medicine, to "repair what were believed to be the dehumanizing effects of scientific specialization, but with a retention of the best of science" (Bloom, 1979:6). The method involved assigning for the first time to the behavioral sciences, including psychology, sociology, and anthropology, a role in the basic sciences of medicine. Thus, the pendulum had swung back toward the holistic model of care.

Additional light on the causes for the shift toward a holistic model of care is shed by Haug (1979). She attributes the erosion of physician authority to the "loss of knowledge monopoly, a function of rising education levels of the general public and increases in health information." She points to the movement toward "consumerism," the demand for accountability and consumer quality assessment, and the popularity of the concepts of self-care and "do-it-yourself." Veatch and Tai (1980:41) also note the "increasing sophistication of the lay population."

At the same time, with the advent of chronic disease and sophisticated medical technology, a concurrent change in the health care delivery system occurred as well (Veatch and Tai, 1980). They point to the change from the "traditional model" of the "isolated physician caring for the isolated patient perhaps with a nurse and family standing by," (although they state that "that model probably never really dominated in pure form," that this was the "image") to the current model: the hospital, which is a health care bureaucracy, if not a team (due to poor interprofessional communication) (Veatch and Tai, 1980:42). For example, in 1976, 70 percent of patients died in the hospital, up from 49 percent 30 years prior (Veatch and Tai, 1980, citing Ryder and Ross, 1971).

Coombs and Powers (1975, citing Parsons and Lidz, 1967) make this same point. They note that in the past, in

rural America, people usually died at home, but in the contemporary urban setting, death occurs primarily in hospitals and other medical facilities. In sum, urbanization and bureaucratization appear to have contributed not only to the development of the medical model, but also to its persistence. Field's (1953:13-14) comments are particularly cogent:

The development of the far-flung urban community created physical separation of the doctor from the patient, with resulting estrangement and less intimate knowledge of the patient's total life situation. This physical estrangement, coupled with the rapid expansion of medical knowledge, which inevitably led to an equally rapid growth of specialization, confined many doctors to the treatment of a specific area of the body. Such specialization with its concentration on the sick organ served to obscure the fundamental concept of the patient as a total human being. As a result, we find that the doctor nowadays is likely to know a great deal more about the pathology of his patients than did his predecessors (the horse and buggy doctor practicing in a small rural community), but is less apt to know what his patient is really like as a person, who his family is, what his children are like, where he works, what he gets from his job, how he lives, and what he lives for.

Similarly, Merton (1957:25-26) asserts that in an earlier day, physicians could know and understand their patients:

In short, the structure of society and the organization of medical practice were such that many practitioners would intuitively and almost automatically take into account both the stresses and the potentials for therapeutic support which the environment afforded the patient...With the growing complexity of the social environment, the increasing specialization of medical practice, and the often diminished association of physicians with their patients outside the sphere of health care, the problem of

taking the social context of the patient into account becomes greatly enlarged.

Merton (1957), then, feels that it is a result of the above social changes that there has been a newly-emphasized concern with the old problem of having the patient regarded as a whole person.

Finally, Shortell (1982:43-44) asserts that "the health system is faced with a number of new issues raised by technological advances and changes in social values and norms regarding issues such as death and dying."

Nonetheless, despite "evidences of a major, perhaps revolutionary, change in the directions of American medical education" toward the holistic model of care (Bloom, 1975: 5), the change does not appear to be complete. To illustrate, in 1957, Merton (1957:25) argues that:

Although the conception of "the patient as a person" is long established and generally acknowledged in medical circles, it is also said to be a conception more honored in the breach than the observance.

Over twenty years later, Bloom (1979:6) notes that the changes from the medical model to the holistic model have "taken some time between conception and application," just as was true of the radical shift toward the medical model that occurred in the early 1900s. By 1970, according to Bloom (1979), it began to be clear that despite the expansion of the numbers of physicians available to society as a result of federal financing programs to stimulate and support medical education, and in spite of the reforms

within medical education to decrease specialization and move medicine from the medical model to the holistic model, the trend toward specialization had not been checked; the patterns of career choice had not been affected. As a result, financial incentives provided by the government for programs of medical school expansion were withdrawn (Bloom, 1979). Also, as Bloom (1979:16) states:

the belief that future physicians could be persuaded to fill the evident social need by a more self-consciously social and humanistic minded education (was) dropped... 'Comprehensive medicine,' the approach that was designed to brake runaway tendencies to specialization, went out of fashion...

Bloom (1979:5) concludes that medical education policy has led and continues to lead to a dramatic increase in medical specialization, and a decrease in general (holistic) practice, or primary care:

Overall, the strong implication is that medical schools of the United States are preparing future physicians mainly for specialty practice, with primary (holistic or comprehensive) care practice relegated to an almost residual "adjunct" status.

Nevertheless, noting "a reaction away from the full thrust of radical change" toward the holistic model, he appears to feel that the medical and the holistic models ultimately may meet somewhere toward the middle:

...it is difficult to conceive of either a full return to the traditional Flexnerian curriculum (medical model) or a rejection of the main themes of the Western Reserve reforms (holistic model) (Bloom, 1979:6).

The dialectical notion of thesis--antithesis--synthesis, then, is evident with respect to the movement between these two models for the provision of health care. Perhaps the meeting of the two models is taking place already. Rosenberg (1979), for example, writes of "Catch 22--The Medical Model" and describes some of the major conflicts for students that arise from medical education and that, in turn, shape subsequent behavior. One of the conflicts she lists is the exposure to the role model of the specialist versus an orientation to the total patient. This suggests that students are exposed to both the medical and the holistic model, and that the disparity between these models may cause conflict for the students.

Summary

In summary, this section of the literature review has pointed out the existence of two principal models of health care provision concerning the relationship between the health care professional and the care recipient or client (the patient or the patient-family unit). These models are the medical model and the holistic model.

It has been shown that the key difference between these two models centers around whether or not the patient's total needs, psychosocial as well as physical, are addressed. Stemming from this central difference are differences concerning: (1) the extent of the physician's

authority over patients (i.e., whether or not the patient, or the patient-family unit, participates or is involved in care-related decisions); (2) whether or not the family as well as the patient is included in the unit of care; (3) the extent of the physician's dominance over other staff, including the issues of (a) whether care is provided by a multidisciplinary team or a set of separate, specialized individuals and (b) the hierarchical relationship between the various care providers (here, specifically, between the physician and the nurse); and (4) the degree to which affect, concern for, or identification with the patient is expressed by the provider.

Adoption of the medical model has been shown to have been linked to urbanization, specialization, and rapid technological development. The recent return trend toward the holistic model has been demonstrated to be attributable to a reaction against the dehumanizing effects of specialization, the predominance of chronic illness as the paradigm disease due to technological advances, the diminishing "competence gap" between patients and physicians as a result of rising education levels of the general public, and changes in social values and norms.

Several major questions arise from this review. First, to which model, medical or holistic, are physicians and nurses professionally socialized; to what extent is one model predominant? What are the outcomes of professional

socialization; to what extent is existing professional practice congruent with the model to which health professionals are professionally socialized? What is the effect of adherence to one or the other model on the quality of care provided? Additional literature bearing on these issues is reviewed in Chapter III, Conceptual Tools. The following section discusses the second body of literature referred to in the introduction to this chapter: that concerning the state of the art specifically with regard to the care of the dying in America today.

CARE OF THE DYING IN AMERICA TODAY

Needs_Of_The_Terminally_Ill

Much of the literature on the needs of people who are terminally ill has arisen in response to perceived inadequacies of conventional medical care for the provision of terminal care. It is important to note that in some cases this literature is based on personal experience, intuition, and/or very limited empirical research.

Six general areas of need are discussed in the literature on the needs of terminally ill people. These areas include: physical care needs; needs for preservation of feelings of dignity and self-worth; needs for love and affection; spiritual needs; needs for assistance with finances and health insurance coverage; and needs related to

concern for their survivors. Each group of needs is described briefly in this section.

It is generally felt that the needs of paramount importance for terminally ill people are their physical needs. Among these needs are those for pain to be controlled, for relief from the physical symptoms of the disease, and for prevention and management of medical crises (Craven and Wald, 1975; Schulz, 1976; Strauss, 1975).

Until patients' physical needs are met, their other needs cannot be addressed, asserts Schulz (1976). This is consistent with Maslow's (1943) "hierarchy of needs." According to Lack and Buckingham (1978), pain and anticipation of pain intensify the distress associated with a terminal illness, which may lead to anxiety, insomnia, and/or depression; these symptoms, in turn, aggravate patients' physical pain. Once patients are free from pain and from the memory and fear of pain, anxiety, depression and feelings of excessive dependency on others are abated (Kron, 1976; Lack and Buckingham, 1978, citing Melzack, 1973; Stoddard, 1978). Effective pain control practices also frequently result in reductions in the amount of analgesic required for the maintenance of comfort (Lamerton, 1973; Mount, 1976). Holden (1976, citing the work of Dr. Cicely Saunders) further notes that the control of pain results in fewer admissions to facilities such as hospitals

and inpatient hospices and in greater numbers of patients being able to die at home.

A second set of needs concerns the preservation of patients' feelings of dignity and self-worth (Davidson, 1978; Schulz, 1976). These needs may be met through maximization of patients' feelings of control (Schulz, 1976), maintenance of a sense of order (Davidson, 1978), and alleviation of fears of dependency on others (Koenig, 1972, cited in National Institute of Mental Health, 1977). Specific suggestions of ways to preserve dying patients' feelings of dignity and self-worth include open communication among care providers, patients, and families (Benoliel, 1979; Dowsett, 1972; Feifel, 1963; Lebow, 1974; Mount, 1976); involvement in the treatment program (Kaylor, 1979; Lack and Buckingham, 1978; Schulz, 1976); and education about special treatments and management by patients of their own care (Kaylor, 1979; Rose, 1976).

The provision of love and affection is a third need of persons who are terminally ill (Schulz, 1976). Koenig (1972, cited in National Institute of Mental Health, 1977) found that terminally ill patients feared isolation and abandonment more than they feared death itself. Similarly, Cohen (1979, citing Feifel, 1963) states that patients can suffer more from emotional isolation and rejection than from their illness per se. Related to this need for love and affection are the needs for social interaction and for a

lifestyle as similar as possible to that prior to their illness (Davidson, 1978; Kaylor, 1979; Strauss, 1975), for intimacy (Coppens, 1977; Jaffe, 1979), and for the security of a caring staff and comfortable environment (Craven and Wald, 1975; Kron, 1976).

Spiritual needs comprise a fourth area of need which has received attention in the terminal care literature (Cohen, 1979; Davidson, 1978; Swift, 1976; Wylie, 1978). As a result of these needs, the inclusion of clergy in care programs has been advocated (Hackley et al., 1978; Wilson, Ajemian, and Mount, 1978; Wylie, 1978). Other services and skills "that assist patients, families and staff with their individual and collective efforts to be whole" are advocated as well (Davidson, 1978:146). Rogers (1978) suggests that the provision of outlets for creativity is important also for meeting spiritual needs.

Given the high economic costs patients are likely to incur due to their illness, a fifth area of patient need is for assistance with finances and health insurance coverage (Kaylor, 1979; Lack, 1978; Strauss, 1975).

Finally, closely related to this need is a sixth area of concern for individuals who are terminally ill: worry about both the economic and the emotional impact of their death on their survivors (Cohen, 1979; Schulz, 1978). To alleviate these anxieties, planning with patients for the future of their families has been suggested (Kaylor, 1979).

In sum, individuals who are terminally ill experience a number of stresses and have a variety of physical, social, psychological, spiritual, and economic needs. Presumably, recognition and addressing of these needs would enhance the quality of life remaining for these persons and would be one indicator of the quality of the care they receive.

Needs Of The Family Of The Terminally Ill

The individual who becomes terminally ill is not alone in experiencing crisis; the introduction of a life-threatening situation exerts tremendous pressure on the family as well (Benoliel, 1979, citing Cancer Care, Inc., 1973; Cohen, 1979). In fact, Buckingham and Lack (1977) discovered that the family member carrying the burden of care for a patient suffers more anxiety, depression, and social malfunctioning than the patient. Several needs of families of terminally ill patients, therefore, have been identified.

Hampe (1975) has divided these needs into two groups: needs having to do with family members' relations with the dying person; and needs related to their own personal physical and mental functioning. Included in the first group of needs are: (1) the need to be close to the dying person (Hampe, 1975); (2) the need to feel helpful and to be involved in the provision of care (Hampe, 1975; Rose, 1976); (3) the need to receive training on actual care procedures (Rose, 1976); (4) the need to be informed about the dying

family member's condition (Hampe, 1975); and (5) the need to feel confident that the patient's physical needs will receive prompt acknowledgement and competent attention by the professional care providers (Hampe, 1975).

The second group of needs of families is related more to the family's ability to personally and collectively cope with the illness and impending death of the family member. Among the needs in this group are those for: (1) preparation, information, and support from professional care providers for the impact, emotional and physical, of caring for a terminal patient (Benoliel, 1979; Buckley, 1979; Clifford, 1979), and (2) support beyond the period after the patient's death (Benoliel, 1979; Lack and Buckingham, 1978). Suggested types of support include opportunities for families to express their emotions and feelings (Hampe, 1975), comfort and support from other family members (Hampe, 1975), and financial assistance and counseling (Rose, 1976).

This brief review of the literature on the needs of patients and families suggests the importance of providing certain services to family members as well as to patients. It has been pointed out, however, that some of this literature is poorly documented, anecdotal, and based on scanty empirical evidence. Required, therefore, is future systematic exploration of the needs of terminally ill patients and their families.

Criticisms Of Conventional Care Of The Terminally Ill

Probably the major criticism of conventional care, or the medical model, for care of individuals who are terminally ill is the emphasis placed in this model on acute and curative care. Kerstein (1973), for example, argues that modern health care is geared to curing and fixing. While great medical progress has been made, the dying patient has been left behind (Benoliel, 1979; Kerstein, 1973; Stoddard, 1978). As Benoliel (1979:20) notes:

The present health care system in the United States is much better organized to implement the cure goals of practice than it is to offer person-centered care. By this I mean that the system is organized mainly for the diagnosis and treatment of disease, for the management of the person as an objective case, and for the implementation of medical treatments and related procedures done to people rather than with them. In general, the system is poorly organized to provide health care consumers with regular help geared to the subjective meanings of the disease experience, the welfare and well-being of the persons involved, and the delivery of activities designed and implemented in collaboration with the consumers.

Benoliel (1979), then, asserts that the medical model is oriented toward curing the physical ailments of patients, not toward addressing patient's psychosocial needs, and also that this model does not facilitate consumer (patient and family) participation in the care. She distinguishes needs for cure from those for care¹. "Cure" needs are those for

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Davidson (1978) notes the irony in a distinction between care and cure when both words have a common root. Citing Foucault (1973), he states that the separation

"curative medical services and life-saving activity;" "care" needs include those for clarification of:

the impact of death-related crises on completion of unfinished business, resolution or nonresolution of old conflicts, and other changes associated with preparation for the coming death or resolution of reactions to a death already completed (Benoliel, 1979:19).

It is asserted by many critics of conventional (medical model) care that, because most care providers, including physicians and nurses, are interested in cure and rehabilitation, terminally ill patients tend to be viewed as failures, people for whom nothing more can be done (Cohen, 1979; Glaser and Strauss, 1965; Kerstein, 1978; Lamerton, 1973; Quint, 1967). Concerning nurses, specifically, Quint (1967:9) notes that the demands of working with the dying "are often in conflict with the primary purpose for being a nurse--namely, helping people get well." As a result, the treatment given to dying patients frequently is poorer in quality and quantity than that given to patients with more positive prognoses (Buckingham et al., 1976; Lack and Buckingham, 1978; Wolfe, 1970).

In contrast, instead of ignoring their terminally ill patients, it is argued that many other health care personnel

occurred concurrently with the development of the clinic in the nineteenth century, when the attention shifted from the person feeling symptoms to the clinician diagnosing disease and pain, and the role of cure became a competing influence for the patient now relegated to the role of object.

react by taking heroic measures to prolong vital signs, long after all hope of recovery is gone (Cohen, 1979; Skillman, 1974; Paulson, 1973). According to Kron (1976), such aggressive measures increase the cost of care unnecessarily. Furthermore, several critics note that both heroic measures and the avoidance of dying patients by health professionals serve to isolate patients and damage their psychological well-being (Budner, 1979; Saunders, 1965).

These attitudes of health professionals and current medical standards and practices have resulted in other perceived deficiencies for care of dying patients as well. Glick (1975), Saunders (1965) and numerous others argue that because of physicians' preoccupation with curing and because of fears of patient addiction, many doctors fail to control their patients' pain. Inadequate pain control practices such as providing pain killing drugs solely on a PRN, or "as necessary," basis not only result in patient discomfort, but they also increase patients' fear of pain and, subsequently, the dosages required to alleviate their pain (Glick, 1975: Saunders, 1965). Saunders (1965) has found that patients who are given pain medication at regular intervals frequently ask if they still need the medications. Similarly, the giving of too much medication, or the "snowing" of patients, is considered an inadequate pain control practice.

According to Holden (1976), many physicians share another fear related to that of patient addiction to drugs: that of being accused of malpractice or neglect. She charges that this fear results in the feeding of patients by force, the administration of antibiotics to combat the onset of pneumonia, the giving of blood transfusions, etc., in order to keep a patient alive, even when there is no hope of cure (Holden, 1976). Critics reproach both the practice of providing pain killing drugs on an "as necessary" basis only and that of sustaining life past a logical point as constituting inappropriate physical care of the dying (Cohen, 1979; Lamers, 1978; Saunders, 1965).

Finally, another perceived inadequacy in conventional care of terminally ill people is the importance placed on sterility and sanitary practices in most health care programs (Kron, 1976; Holden, 1976). While such insistence is a part of normal standard operating procedures and is critical in the treatment of many acute conditions, Kron (1976), Holden (1976) and others argue that sanitation and sterility are of considerably less importance in caring for the dying. They declare that this overemphasis tends to produce alienating physical and social environments. Simpson (1976) argues that such environments themselves may contribute to the difficulty of the already burdensome task of coping with a life-threatening illness. For example, for sanitary reasons, most hospitals and nursing homes do not

allow children or pets into patients' rooms; intensive care units require visitors to wear gowns and masks; and furniture is designed for staff ease in cleaning and moving rather than for patient or family comfort. Such practices may inhibit social interaction. Furthermore, routines for the personal care of patients and for facility maintenance often are established for the staff's, not the patient's, convenience and preference.

The Hospice Model As An Alternative

An alternative to conventional (medical model) care for care of the dying--the hospice concept--has emerged in response to the numerous perceived inadequacies of conventional care for this population. This model conforms to the characteristics of the holistic model of care. The hospice philosophy of care holds that it is the quality, not the quantity, of life remaining to the dying and their families that is important, and that attempts must be made to satisfy not only patients', as well as families', physiological needs, but also their psychological, spiritual, and social needs (Lack and Buckingham, 1978). This notion of a comprehensive approach to patients' needs ("treating the whole patient" or "holistic care") is central in the hospice model for care of the terminally ill.

Description Of Hospice Care. About two thousand years ago, a hospice was a place of meeting, a way station, a place of rest for travelers making a pilgrimage (Stoddard, 1978). The term "hospice" as used today refers to a concept of care for the terminally ill. Modern hospice care was initiated in the 1950's by British physician Dr. Cicely Saunders, who observed that contemporary medicine was unable to respond adequately to the dying (Butterfield-Picard and Magno, 1982). As Butterfield-Picard and Magno (1982:1254) state, modern medicine:

seemed helpless when faced with the dying patient... not because the tools of medicine were themselves useless or wrong but because the organizing principle for their use among the dying was missing. A conceptual framework was needed, an alternative to the inadequate acute care framework. Saunders recognized in the medieval principle of hospice care an opportunity for a new synthesis of centuries-old ideal and contemporary technique.

Markel and Sinon (1978:15) describe the hospice program as "a humane, holistic approach to medical care." Davidson (1978:160) describes it as follows:

Hospice is a metaphor that attempts to link the needs of the terminally ill patient, the family, and the staff, with that medieval religious institution of hospitality where a community assisted the vulnerable traveler at points of great danger.

There is no standard definition of hospice. A General Accounting Office report (1979, cited by Reiss, 1982:5) states there are "four basic principles that, according to hospice advocates, distinguish hospice care from conventional health care":

- a. the patient and his/her family, not just the patient, are considered the unit of care;
- b. a multidisciplinary team is used to assess the physical, psychological, and spiritual needs of the patient and the family, develop a plan of care, and provide coordinated care;
- c. pain and collateral symptoms associated with the terminal illness and its previous treatment are controlled, but no heroic efforts are made to cure the patient; and
- d. bereavement followup is provided to the family to overcome their emotional suffering.

Osterweis and Champagne (1979:492-493) attribute the following characteristics to the British model of hospice:

- a. control of physical, sociological, psychological, and spiritual symptoms;
- b. coordinated home/inpatient care with a central hospice administration;
- c. inclusion of the family in the unit of care;
- d. provision of care by an interdisciplinary team, including volunteers;
- e. structured staff support and communication systems;
- f. acceptance of patients on the basis of need rather than ability to pay.

And Parks (1979a:58) states:

Typical hospice services include rather unconventional, sometimes sophisticated drug regimens designed to control pain; psychological and social support services for the patient and his family, including bereavement support following the patient's death; and counseling for staff members who provide care.

According to Davidson (1978:147), "What determines whether the hospice model can provide unique institutional care depends on whether it is the patient rather than staff who defines what care is."

Butterfield-Picard and Magno (1982) note the following ways in which the hospice approach differs from the traditional medical model of care for the terminally ill:

- a. control for decisions is placed in the hands of the patient/family unit;
- b. many aspects of conventional care are no longer continued when the patient does not wish them, such as acute and cure-directed treatments, which are inappropriate because (1) they often cause suffering, (2) by definition of the disease as incurable they cannot be effective, and (3) they are devastating both in terms of their financial expense and in the loss of dignity and feelings of self-worth;
- c. palliation, not cure, is the major descriptive element of hospice care; patients are to be free from pain (including psychological, social, and spiritual pain as well as physical pain), but alert and at ease;
- d. care is provided by an integrated team including physicians, nurses, psychologists, social workers, volunteers, and it is provided 24 hours per day, seven days per week;
- e. the "normal" surroundings of home are emphasized, even if care is being provided in an inpatient facility;

- f. where feasible, care is given in the patient's own home as long as this is considered appropriate by the parties involved;
- g. bereavement care and counseling are offered to family members during and after the patient's dying.

The hospice movement says, "You matter because you are you" (Butterfield-Picard and Magno, 1982:1258). In this movement, according to Butterfield-Picard and Magno (1982:1258):

Here human value and dignity exist in sickness or in health independently of external measures of productivity. Here, suffering is not ignored and death is not a failure of the medical profession.

Holden (1976) notes that the patient, not the disease, is attended to, and that the concept on which the hospice approach to treatment is predicated is "appropriate care" for each individual patient. Hospice care is a simpler, more personal type of care than that offered in the high technology hospital environment (Holden, 1976). In hospice care, the challenge is to care, not cure (Osterweis and Champagne, 1979).

A synthesis of the above descriptions of the tenets of hospice care yields the following characteristics:

- a. both the patient and the family are considered the unit of care;

- b. care is individualized, or personalized, to the needs of each patient and family;
- c. psychological, social, and spiritual needs are addressed as well as physical needs;
- d. care is provided by a multidisciplinary team of providers, including volunteers;
- e. control of pain and symptoms is of paramount importance; palliation, not cure, is the goal;
- f. the patient and the family are involved in care-related decisions;
- g. care is provided in surroundings as "normal" as possible, preferably in the patient's own home;
- h. bereavement care and counseling are provided to the patient's family members during and after his or her dying;
- i. care is available 24 hours per day;
- j. patients are accepted based on need, not ability to pay; and
- k. staff's needs are recognized and attended to, such as through the provision of counseling.

Goals Of Hospice Care. In hospice care, the intent is to help terminally ill individuals maintain a personally acceptable quality of life until death (Osterweiss and Champagne, 1979). According to Davidson (1978), the commonly accepted goal of care for the terminally ill is that a patient has a right to die with dignity, as having a

status of worth and being treated in ways of honor. He states that the hospice movement seeks to provide care for people who are terminally ill "that affirms their dignity and is not readily available in health care institutions committed to cure of disease" (Davidson, 1978:159). He argues further that patients' taboos must be respected if they are to have dignity.

As articulated by Cohen (1979:72), the goal of hospice care is to help patients:

continue life as usual--working, being with a family, doing what is especially significant before life comes to a close and feeling a part of the ongoing life--not being different.

Hospice care attempts to reach this goal through the palliation of symptoms, the provision of the security of a caring environment, provision of sustained expert care, and the provision of assurance that the patient will not be abandoned (Craven and Wald, 1975, cited by Cohen, 1979). Parks (1979a) and Holden (1976), too, argue that the principal aim of hospice care is to make the patient as comfortable, alert, and pain-free as possible so the last days can be meaningful.

For Whom Is Hospice Care Appropriate? Hospice care is appropriate for people who have fatal diagnoses, for whom curative therapies have failed and hence active treatment is no longer warranted. Cancer is the disease most likely to involve such a prolonged terminal phase; thus, cancer

patients are the most likely hospice candidates (Osterweis and Champagne, 1979). Reiss (1982) notes that because not all patients wish to die at home, because not all families are equipped to provide the necessary supportive care, and because not all patients want to forego heroic treatments to extend life, hospice care is not appropriate for all terminally ill patients.²

Delivery Of Hospice Care. According to Holden (1980), American hospices generally take one of three basic service delivery forms:

- a. a home care program which supplies medical supervision, counseling, and visits to patients whose families can take care of them at home
- b. a freestanding facility
- c. a hospice program of care within a hospital, with hospice patients either being overseen by a special team and being interspersed among regular patients, or being placed in a special palliative care unit.

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There is disagreement among hospice proponents concerning the requirement of home care. Since not all patients have the necessary familial support required for successful home care, and with the increasing availability of inpatient hospice beds, most hospice advocates now agree that death at home is not a requirement for hospice care. Reiss' (1982) latter argument (not all patients, or the families of patients, wish to forego heroic treatments to prolong life) continues to be a valid one.

Concerning hospice home care services, Butterfield-Picard and Magno (1982) note further that these services may be community-based, hospital-based, or nursing-home based. They also point out that freestanding hospices may be either hospital-affiliated or completely autonomous (Butterfield-Picard and Magno, 1982). Butterfield-Picard and Magno (1982) add that hospice care may be given within an extended care facility or a nursing home.

In sum, hospice care may be offered through a variety of service delivery modes. The basic tenets of hospice care do not change, however, regardless of the care setting.

Growth Of The Hospice Movement. In asking the question, "Is hospice care just another fad or a signal of a humanistic revolution in American health care?", Holden (1980:60) notes the rapidity with which the concept caught on, which she states indicates there were already forces at work, such as the holistic health movement ("humanistic medicine which provides a strong counterforce to dehumanizing over-specialization") and the consumer movement (which "emphasizes the demystification of authority"). Cited as well are the cost considerations as an impetus for the spread of the hospice concept (Holden, 1980; Osterweis and Champagne, 1979). These considerations will become even more pressing as the U.S. population ages and an ever larger proportion of citizens are dying of chronic degenerative

diseases (Cohen, 1979; Holden, 1980; Osterweis and Champagne, 1979).

Holden (1980:60) also attributes the growth of the hospice to the increasing specialization of medicine:

While the intense specialization characterizing American medicine may be appropriate for acute health problems, a multidisciplinary team approach is more effective when the whole person is involved.

Questions And Concerns About Hospice Care

The "hospice movement," as it is called (Stoddard, 1978), has grown rapidly and with fervor in its approximately twelve-year existence in the U.S. Nonetheless, even among hospice supporters, the swift proliferation of hospice programs has given rise both to concerns and questions regarding the continued viability of the hospice concept in the U.S.

For example, in reporting on a symposium held in October of 1979 sponsored by the Connecticut Hospice, Inc. and Hospice Institute for Education, Training and Research, Inc., New Haven, Parks (1979b:68) described the proceedings as being characterized by "realism" instead of "the unbridled enthusiasm for hospice care, which was so often displayed during other hospice meetings." Rodek and Jacob (1983:185) assert that "the need for holistic care for our dying is apparent but whether or how well hospice will fill the role remains to be seen." And Osterweis and Champagne

(1979:1259) note that hospice "continues to have many unresolved problems in moving from a fully developed philosophical base to feasible administration."

The specific concerns expressed in the literature relative to the hospice movement in the U.S. center around the fundamental questions of "whether," "how," "for whom," and "why." These questions are further specified below.

Feasibility Of Implementing This British Concept In The U. S. One of the first concerns relates to the feasibility of taking a concept developed in another country and implementing it in the U.S. As noted by Holden (1980:59):

Hospices are basically a creation of the British and it is still unclear how--or even whether--the principles they embody can be successfully incorporated into American medicine.

Osterweis and Champagne (1979) make a similar point, describing differences in health care delivery mechanisms and cultural characteristics between the U.S. and Britain. Included are the limited development of home care in the U.S., the relatively infrequent reliance on volunteers for direct service provision in the U.S., various differences in legal requirements and financial constraints between the U.S. and Britain, and the lesser societal acceptance of death in the U.S. compared to Britain.

Feasibility Of Integration Into The Traditional Health Care System. Several observers note that a principal condition for viability of the hospice concept in America

rests on the ability of hospices to become integrated into the traditional health care system (Osterweis and Champagne, 1979). Dr. Cicely Saunders, founder of the modern-day hospice, (cited in Parks, 1979b) argues that hospices must become integrated with general medical science, as does Irwin Krakoff, M.D., director of the Vermont Regional Cancer Center and himself an oncologist. He agrees with Saunders that there is a need for hospice care to interface with acute care. At the symposium mentioned above, Dr. Krakoff "charged that individuals in this (hospice) movement are using hospice care as a way to further their antiestablishment feelings about medicine and physicians" (Parks, 1979b:68) and that these individuals "fail to recognize that oncologists do care about their patients and that medical oncology acknowledges that all patients eventually die" (Parks, 1979b:68).

Reiss (1982:34) notes that as States address the place of hospice in the context of certificate of need requirements:

Consideration will be given to the value of integrating hospice concepts into existing patterns of care, rather than adding a new layer onto the system. Attention will be paid to the opportunity to convert excess hospital beds into special hospice units, as a way of avoiding the capital costs associated with construction of new free-standing hospice facilities (Reiss, 1982:34).

Asserting the need for integration while preserving program integrity, Osterweis and Champagne (1979) propose

numerous methods for achieving such integration. Included are location of programs within existing facilities (hospitals or nursing homes), inclusion of hospices within the health planning process, creation of standards and licensure requirements, and achievement of third-party reimbursement through replacement of acute care hospital beds with hospice care. Recent legislation providing for Medicare reimbursement of hospice care incorporates many of these methods.

Finally, Osterweis and Champagne (1979:1259) ask the question, "Can hospice care become a solidly established health care service available in almost every community without becoming a "big business" and without losing the characteristics that make it so important and so necessary?"

Rapid proliferation of hospices. According to Rodek and Jacob (1983:181) and Parks (1979a), the rapid growth of hospice care is creating hazards which compromise its quality. Pointing out that "the hospice philosophy evokes certain principles of care," and that there are now over 750 hospices, Rodek and Jacob (1983:181) ask, "Are all hospices delivering quality hospice care?" They express this concern because "at the present time no universal standards for hospice care exist. This situation permits many programs to be called hospice even if they only vaguely resemble the total concept" (Rodek and Jacob, 1983:181).

With the expansion of public program reimbursement (e.g., Medicare) of hospice care, Reiss (1982:28) notes that there will most certainly come concern about the quality of care provided by hospice programs, particularly as there is a "fear that expansion of payment for hospice care may lead to abuse by certain potential providers." Such reimbursement may encourage programs to state that they offer "hospice care" (Reiss, 1982; Rodek and Jacob, 1983). Also a threat to program quality are the "opportunists whose only motive for developing hospice care is to fill empty institutional beds..." (Osterweis and Champagne, 1979:1259). Many observers feel that standards pertaining to quality of care should be devised to preserve the current philosophy and principles of hospice care" (Reiss, 1982:28).

At the same time, however, Reiss (1982:28) notes that others argue that licensure and the imposition of rigid requirements for adherence to routines, reporting procedures, and patient monitoring may cause loss of flexibility, "may stifle innovation in a developing field," and may result in a loss of "much of the human element in hospice care which is probably undefinable but nonetheless key to the movement's success."

Recruitment And Selection Of Staff. Another concern centers around the selection of staff with appropriate qualities. Rodek and Jacob (1983) describe as desirable the following qualities: an adequate basic understanding of the

hospice concept, that is, not being oriented to curing and to the perpetuation of life at all costs; warmth; patience; awareness of one's own values and beliefs toward death; assertiveness; sensitivity; maturity; and technical expertise in the care of the dying. Rodek and Jacob (1983:183) argue that hasty staff selection occurs because everyone wants to "get on the bandwagon" with a hospice program. Similarly, Osterweis and Champagne (1979:1259) note the presence of "death groupies on the peripheries, full of good intentions and slightly crazy ideas, giving the public false impressions of the nature and purpose of hospice care."

Rodek and Jacob (1983:183) assert further that "hospice workers are not made, they are born" (Rodek and Jacob, 1983:183). Clearly, such a statement has serious implications for recruitment, training, and credentialing of hospice professionals.

Training Of Staff. According to Davidson (1978:vi), "the unquestioned assumption in the hospice movement" (and an assumption that he and many others apparently feel does not require questioning) is that "staff who care for the terminally ill must be specially trained and oriented if this care is to be different from that given in a hospital or nursing home." Reiss (1982:34) agrees, stating that "hospice programs use highly trained personnel with a variety of skills and special education in the needs of terminally ill patients and their families." She points out

that as the number of hospices increases, the need for such trained personnel will increase, and current training programs will have to be expanded and/or upgraded to meet this need. Reiss (1982:35) also suggests that "shortages of key health personnel, particularly nurses, may have an impact on the future development of the hospice movement."

Rodek and Jacob (1983:185), too, enumerate the "lack of appropriate staff education and support" as another hazard to "quality hospice programs." Noting the "zeal in studying the renowned hospice programs," they caution hospice programs to consider and utilize the resources of their own communities for training their staff.

Patient And Provider Acceptance Of The Hospice Concept. Osterweis and Champagne (1979:492) assert that among the factors affecting the long-term viability of hospices in the United States is "their acceptability to both the consumers and the providers of care." Rodek and Jacob (1983) also state that both the public and professionals need to understand the philosophy and the process of the hospice concept. They advocate public and professional education concerning hospices.

Competition Within The Hospice Movement. Rodek and Jacob (1983) note several areas in which competition is evidenced within the hospice movement. Included are competition within a given hospice program or agency, between hospice agencies, between the patient/family and the

hospice team, and between the private physician and the hospice nurses. This latter form of competition may lead to conflicts over expertise in assessment, in particular, and is especially detrimental as it directly affects the quality of care. Conflict between the recipients of care and the hospice team is also detrimental. These two groups may have incongruous values and goals, and the professionals (the hospice team) may be tempted to dictate "not only the 'best' medical regimen but also the 'best' emotional reactions, and even the 'best' place to die whether it be at home or in the hospital" (Rodek and Jacob, 1983:184).

Interagency competition can arise between a home health agency and a hospice program within the same agency. The traditional home health nurses may feel that they "have been taking care of the dying patient for years;" however, the approach used may not have been the holistic one embodied in the hospice concept (Rodek and Jacob, 1983).

Competition between hospice programs often is subtle but it does exist. There is anxiety about sharing ideas or insights, and communication paths become narrow or blocked. This restricts learning, fragments community resources, and diminishes the impact of hospice care on the community (Rodek and Jacob, 1983).

Appropriate Recipients Of Hospice Care. There is a lack of knowledge regarding for how many patients hospice care is needed or appropriate or desirable (Breindel and

Acree, 1980; Osterweis and Champagne, 1979; Reiss, 1982). There is a questioning of basic assumptions about for whom hospice care is appropriate. Among the assumptions challenged are: (1) that hospice care is limited only to dying persons and (2) that hospice care is appropriate primarily for those who have cancer (Osterweis and Champagne, 1979). Dr. Cicely Saunders (cited in Parks, 1979b) believes that hospice care should be offered to frail and elderly persons as well as those who are dying. Holden (1980) notes that the hospice principles, particularly in the emphasis on treating the whole person, have implications for all health care.

The Need For Research In Hospice Care. Parks (1979b) reports that Irwin Krakoff, M.D., challenged attendees of a symposium on hospice care to prove the merit of hospice care. Colin Murray Parkes, a psychiatrist at St. Christopher's Hospice in London, and Robert Buckingham, D.P.H., spoke at the symposium about the need to look at the validity of hospice care, to look at its effectiveness and legitimacy. Dr. Buckingham pointed to the anecdotal nature of current research, stating it is based on value judgment-laden case studies, and argued for the need for research that will prove the legitimacy and effectiveness of hospice programs (Parks, 1979b).

Dr. Colin Murray Parkes (cited in Parks, 1979b), however, pointed out a "Catch-22," in that despite this need

for research, established research techniques cannot be employed due to ethical reasons. Specifically, he argued that because hospice care is now so widely known, it cannot be refused to patients in order to randomly assign patients to control and experimental groups.

At this same symposium, Dr. Cicely Saunders also stressed the importance of research to determine the effectiveness of specific hospice care techniques (Parks, 1979b) and Dr. Krakoff questioned the hospice philosophy of "withholding active treatment, such as intravenous therapy" for dying patients, since such treatment can increase patients' comfort and thus be very humane (Parks, 1979b).

Also related to the need for research on hospice care is the question of the cost-effectiveness of this care. Cost-effectiveness is one of the factors that is stipulated by Osterweis and Champagne (1979) as being critical for assuring continuation of this model of care.

Summary

In sum, hospice skeptics and proponents alike note a number of concerns related to the long-term viability of hospices in the United States. These concerns include: (1) the feasibility of adapting a British concept for application in this country; (2) the need for hospice care to be integrated with the existing health care delivery system, while at the same time preserving its integrity as a

distinct model of care; (3) the establishment and maintenance of quality of care, yet the preservation of flexibility and innovation in the concept; (4) the cost-effectiveness of hospice care; (5) its acceptability to both the consumers and the providers of care; (6) the elimination of competition on several levels that is detrimental to quality care; (7) the availability of staff with the characteristics necessary for the provision of quality care; (8) the recruitment, selection, training, and support of hospice professionals; and (9) the need for research into the validity and effectiveness of the concept as a whole and of its specific parts.

DEFINITION AND ASSESSMENT OF QUALITY CARE

Defining "Quality Care"

The definition given to "quality care" provides the basis on which health care programs are developed, actually provide care, and are evaluated. Yet "quality" is extremely difficult to define. Generally, it implies excellence, but both excellence and quality are subjective concepts. Not surprisingly, the phrase "quality is in the eye of the beholder" appears frequently in the medical literature (Mitchell, 1973). Judgments of quality vary considerably both within and between professional circles and often reflect professional biases and norms (Paulson, 1973). For example, Hover and Zimmer (1978) state that physicians and

nurses tend to differ widely in the emphasis they place on the provision of information to patients about their disease or illness as a necessary criterion for "quality" care.

According to Donabedian (1966), defining quality medical care involves the application of value judgments to the various aspects of that care. Among these aspects are provider and client behaviors, interactions, treatment procedures, and health status. Once pertinent dimensions of care have been identified, standards which will indicate what constitutes "goodness" or "badness" must be specified (Brook et al., 1976; Donabedian, 1969; Kaylor, 1979). Since these standards usually are applied to specific situations, they need to be detailed. At the same time, they must be general and flexible enough to be able to incorporate new knowledge as it is developed (Donabedian, 1969).

Many criticisms of past definitions of "quality care" reflect this latter dilemma. On the one hand, several definitions have been judged as being too narrowly focused and as not addressing important aspects of care (Brook and Davies-Avery, 1977; Kerr and Trantow, 1969; McNerney, 1976). For example, much of the quality of care literature examines the activity of the physician within a hospital setting, with little attention given to the role of other care providers or other aspects of care (e.g., preventive, chronic, or rehabilitative care). On the other hand, definitions of quality often have been criticized for being too broad to be

useful, such as those incorporating the phrase "appropriate procedures." Concepts such as this provide insufficient guidance and are difficult to operationalize.

Many researchers and practitioners have attempted to define quality care despite the inherent difficulties. Providing the basis for these definitions has been the identification of dimensions of care felt to determine the quality of care. The dimensions that have received attention in the literature can be characterized as follows: (1) the scope of care, or the spectrum of services available; (2) the location of care; (3) the process of care, or the way in which care is provided; (4) the focus, or target of care; (5) the results of care; and (6) the cost of care. The following paragraphs discuss these dimensions.

The first dimension of care concerns the range of services available within a care program and the accessibility of those services (Mitchell, 1973; Sherman, 1968; Pellegrino, 1973; Rosenfeld, 1973). According to Pellegrino (1973), a spectrum of care must be available in order for this care to be considered of high quality. Such a spectrum includes preventive care, health maintenance, and emergency services, in addition to traditional mechanisms (inpatient and outpatient) for the diagnosis and treatment of acute conditions. Rosenfeld (1973) and numerous other scholars already discussed in the previous section argue that needed

psychological and social services should be available as part of the care program as well.

The second dimension of quality refers to the location of service provision (Brook and Davies-Avery, 1977; Sherman, 1968). The type of facility in which care is given (e.g., hospital, clinic), the physical characteristics of the facility, and the technical equipment available are part of this dimension and are thought to influence providers' ability to provide quality care.

A third dimension of quality care, and the one most often discussed in the quality of care literature, concerns the way care is actually provided, with focus on the diagnosis and management of common disorders (Pellegrino, 1973). One aspect of this dimension of quality is the appropriateness of treatment based on professional judgments and/or accepted standards of practice (Brook and Davies-Avery, 1977; Mitchell, 1973; Myers and Graham, 1973; Pellegrino, 1973; Rosenfeld, 1973). The competence of those providing care, their professional ethics and etiquette, and the continuity of care are other factors within this dimension which are incorporated into some definitions of quality (Sherman, 1968; Rosenfeld, 1973; Paulson, 1973).

A focus on the patient in the care process is a fourth dimension often seen as vital for care to be of high quality. Kerr and Trantow (1969), for example, base their definition of quality care on the ability of the system to

respond to patient needs. Sherman (1968) feels similarly; he argues that responsiveness of the system and its ability to focus on individuals are important correlates of quality. Pellegrino (1973) states that services must be humanely administered in order for care to be of high quality.

The results, or outcomes, of care are a fifth dimension used to define quality care that appears in the literature. Outcome criteria are generally patient-oriented and include such factors as acceptability of or satisfaction with care, the patient's degree of knowledge relative to his or her diagnosis, compliance with treatment regimens, and self-care capacity (Hover and Zimmer, 1978; Mitchell, 1973; Myers and Graham, 1973; Rosenfeld, 1973). McClure (1973) uses a more elaborate definition that incorporates assessment of the extent to which outcomes which could have been medically avoided are minimized over time.

The sixth and final dimension of quality that has appeared in definitions of quality care concerns the cost of care. Specifically, some authors argue that the extent to which services are efficient and affordable is influential in determining the quality of care and, therefore, should be included in definitions of quality (Mitchell, 1973; Myers and Graham, 1973; Pellegrino, 1973).

In sum, it is clear that "quality care" is a complex, multifaceted concept. The specific criteria of quality care that are delineated above are by no means exhaustive of

those employed by scholars in this field; the wide range of dimensions of care that are considered important, however, is evident.

Empirical Research. Donabedian (1980:35) points out that there has been little empirical research that has dealt directly with the subject of the definition of quality care. There is, however, a great deal of work that touches on the subject. He then proceeds to review relevant aspects of selected studies. His review is the most comprehensive one found. A few of these studies are highlighted here in this section; attention is focused, though, on Donabedian's summaries of the state of the art.

Most of the empirical research conducted in this area has centered around individuals' (clients', providers' or both) opinions about the attributes of providers, with inferences drawn regarding the "ingredients of goodness" in the care they give. Typically, the care given is divided into two domains: the technical and the interpersonal. Technical care is "the application of the science and technology of medicine, and of the other health sciences, to the management of a personal health problem" (Donabedian, 1980: 4). Interpersonal care is "the management of the social and psychological interaction between client and practitioner" (Donabedian, 1980:4).

Coser (1956, 1962) found, for example, in her studies of clients' views, that the ideas patients had of a good

doctor could be classified into these two categories. Somewhat more than half of the patients interviewed saw a good doctor as one who provided kindness, love, and security, while the others focused on the doctor's "scientific and professional competence." Freidson (1961) had similar findings, but he made the point that "in reality, people wanted both "personal interest" and "competence," and that "while the two attributes...were distinguishable properties and could be discussed separately, patients insisted that one could not exist without the other" (Donabedian, 1980:38 quoting Freidson, 1961).

Practitioners, in contrast, "tend to define quality not in general terms, but by specifying in detail the clinical activities of patient care, focusing almost exclusively on technical management," according to Donabedian (1980:48--49).

A few studies have expressly compared clients' and providers' views of the quality of care. Some of these studies found the views to be similar, while others discovered differences in the relative importance attributed to particular aspects of care according to the respondent's role (Donabedian, 1980:71).

Approaches For Assessing The Quality Of Care

Once the critical components of care have been identified and standards for quality have been defined, ways in which to evaluate the quality of the care given must be determined. Such evaluation is important for measuring the extent to which the health care system achieves its goals and for indicating areas which need improvement. Yet the measurement of quality has always been one of the most difficult activities to undertake in the health field.

One of the foremost scholars, and probably the principal scholar, in the area of definition and assessment of quality care is Avedis Donabedian. Donabedian (1966, 1969, 1978, 1980) lists three major approaches to evaluating the quality of care: assessment of the structure of care, assessment of the process of care, and assessment of the outcome of care. As Brook et al. (1976) note, these three approaches are defined somewhat imprecisely; some measures may be labeled and categorized as variables of more than one approach. However, the conceptual distinction is important to maintain, as each approach focuses generally on quality in a way different from the other two approaches. This next section briefly describes each of these approaches, their strengths, and their weaknesses.

The Structure Approach. The appraisal of structural variables is one of the most common approaches to assessing

the quality of care. This approach focuses on evaluating the adequacy of the organization, the training and qualifications of the staff, the physical facilities, and the rules and policies governing professional work (Rosenfeld, 1973). Donabedian (1978:13) defines the approach as encompassing assessment of "the materials and social instrumentalities that are used to provide care."

The premise of the structure approach is that quality care may be ensured by assuring the capability of the health care system to provide good medical and health care. An assumption is made, for example, that well-trained professionals in well-equipped facilities will automatically provide good care for their patients. There is, however, relatively little empirical evidence to support this contention. In addition, according to Donabedian (1969), most researchers concede that the appraisal of structural variables is too indirect to provide a definitive method of assessing care quality. A final criticism of this approach is that the structural aspects of care change slowly and generally are not considered to be useful tools for continuous surveillance of care to monitor or assure quality.

The Process Approach. The second approach to appraising the quality of care involves an examination of the process of providing care, usually focusing on diagnosis and treatment procedures. Evaluations utilizing this approach are directed toward determining the extent to which health

professionals adhere to accepted standards of practice (Rosenfeld, 1973). The assumption in this approach is that procedures based upon accepted standards of practice are related to the outcomes of the care and are useful in maintaining or promoting health (Donabedian, 1969). Standards of good practice are established by recognized leaders in the profession and involve the identification of optimal care procedures against which other professionals examine their work.

Both implicit and explicit criteria may be utilized to assess procedural aspects of care. Implicit criteria for quality care are those which are based on normative standards, or the conventional wisdom of a number of physicians or other trained personnel. Because judgments are made on a case-by-case basis as to whether correct procedures have been followed, the use of implicit criteria has been criticized as being time-consuming, costly, and unreliable (Donabedian, 1978).

Explicit methods of evaluation are based upon previously established criteria that specifically state correct procedures. Actual practice is then compared with these criteria. Advantages associated with the use of explicit criteria include the reduction of professional bias, the practicality of implementing these criteria, and the ability to replicate results (Payne, 1968). At the same time, a reliance on explicit criteria makes it difficult to address

adequately individual variability. In addition, explicit criteria for assessing the quality of care are difficult to develop, and there is considerable doubt surrounding the utility and validity of some of the explicit criteria and standards which have been used (Donabedian, 1978). Finally, it has been argued that reliance on predetermined criteria may stifle innovation and may lead to over-utilization of tests and procedures which, in turn, is likely to result in unnecessary costs (McNerney, 1976).

While resolution of the debate between the relative merits of implicit versus explicit criteria may not be forthcoming, Donabedian (1978) has proposed a solution for facilitating the use of the process approach for assessing the quality of care. This solution is to combine both sets of criteria into a two-stage approach. First, explicit criteria are developed and applied to all individual cases. Then, those cases which do not meet the explicit standards or for which application of explicit criteria is inappropriate are identified and subjected to critical review by peers, who determine implicitly whether or not the procedures used were adequate under the circumstances.

Despite this suggestion, many researchers question the wisdom of examining process variables at all. A major criticism is that once a certain procedure has been identified as being an important component of quality care, other aspects of care have tended to be overlooked or neglected

(McAuliffe, 1979). To illustrate, when treatment procedures are examined, little is done concurrently to determine whether or not the condition being treated was correctly diagnosed in the first place. Similarly, a focus exclusively on physician behaviors leaves unknown the impact of other health professionals on the care process.

In addition to the substantive issues concerning the use of the process approach to quality of care assessment, there are methodological problems associated with its use. The primary difficulty is that medical records generally are heavily relied upon as a source of data. Fessel (1972) and others report that these records are often incomplete and inaccurate and that the information contained therein is typically unrelated to outcome. A related criticism is that what actually may be assessed is the quality of the recording rather than the process of care (Donabedian, 1978). In addition to the questionable reliability and validity of using medical records, their examination requires sifting through large amounts of irrelevant information; it is, therefore, quite unwieldy. To alleviate this particular problem, abstracts of medical records frequently are utilized (National Academy of Sciences, 1974; Rosenfeld, 1973). The standardization of recording formats and the isolation of key criteria for examination could be of assistance in this regard as well (McAuliffe, 1979).

The second principal method for obtaining process-related data is through direct observation. As might be expected, criticisms of this method abound also. Among these criticisms are the potential for observer bias, the tendency for those being observed to behave in a socially desirable fashion, and the difficulty of observing certain important aspects of care (Rosenfeld, 1973).

The Outcome Approach. The third major approach which has been used to appraise the quality of care involves the study of the outcomes or results of the care provided. Theoretically, an individual's health status is affected (although not necessarily determined) by the treatment received. Therefore, advocates of the outcome approach propose that the quality of care provided be determined by examining the various changes in health status. Many researchers submit that, in fact, quality of care can be assessed ultimately only through the examination of these end results or outcomes (Lembcke, 1977; National Academy of Sciences, 1974; Shapiro, 1967; Williamson, 1970). Variables included by those utilizing this approach encompass patient mortality, morbidity, mobility and other functional abilities, amelioration of discomfort and disability, satisfaction or dissatisfaction with care received, patient compliance, and loss of time from work (McAuliffe, 1979; Payne, 1968; Rosenfeld, 1973; Starfield, 1974).

In general, advocates of the use of outcome criteria to determine the quality of care provided feel that outcomes reflect the overall adequacy of the process used by health care providers. This method also emphasizes the importance of the health and well-being of the client, which leads to a broader and more comprehensive concept of health care.

At the same time, there are a number of problems associated with the use of outcome measures. First, it is not always easy to determine what is a satisfactory or unsatisfactory outcome. Second, it is often difficult to determine precisely what effect the practitioner or treatment procedure has had on the patient. Rosenfeld (1973), for example, notes that medical care is only one of several factors influencing outcome. McNerney (1976), too, suggests that medical care has relatively little influence compared to environmental, societal, genetic, and life style factors. Even more serious is the argument that outcome and quality of care are not necessarily correlated. McAuliffe (1979) points out that good medical practice does not necessarily result in a positive outcome nor are people always adversely affected by poor care. In addition, he and others suggest that there is a plethora of methodological problems surrounding the use of outcome measures, including the absence of followup procedures and the lack of empirical validation procedures. Finally, in the case of terminal care, death is the imminent outcome. Clearly, outcome

measures other than improved or maintained health are necessary in this situation.

Strengths And Weaknesses Of The Three Major Approaches To Quality Of Care Assessment. As shown in Table I, each of the three major approaches utilized in the past for assessing the quality of care has both advantages and disadvantages. To address the shortcomings of these individual approaches, arguments have been made for combining the three (Block, 1975; Donabedian, 1978; National Academy of Sciences, 1974; Payne and Lyons, 1969; Pellegrino, 1973). For example, Pellegrino (1973) contends that the major task for those involved in the evaluation of health care should be to determine the linkage between process and outcome. Similarly, Donabedian (1978) and Block (1975) advocate the use of methods of assessing quality of care which combine process and outcome measures. They, along with others, contend that accurate and meaningful assessments of care which will contribute to improving quality of care require this combination of approaches.

Summary

In this section of the Review of the Literature, the three major approaches to assessment of the quality of health care have been outlined and their strengths and weaknesses noted. The structure approach focuses on evaluating the adequacy of the organization, the training

TABLE I
SUMMARY OF ADVANTAGES AND LIMITATIONS OF THE
METHODS OF QUALITY CARE ASSESSMENT

<u>Approach</u>	<u>Focus</u>	<u>Limitations</u>	<u>Advantages</u>
Structure	<ul style="list-style-type: none"> • Capability of organization/program to provide care • Determined through examination of staff credentials, physical facilities, and rules and policies 	<ul style="list-style-type: none"> • Little evidence to link structure to quality care • Limited focus 	<ul style="list-style-type: none"> • Data readily available • Helps to maintain minimal standards
Process	<ul style="list-style-type: none"> • Adequacy and appropriateness of procedures followed in care delivery based upon standards and practices • Determined through application of implicit or explicit criteria; usually involves use of medical records 	<ul style="list-style-type: none"> • Little evidence to link process to outcome • Limited focus (e.g., no critical examination of original diagnosis; often focus only on care provided by physician) • Data sources often unreliable 	<ul style="list-style-type: none"> • Specific procedures for improving care and upgrading standards may be identified
Outcome	<ul style="list-style-type: none"> • The results of care; the change in Health Status following treatment • Determined through examination of patients' satisfaction with care, physical status, functional capacity 	<ul style="list-style-type: none"> • Difficult to determine what is satisfactory outcome • Difficult to control for confounding factors • Outcome and quality care may not always be correlated • Absence of adequate follow-up procedures 	<ul style="list-style-type: none"> • Encourages broader and more comprehensive concept of health care • Reflects overall adequacy of the care process

and qualifications of the medical staff, the physical facilities, and the rules and policies governing professional work (Rosenfeld, 1973). The premise is that quality care may be ensured by assuring the capability of the health care system to provide good care.

The process approach involves an examination of the care process, using implicit or explicit criteria for determining the extent to which health professionals adhere to accepted standards of practice (Rosenfeld, 1973).

The outcome approach involves the study of the results of the care provided, usually by examining changes in the patient's health status or satisfaction with care.

The present study has benefited by taking note of the weaknesses of the structure, process, and outcome approaches when applied separately and heeds the advice that these approaches should be combined. Drawing from the structure approach, the assumption is made that the training of the staff (specifically, the role expectations to which health professionals are socialized) will have at least some impact on the quality of care received by the patient. Also examined are the individual characteristics of providers that terminally ill patients, family members, and health professionals feel contribute to professionals' ability to provide quality terminal care.

In keeping with the process approach to quality of care assessment, the patients, families, and health

professionals interviewed were asked to describe behaviors of health professionals that they particularly liked or felt contributed to the provision of "quality" terminal care, and those which they disliked or felt impeded the provision of "quality" terminal care.

The outcome approach variable of satisfaction with care is incorporated into the framework, albeit indirectly. Those elements which would contribute to patient and family satisfaction with care, at least with regard to provider-related aspects of care, can be inferred from the expectations for the health professional role of those patients and families who were interviewed. Similarly, the role expectations of the sample of health professionals themselves involved in the provision of terminal care can point to the attributes and behaviors on their part that would contribute to their satisfaction with the care.

This research also responds to several concerns and criticisms of previous research that are expressed by Donabedian (1980:36-67):

There is an overabundance of more or less fanciful opinions, among them my own, about what quality means or what it should mean. I wish there were as much attention given to studying how clients, practitioners, administrators, and policy makers define quality when asked to do so, and what definitions can be inferred from their actual behavior...

People are seldom asked to say what they think the quality of medical care means. The question is put indirectly. What is a good doctor, nurse, or

clinic? What is a bad one? What does the respondent like and dislike about his doctor, nurse, clinic, and so on? From these opinions about the attributes of providers inferences must be drawn about the ingredients of "goodness" in the care they give. In order to make the task simpler, the respondent is often given a list of attributes and asked to rank all these or to select some. When this is done, the questioner's view of the boundaries and content of the concept of quality may be imposed on the respondent. Moreover, the respondent's answers are influenced by his interpretation of the language in which the choices are presented. Finally, studies of this kind often deal with particular populations in special situations. When this is the case, it is not clear how generally applicable the findings are.

The research to be described here addresses the first part of this wish, soliciting the opinions of a sample of patients, family members and health professionals with regard to their definitions of quality terminal care. Respondents' views also are obtained indirectly through questions about health professionals' attributes and behaviors that are liked. These questions, however, are open-ended questions that permit respondents to use their own words, without constraint from the interviewer's biases. This work, like that of its antecedents, is targeted toward a special type of care; its applicability is, therefore, limited. Nonetheless, this study represents a preliminary step toward assessment of the quality of terminal care, an area largely unexplored to date.

CHAPTER III

CONCEPTUAL TOOLS

The purpose of this chapter is to describe the conceptual tools that have guided the framing of the research problem and the approach to its solution. First, role theory and role theoretic concepts are reviewed. Next, some of the critical issues in socialization theory and research are detailed.

ROLE THEORY

According to Conway (1978:17), role theory:

represents a collection of concepts and a variety of hypothetical formulations that predict how actors will perform in a given role, or under what circumstances certain types of behaviors can be expected.

Turner (1974:161) notes that role theory is built around an analogy drawn between the players on a stage and the actors in society; role theorists view the social world as "a network of interrelated positions, or statuses, within which individuals enact roles." For each position, there are expectations about how incumbents of roles are to behave. Role expectations are derived from: (a) the "script" (the norms that specify how individuals ought to

behave); (b) other "players" (the demands of the other players in the interaction situation); and (c) the "audience" (the "reference group that circumscribes the behavior of actors in various statuses") (Turner, 1974:162).

Role theory is not a well articulated and unified theory (Turner, 1974). Stryker (1959, quoted in Heiss, 1968:3) argues that:

There is considerable confusion and controversy regarding the nature and boundaries of role theory...there are even some who would deny its very existence as a distinct entity...however...most sociologists seem to acknowledge that there is a distinctive theory, though one would be hard pressed to get complete agreement as to exactly what is encompassed by the term.

The Concept of Role

Originally used in theater, the word "role" refers to a part played in a drama. The word began to appear in social science literature in the 1920's (Conway, 1978, citing Thomas and Biddle, 1966).

The concept of role has been defined variously by numerous sociologists. According to Biddle and Thomas (1966), a role is a set of prescriptions defining what the behavior of a position member should be. Thornton and Nardi (1975:8781) state that a role is a "set of expectations impinging on an incumbent of a social position." Shortell (1982:27) defines the concept of role as a set of "collectively held expectations which define appropriate

behavior for persons in a given social position." Coombs (1978:14) states simply that a role is "that which a person in a given status is expected to do." Heiss (1968:3) defines role as a set of "prescriptions for interpersonal behavior which are associated with particular, socially recognized, categories of persons." Hardy (1978) notes that the concept of role is useful for linking individuals and society.

Perspectives in Role Theory

Sociological theory is dominated by three different perspectives, two of which historically have treated the concept of role. One cause for the confusion concerning role theory may be the existence of these distinct perspectives. These three perspectives are structural-functionalism, symbolic interactionism, and conflict theory.

The principal social theory guiding this analysis of the health professional role in the provision of quality terminal care is structural functional theory. Structural-functionalism views society as a biological system with: (1) bounded, self-regulating subsystems, capable of maintaining equilibrium; (2) basic society needs that, like bodily needs, must be met; and (3) parts and structures which serve specific key functions for survival and equilibrium (Shortell, 1982:29 citing Maykovich, 1980). As

noted by Shortell (1982:29, citing Levine, 1977), the structural-functional approach is helpful in conceiving the health care system, as it "helps to draw attention to how behavior is influenced by values and beliefs, and not solely by physical or psychological symptoms."

Symbolic interactionism, unlike structural-functionalism, views behavior not merely as a function of adherence to normative standards, but as a direct result of the individual's interpretation of the situation, that is, the meaning attached to the interaction (Shortell, 1982).

Conflict theory focuses on conflict, deviance, and change (Shortell, 1982). For example, instead of viewing the doctor-patient relationship as one of asymmetric equilibrium in which patients are willingly subordinate, as does the functionalist Parsons, conflict theorists such as Freidson assert that patients' and doctors' interests clash (Shortell, 1982). The conflict perspective also is useful for the study of professional behavior within health care organizations and competition between professional groups and organizations for scarce resources (Shortell, 1982).

The structural tradition and the symbolic interaction tradition are evident in the two contrasting perspectives in role theory. These two perspectives are outlined briefly below.

Structural-functional_role_theory. Structural role theory has been distinguished from structural-functional

theory by Heiss (1968), who states that structural role theory:

can be viewed as that segment of structural-functionalism that operates on a micro-level of analysis rather than on a macro-level...it shares the interests and basic postulates of structural-functional theory but it focuses on a small unit, the role, rather than on a larger unit such as the group, institution, or society (Heiss, 1968:25-26).

As described by Hurley (1978:37, citing Turner, 1962), the structural-functional model of role specifies:

that the individual enacts the prescribed set of expectations appropriate to individuals in relevant other statuses, conforms to others' expectations, and receives in return some indications of approval.

Heiss (1968:28) points out that the distinctive concerns of structural-functional role theorists are their interest in the content, organization (structure) and functions of social statuses and roles. The structural-functionalist view postulates that role behaviors are learned early in life, perfected through practice in schools and early adulthood, performed on the occasions called for by the society, and then passed on to others. In this view, role behavior itself is fairly static, consisting of a rehearsed set of performances (Frank, 1974:246). The role occupant is seen as a passive recipient and enactor of cultural norms and contents.

Symbolic-Interactionist Role Theory. In the contrasting Meadian, or social interactionist, view of role theory, the principle of role reciprocity is emphasized, in

which the individual devises his role performance on the basis of the role that he imputes to the other" (Hurley, 1978, citing Heiss, 1976). This symbolic interactionist view maintains that individuals are constantly in the process of constructing roles as they interact with others, and that people adjust their behavior according to how they perceive others interpreting it (Frank, 1974:246).

Heiss (1968:5), taking the interactionist view, states that the basic postulate of role theory is that:

Social interaction is required for the development of the characteristics which make a Homo sapiens into a social being...All the basic human characteristics require social interaction at a symbolic level to develop; biological maturation and self instruction are not enough (Heiss, 1968:5). Social interaction provides a person with a self, with role-prescriptions, etc., and these are, in turn, required for social life. A circular and cumulative process is postulated.

Citing Mead (1947), Shuval (1975b:414) states that the socializee responds selectively to the expectations of significant others and internalizes the role they define for him. Robinson, 1974:18), also adheres to the symbolic interactionist perspective:

It is unhelpful to seek for the correct script for someone who occupies a particular social position or to expect there to be universal or even widespread agreement about the way the role should be played.

Criticisms Of Both Perspectives Of Role Theory. Both the structural-functionalist view and the symbolic interactionist view of role theory have been criticized. Among the major criticisms of the structural-functional

approach to role theory are that: (1) it ignores the determinative consequences of role enactments for changes or alterations in the social structure; (2) that it doesn't indicate when, where, or how processes are to occur (it simply says what processes must occur); and (3) it does not recognize reciprocity among status networks, expectations, the self, role-playing capacities, and role behavior. It is principally a classificatory concept; its main thrust is how specific social contexts determine variations in individual conduct. It does not account for the variety of patterns of social organizations (Turner, 1974). The principal, and very serious, criticism of symbolic interactionist role theory is that it has little predictive ability (Turner, 1974).

In the context of role theory, then, the primary distinction between the structural-functionalist and the symbolic interactionist perspectives appears to be that in one (structural-functionalist) roles are viewed as being scripted, while in the other (symbolic interactionist) they are viewed as being negotiated, with there being no such thing as the correct script.

According to Heiss (1968), role theorists do share two basic assumptions: (1) that roles are learned in the process of social interaction and (2) that when people interact with others, they see themselves and these others as occupants of particular statuses. The expectations

associated with those statuses are what guide the individuals' actions (Heiss, 1968:3-4). The following paragraphs describe what is meant by "expectations," as well as other pertinent role theoretic concepts.

Role Prescriptions Or Expectations

As Robinson (1974:17) notes:

The notion of expectations about others' actions, and the way in which such expectations inform the action of particular categories of people in particular situations lies at the heart of the sociologist's concern.

One framework for viewing the expectations associated with a particular role is that provided by Parsons' (1951) pattern variables of role expectation. This framework is described in detail in Chapter VI, Analytical Model.

Role prescriptions and role behaviors are learned through socialization (Hurley, 1978:34). She states that:

Role prescriptions for the occupant of a particular status not only explicitly specify how that individual is to behave, but implicitly specify as well the behaviors of persons in related positions toward the occupant of that particular status (Hurley, 1978:35, quoting Brim, 1957:345-347).

Sources of role expectations include the societal norms present in a culture or sub-culture and the individuals with whom one interacts. According to Thornton and Nardi (1975), most role behavior is prescribed and expected by others.

Role expectations may be behavioral, attitudinal, or cognitive in content (Thornton and Nardi, 1975). They may

be covert or overt; they can be described in terms of the degree of consensus concerning them, both within a source, and between two sources. Consensus/dissensus may be actual or supposed (Thornton and Nardi, 1975).

Thornton and Nardi (1975) state that there are three possible reactions to role expectations: (1) social adjustment, where there is adequate meeting of role expectations and performance, (2) psychological adjustment, where congruity is achieved between the individual's desires and needs and the role, and (3) adaptation, which occurs if the role is internalized and assimilated so the person and the role are, in a sense, inseparable. This third reaction is possible only if the first two reactions are accomplished. When there are conflicts among expectations, role conflict occurs (Turner, 1974). When it is impossible to meet all expectations associated with a given role, role strain may result (Turner, 1974).

Other Role Theoretic Concepts

Other concepts with respect to role theory also are important to delineate and define here. These include "norms," "role set," and "status" or "position."

Norms. Hardy (1978:3) defines a norm as a concept that originates in the concept of role and that "refers to a set of rules or standards guiding behavior." Gordon (1966:32) defines norms as patterned or commonly-held

behavior expectations, or as learned responses, held in common by members of a social group.

Role_Set. As defined by Merton (1957a, cited in Huntington, 1957:181), role set is "the complex of role relationships which persons have by virtue of occupying a particular status." As Becker et al. (1961:47) argue, "to understand the behavior of any one category of people in the organization, we must see them in their relations with other persons with whom they come in contact." They state further that each group "has its own perspective on the problems that arise out of their mutual interaction" (Becker et al., 1961:48). In other words, the perspectives held by occupants of a given role are related very much to the role, or position, that they hold. As articulated by Becker et al. (1961), medical students, as occupants of a position or role:

have the rights and privileges, the duties and obligations, associated with that position. Because they all occupy the same institutional position, they tend to face the same kinds of problems, and these are problems which arise out of the character of the position...The opportunities and disabilities of the student role are decisive in shaping the perspectives students hold.

To further illustrate this concept of role set, Alexy's (1981-82) research is useful. In studying the perceptions of ward atmosphere on an oncology unit, Alexy (1981-82) found that patients, family members, and staff perceived the ward atmosphere differently. He concluded

that each of these groups (patients, family members, and staff) "assumed diverse roles on the Unit which provided them with access to varying amounts of information about the relationship, treatment program, and systems maintenance dimensions of the environment" (Alexy, 1981-82:334).

Freidson (1961) also points out that members of the role set will have varying expectations of each other. He argues that this explains the conflict that appears in the doctor-patient relationship. Freidson (1961) criticizes Merton's concept of role set, however, due to its inability to allow us to assess the importance of each perspective in exacerbating or reducing conflict. He notes that an expectation has no influence in itself (Freidson, 1961).

"Status" Or "Position". Linton (1936) defines status as a position in a particular pattern of reciprocal behavior. Coombs (1978:14) states that status is "a social position that is set in the structure of a group before a given individual comes along to occupy it." Status may be defined on another level, as well, as representing an individual's position with relation to the total society. More recent theorists have used the term "position" rather than "status." Williams (1960) suggests that there are three major elements which make up a position. These are: (1) role, or functional content of the position, (2) status, or moral evaluation of the position, and (3) social power, or amount of influence carried by the position.

According to Williams (1960), position (or status) and role are inseparable. One cannot perform a role without occupying a social position.

The Role Of The Professional

Prior to discussing expectations associated with the role of the professional, it will be useful to delineate what is meant by a "profession" and a "professional."

The Concepts Of "Profession" And "Professional."

Goode (1960, quoted from Robinson, 1974:93) derives ten characteristics of "professions." These include:

1. The profession determines its own standards of education and training.
2. The student professional goes through a more far-reaching adult socialization experience than the learner in other occupations.
3. Professional practice is often legally recognized by some form of licensure.
4. Licensing and admission boards are manned by members of the profession.
5. Most legislation concerned with the profession is shaped by that profession.
6. The occupation gains in income, power and prestige ranking and can demand higher calibre students.
7. The practitioner is relatively free of lay evaluation and control.
8. The norms of practice enforced by the profession are more stringent than legal controls.
9. Members are more strongly identified and affiliated with the profession than are members of other occupations with theirs.
10. The profession is more likely to be a terminal occupation. Members do not care to leave it, and a higher proportion are certain that if they had to do it over again they would again choose that type of work.

Freidson (1970a) extracts from Goode's formulation the one characteristic distinguishing a profession from an

occupation: the right to control its own work. Robinson (1974) condenses Goode's derivations and adds this point made by Freidson to arrive at a three-part definition of a professional: (1) one who has had prolonged training, (2) one who has a collectivity or service orientation, and (3) one who has the right to control his or her own work.

Jacox (1974) uses these same three points in her definition of a professional and points out that occupations are considered more or less professional to the degree that they possess these three major characteristics. She adds:

Because of the esoteric nature of the knowledge held (by a profession), only members of the profession are recognized as competent to define what tasks and practices are necessary and safe" (Jacox, 1974:4).

Becker et al. (1961:5), in their study of medical student socialization, define people as practicing a profession when they "apply knowledge and skill in performing services for other men, for organizations, or for society at large, and when those services are accepted on trust (or at least in the short run)."

The Medical Profession And The Medical Professional.

Merton's (1957:71) definition specifically of the profession of medicine provides further elucidation:

The profession of medicine, like other occupations, has its own normative subculture, a body of shared and transmitted ideas, values and standards toward which members of the profession are expected to orient their behavior. The norms and standards define technically and morally allowable patterns of behavior, indicating what is prescribed, preferred, permitted, or proscribed. The subculture, then, refers to more than habitual behavior; its norms

codify the values of the profession. This extends even to the details of language judged appropriate by the profession; like other occupations, medicine has its own distinctive vocabulary, and like the vocabularies of other occupations, this one is often described derisively as jargon by outsiders and described appreciatively as technical terminology by insiders. The medical subculture covers a wide range--from matters of language to matters of relations to patients, colleagues, and the community--and it is the function of the medical school to transmit this subculture to successive generations of neophytes.

As Parsons (1951) states, the role of the physician belongs to the general class of "professional" roles, a subclass of the larger group of occupational roles. He then goes on to apply his pattern variable framework for viewing role expectations to this role of the physician, as will be detailed in Chapter VI, Analytical Model.

The Role Of The Patient

The Sick Role. As pointed out by Noyes and Clancy (1977), the sick role, or the social role accompanying illness, was first described by Parsons (1951). This role, like other roles, is a "constellation of expectations involving both rights and duties" (Noyes and Clancy, 1977: 41). The rights of a person occupying the sick role include: (1) exemption from the duties of his or her normal social role; and (2) the right to be cared for; since the person is not to be blamed for being sick, "members of society become obligated to him" (Noyes and Clancy, 1977:

41). These members are primarily the individual's family and his or her physician (Noyes and Clancy, 1977).

The duties of the person in the sick role also are twofold: (1) to wish to get well, since society regards illness as an undesirable state; and (2) to obtain competent help in order to get well and to cooperate with the treatment prescribed (Noyes and Clancy, 1977).

The sick role is an involuntary, temporary form of undesirable and disruptive social deviance which is conferred by the physician in his or her diagnosis of illness (Bloom and Summey, 1976). Bloom and Summey (1976:23) note that the sick role is one which "must be controlled to prevent abuses by persons who gain psychological rewards as a result of the legitimized dependency of illness."

The dying role. Only in the past few years have references to the "dying role" appeared in the literature. Like the sick role, the dying role is time limited. Instead of terminating in the restoration of health, though, the dying role ends in death (Noyes and Clancy, 1977). Both the sick role and the dying role are conferred by the physician (Noyes and Clancy, 1977). The obligations and rights of persons in the dying role differ, however, from those of persons in the sick role.

Occupants of the dying role are expected, or obligated: (1) to retain their "will to live;" (2) to make arrangements for the orderly transfer of their property and

authority; (3) to avail themselves of the necessary supports and to cooperate with caregivers; (4) to decrease their dependence upon the physician, since "society reserves the physician's role for the more important restorative function and, in so doing, jealously guards against inroads upon the physician's time and energy;" (5) to accept any loss of freedom and privileges imposed by caregivers, and cooperate with the rules and routines of caregivers; and (6) to maintain as much independence as possible. While dependency in persons in the sick role is encouraged, persons in the dying role are expected to rely upon themselves to a greater degree so as to avoid imposing an unnecessary burden on the caretaking system (Noyes and Clancy, 1977).

The rights of persons in the dying role include: (1) permanent exemption from the responsibilities and commitments of their previous "well" social roles, and the right to gradually disengage from the social system; (2) the right to be taken care of; and (3) the right to continuing respect, status and dignity (Noyes and Clancy, 1977).

Osmond and Seigler (1976, cited in Mullaly and Osmond, 1979) and Williams (1982) also have differentiated between the "sick role" and the "dying role." All three of these researchers, as well as Noyes and Clancy (1977) note that recent years have continued to see the assignment of dying persons to the sick role. They argue that such assignment is inappropriate. Mullaly and Osmond (1979:411) assert:

Doctors and nurses are responsible for recognizing these differences (between the sick and the dying role), and for insuring a proper transition from the sick role, where every effort must be made to save the ill person's life, to the dying role, where the goal is not to save life but to insure a relatively painless and timely death.

Mullaly and Osmond (1979:411) argue that "history shows that for centuries these roles were clearly defined and these skills practiced effectively." Williams (1982:8) concurs:

Historically, the care of persons who could not be cured has always been a part of the role of health professionals--in particular, of physicians and nurses. Only within the twentieth century has it become possible for the curative emphasis to become dominant in medicine.

To substantiate this claim, Williams cites Feifel (1977) and Kastenbaum (1977). Williams (1982:8) goes on to note the negative implications of "denial of a legitimate professional role related to the dying," including the viewing of every death as a treatment failure, with consequences of burnout, isolation and neglect of patients, intrastaff conflict, and patient-staff conflict.

The Role of the Health Professional

Williams (1982) notes that physicians and nurses have components to their professional roles that are reciprocal to the sick role and to the dying role. The "therapeutic," or curative, role is reciprocal to the sick role and is "that role associated with active medical treatment and aimed at the restoration of the patient to health"

(Williams, 1982:9). The "supportive" role is "that set of role behaviors aimed at caring for the patient, supporting independent functioning, and easing pain and discomfort" (Williams, 1982:9).

Summary

This section has reviewed a number of concepts with respect to roles, role expectations, and role theory. As discussed in the following section, the processes of socialization through which these role prescriptions and expectations are acquired is the subject of considerable disagreement. Relevant issues in socialization theory and research are presented.

ISSUES IN SOCIALIZATION THEORY AND RESEARCH

The literature pertaining to socialization theory and research is fragmented and noncumulative (Levinson, 1967). One explanation for this may be that, as noted by Hurley (1978), the area known as "socialization" has emerged from three different traditions: sociology, anthropology, and psychology. As a result, there is no one general theory of socialization (Levinson, 1967; Hurley, 1978). Nor, as might be expected, is there consensus with regard to how to define the term "socialization." In addition to the question of the definition of "socialization," there are a number of major theoretical issues differentiating the sociologists,

anthropologists, and psychologists who are concerned with the process of socialization. These issues, as summarized by Hurley (1978:30, citing Goslin, 1969), include:

the relative importance of early as opposed to later experiences on socialization outcomes; the relative emphasis attached to individual needs, motives, and drives as opposed to environmental determinants of behavior; the relative importance attached to process as opposed to content in predicting the outcomes of social behavior; the emphasis placed upon the unique aspects of the socialization experience as opposed to its common properties; and, finally, the focus upon the processes promoting conformity to societal norms as opposed to the causes of deviations from these behavioral norms.

Further distinguishing psychologists from sociologists are "differences in views regarding the characteristics of the learner and the learning process and differences in the conceptualization of socialization as an active or passive process" (Hurley, 1978:30).

This section provides an overview of certain issues related to socialization from a sociological perspective that have relevance for this study, including:

1. What is "socialization?"
2. How does socialization occur? That is, who are the socializers or socialization agents, and what is their relative importance?
3. Is the socializee an active participant or a passive recipient in the socialization process?

4. Does the attitudinal learning that occurs represent change or maturation in the individual?
5. What is the status of the socializee during the socialization process?
6. What are the outcomes of socialization and how enduring are they?

Definition of Socialization

Socialization has been defined differently by various sociologists. The definitions of Merton (1957a) and Jette (1974) are most useful for the purposes of the present study.

Merton (1957a:40-41) defines socialization as:

the process through which individuals are inducted into their culture. It involves the acquisition of attitudes and values, of skills and behavior patterns making up social roles established in the social structure.

Jette (1974:272) defines socialization as:

the process whereby individuals learn and internalize the attitudes, values, and behaviors appropriate to persons functioning as social beings and responsive, participating members of their society. Socialization ensures that the individual will develop an identity, or self, and also the motivations and requisite knowledge to perform adequately in the social roles he is called upon to enact throughout his lifetime.

Jette (1974) goes on to state that, once recognized, the societal and cultural patterns of socialization help to explain consensus in role definitions and behaviors,

attitudes, and values observed in the majority of individual members of a society.

As summarized by Elkin & Handel (1972:29-32, cited in Hurley, 1978:32), the goals of socialization, from the societal perspective:

focus primarily on the attainment of some form of competence that the society accepts as appropriate for adult performance, as well as an internalized commitment to continuing responsible participation in society.

Types of Socialization. There are several types of socialization, including child socialization, adult socialization, role socialization, occupational socialization, professional socialization, developmental socialization, and resocialization. In the present study, the focus is on adult role socialization, and specifically, professional socialization.

Role socialization, or role acquisition, while it may not encompass the whole of socialization, is a very important aspect of adult socialization (Bloom, 1979). Role socialization is "the acquisition of the habits, beliefs, attitudes, and motives which enable a person to perform satisfactorily the roles expected of him in his society" (Bloom, 1979:39, quoting Brim and Wheeler, 1966:53).

By "professional socialization" is meant socialization into a professional role. Professional socialization is a form of occupational socialization, which, in turn, is a particular type of role socialization.

The professional socialization of physicians, in particular, has received considerable attention from sociologists interested in occupational socialization. Merton (1957) points out that this is due to the fact that the medical profession commands the greatest amount of prestige in American society, and that other professionals often look to the profession of medicine as a model. This attention is reflected in the remainder of this review of the professional socialization literature.

Shuval (1975b:413) defines professional socialization as a process occurring "over a period of years during which candidates gradually learn the values, attitudes, and normative behaviors of the professional group in which they are seeking to acquire membership." She notes that professional socialization may be viewed as a special form of adult socialization. Finally, Jacox (1974) points out that the formal beginning of professional socialization is admission to a professional school.

Developmental socialization and resocialization are two final types of socialization. Examples of developmental systems include schools and universities. Resocialization systems are those that attempt to correct deficiencies in earlier socialization, such as prisons and mental hospitals (Bloom, 1979). While developmental socialization is of primary interest in the current research, the possibility of a need for resocialization also will be considered.

The following sections devote attention to specific issues in socialization theory and research as they relate to professional socialization.

Who Are The Socializing Agents And What Is Their Relative Importance In The Process Of Socialization?

The basic dilemma raised in this question, as it relates to professional socialization, centers around the importance of the educational institution in the process of socialization. With regard to the professional socialization of physicians and nurses, the question is whether the socializing agents are the medical school and the nursing school exclusively.

Lurie (1981) points out that there are three major sociological approaches to professional socialization. These include: (1) the Mertonian school, in which education and training are seen as the primary determinants of professional socialization; (2) the Becker-Freidson school, in which the effect of situational factors in the work setting is considered; and (3) the Light (1980) school, in which professional socialization is viewed as an interactive process choice among role models on the basis of personal compatibility. The present study incorporates the first two views; while the contribution of personality to professional socialization is recognized, this issue is not directly addressed (see Chapter IV, Conceptual Framework).

The view that the medical school is the sole socializing agent for the physician's role is advanced in the classic work by Merton et al. (1957), The Student Physician. Merton (1957b:76-77) states that medical schools "have the double function of transmitting to students the cognitive standards of knowledge and skills and the moral standards of values and norms." The function of medical schools, Merton (1957:7) asserts, is:

to transmit the culture of medicine and to advance that culture...to shape the novice into the effective practitioner of medicine, provide him with a professional identity so he comes to think, act, and feel like a physician.

Becker et al. (1961), however, take another view. They argue in their classic study, Boys in White, that both the medical school and the collective character of students (medical school culture) influence physicians in training, but the role of the medical school is of low influence.

Coombs (1978:16) asserts that:

In sociological terms, the medical school is a formal socializing organization whose mission is to process medical aspirants so that they can function effectively and confidently in their new status as physicians.

He also argues, however, that informal sources (e.g., classmates, friends) as well as formal sources (i.e., the school) are involved in the process. In a similar vein, Brim (1976) asserts that socializing agents can be formal or informal.

Alternatively, Jette (1974:272-273) takes the view of socializing agents primarily as informal sources, declaring that the socialization process "emerges in the context of mutual interaction with others in interpersonal relationships." Bloom (1979), too, questions the importance of the school (formal institution) in the socialization process. Citing studies by Jacob (1957) and Barton (1959) of college student attitudes, Bloom (1979:28) notes that "there is indeed a doubt whether, at the higher educational level, schools have any significant influence at all on student values." He goes on to state:

Much has been taken for granted about the relationship between the medical school and the profession it serves, but there has been comparatively little study of this relationship. Although "socialization for the professional role" has been conceived of as the major theoretical problem, the concentration of data collection has been in the medical school. The relevance of the findings of such research for behavior (emphasis added) in the physician's role has been largely a matter of assumption.

Traditionally, the medical school has been closely tied to its parent profession. In taking the Hippocratic oath, still used for the ritual entry into the profession, the new medical school graduate swears "to teach...this art...by precept, lecture, and every other mode of instruction... (to) impart knowledge of the art of (his)...own sons and those of... (his) teachers, and to disciples...according to the laws of medicine." By this symbolic act, the point of formal entry into the profession is rooted in a strong tradition that to practice is also to teach (Bloom, 1979:32).

Bloom's (1979) caveat with respect to the unknown nature of the link between professional socialization to the role and actual behavior in the role is important to

note. Nonetheless, Bloom (1979:32) argues that given the continued use of the Hippocratic oath, "the assumption that the faculty of the medical school still represents, broadly speaking, the prevailing norms of the medical profession seems justified." At the same time, pointing out the advent of new professional medical roles such as the full-time faculty physician and the nonmedical professionals who now have teaching, research, and patient care responsibilities in the medical school, he questions the feasibility of assuming that the medical school is the one legitimate socializing agent of the profession (Bloom, 1979).

Furthermore, arguing that by definition, socialization produces "an internalized set of behavioral guides," Bloom (1979:36) raises the possibility that these guides "may or may not be appropriate for the operating behavioral requirements of the situation for which it is preparatory." He asserts that the issue of predominant socializing agents remains to be answered:

Is the medical school a separate institution, the setting mainly for its own distinctive culture and experience? Or is the medical school the direct representative of the medical profession, a socializing agency with a major function in preparing the total physician in attitudes and values as well as in the skills and knowledge necessary for his or her professional role?

A final perspective is revealed in a survey by Blumenfield, Levy, and Kaufman (1979) specifically of attitudes of

medical students toward communication with patients. These researchers found no statistically significant differences between different classes or between residents in different years of training. They conclude: "These attitudes are not altered by formal education or clinical experience" (Blumenfield, Levy and Kaufman, 1979:307).

Questions and findings along similar lines are found in the literature concerning the professional socialization of nurses. Gliebe (1977), Myers (1982), and Strauss (1968) all point to the disparity between what a nurse must know in the work setting, (as well as what beliefs, attitudes, and behaviors she or he learns at work) and what is taught at school.

Confusing the issue even further is the fact that aspiring nurses may enter the profession through any one of three educational structures: an associate (two-year) degree program; a hospital-affiliated (three-year) diploma school, or a baccalaureate (four-five year) university-affiliated program (Alutto et al., 1971). In their cross-sectional study of a total of 380 senior nursing students in these three different types of programs, Alutto et al. (1971) found a correlation between the type of program entered and personality type (e.g., students in associate degree programs had higher levels of authoritarianism). They note that the training and primary occupational socialization of new members into a profession "has been

assumed to be relatively constant and reliable" and, similarly, that "it has perhaps been natural to assume that members of any given professional society are relatively homogeneous in terms of skills and values" (Alutto et al., 1971:140). Their research was designed to test empirically this set of assumptions for the nursing profession.

Given the differences in personality found, Alutto et al. (1971) conclude that "homogeneity of the socialization of the nursing profession may be neither desirable nor possible, if the assumption is made that the minimum professional knowledge of incoming professionals is relatively equal. The variations allow for assimilation of individuals with different personality characteristics.

Gliebe (1977) points out that the effectiveness of professional socialization is determined by the degree of consensus on the part of the school's faculty. Quint (1967) also observes differences in teacher perspectives and the effect of these differences on student attitudes. And Jacox (1974) notes that expectations regarding a profession begin to develop long before professional socialization (formal education) begins; these expectations can influence the effectiveness of professional socialization. The socializing agents posited by Jacox (1974) to contribute to professional socialization of the student include the faculty, the clinical settings, the patients, other

students, members of other disciplines, and the larger community of which the school is a part.

In the present study, the focus is on the faculty and the clinical setting (the "school experience" of physicians and nurses in training) as well as the workplace. The potential for self-selection of personality types into professions, while important to keep in mind, is not directly examined. This latter possibility has implications both for the training and the recruitment of health professionals. For example, Searle (1981) notes that physicians learn an obsessive-compulsive role as part of their professional socialization and as a reaction to their work situations. She further argues, however, that a physician's "personality type may predispose him to accept role demands: Type A personalities are particularly susceptible" (Searle, 1981:185).

Is The Socializee An Active Participant Or A Passive Recipient In The Process?

One of the issues that most clearly distinguishes positions on socialization is that of whether the person being socialized (the socializee) is seen as an active participant or a passive recipient in his or her socialization. The view of the socializee as a passive recipient of cultural norms and contents sees the effects of socializers as being unidirectional. The view of the

socializee as active sees socialization as a reciprocal process in which the socializee and the socializer are mutually influenced. This latter view has become increasingly popular (Hurley, 1978).

The dilemma in this question, once again, can be attributed to the issue of whether a structural-functional or a symbolic interactionist perspective is taken. Adherents of the structural-functionalist view see the socializee as passive, while symbolic interactionists see the socializee as active (Hurley, 1978).

Does The Attitudinal Learning That Occurs Represent Change Or Maturation In The Socializee?

Early research into socialization for the role of physician found that changes occur in students' attitudes while they are in medical school. Eron's study of cynicism-humanitarianism (1955, cited by Bloom, 1979), for example, found increasing cynicism among medical students as they progressed through school and decreasing cynicism among law students and nurses. (Bloom (1979) cautions readers, however, that the attitudes held by law students at the outset of their studies generally are quite different from those of beginning medical students, with law students cynical and medical students humanitarian). Lasagna (1968), too, found changes that occur in medical school, including a decrease in idealism, increased cynicism, and increased

emotional detachment. The findings of Gordon and Mensh (1962, cited in Bloom, 1979:30) in their comparison of freshmen and seniors corroborate those of Eron and Lasagna. Gordon and Mensh (1962, cited in Bloom, 1979:30) concluded that their study:

confirms the findings of other investigators that from the first year on, being benevolent, in the sense of wanting to help other people, becomes decreasingly important to the medical student.

Bloom (1979:30), however, questions whether these and similar findings are "a valid indication of the medical schools' functioning in some way to make cynics of idealists, and therefore to dehumanize the approach of future physicians toward their patients." He notes, for example, that Becker and Geer (1958, cited in Bloom, 1979) assert that medical students, like others their age, simply become more realistic. This change toward realism was interpreted by Becker and Geer as a functional learning process, since "for a doctor, this growth toward realism is especially necessary if one is to be effective as a physician" (Bloom, 1979:30). Bloom (1979) also notes that Fox (1957) speaks of a developmental process, but instead of viewing this change of attitude as a correction of naive stereotypes, she sees it as a "patterned experience built into medical educational situations that produce attitudes specifically fitted to the doctor's role" (Bloom, 1979:31).

Support for the view of the socialization process as a developmental, or maturational, one also comes from the work of (1) Thornton and Nardi (1975), two sociologists working in the area of role socialization generally, and (2) Coombs and Powers (1975), who have examined the process of socialization for the physician's role specifically as it pertains to death and dying.

Thornton and Nardi (1975) suggest that there are four stages of role acquisition, beginning with anticipation and followed by formal, informal, and personal stages. In the anticipatory stage, those aspiring group membership begin to adopt group values, idealizing what the role should involve rather than what it does involve; a role is broadly defined, incomplete and ambiguous. They state that future adjustment to a role may depend upon the degree of accuracy of what is conveyed and perceived about the role at this stage.

In the formal stage, the individual shifts from viewing a position, or role, from the outside to seeing it from the inside as a member of a role set. In this stage, role expectations and requirements are clearly defined, often in formal, written terms. These expectations are also idealized and tend to refer to expected behavior, knowledge and skill. Attitudinal elements may be present, but usually they are not emphasized. Examples include professional standards and norms. The instrumental purposes of the role are emphasized, and there is a fairly high degree of

consensus concerning appropriate behavior and the skills and knowledge necessary for role performance (Thornton and Nardi, 1975).

In the informal stage, Thornton and Nardi (1975) suggest that informal features of the role arise and are transmitted through the interaction of individuals, especially colleagues. Personal expectations of the role may be in opposition to formally expressed ones, so there usually is role dissensus. In this stage, individuals begin shaping the role to themselves.

The personal stage is described by Thornton and Nardi (1975) as a time of relative role consensus, where the individual is able to influence others' expectations of him/her. This stage is viewed as the most important in terms of adjustment to the role. While this personal stage is not necessary for role performance, it is important for adjustment to the role and satisfaction with one's position.

Coombs and Powers (1975) speak similarly of a developmental role socialization process whereby physicians-in-training specifically master the complexities of the clinical role pertaining to death and dying. Their thesis is that medical practitioners evolve through five fairly predictable, but not inevitable, developmental stages.

The first stage, according to Coombs and Powers (1975), is the preprofessional stage. In this stage, the student still has the layman's attitude and personally

identifies with the dying patient. The student has an idealized view of the doctor role: "the doctor as a bulwark against death and suffering" (Coombs and Powers, 1975:253) and "the physician, like the proverbial country doctor, should be warm and compassionate" (Coombs and Powers, 1975:254).

The second stage which Coombs and Powers (1975) found medical students to go through was that of "desensitizing death symbols." They found that students have repressed anxieties and use a number of coping mechanisms, including humor, overwork, and adopting a "detached scientific attitude" (Coombs and Powers, 1975:257). According to Coombs and Powers (1975:257), students learn "the expected professional response" which is "a calm, objective rationality and a full control of emotion" in preparation for encounters they will have with living patients.

The third stage is "objectifying and combating death" (Coombs and Powers, 1975). Students develop a protective shield to reduce the emotional impact when a patient dies. The principal method used in this depersonalizing is to objectify death, to deny the subjective features:

The clinician learns to view dying patients not as people with feelings, but as medical entities, specimens, or objects of scientific interest...the old scientific fragmentalization method...heavy demands are routinely made upon medical trainees to be exhaustively thorough in trying to keep people alive and well...Not until every life-saving attempt has been exhausted do they let up. In the hospital setting, such extraordinary efforts to revive the

patient and prolong life are routine (Coombs and Powers, 1975:259).

Coombs and Powers (1975) note further that in the clinical pathology conferences ("death rounds"), poor clinical performance and methods which could have prevented death are discussed, but there is no forum for the giving of praise for a job well done. The assumption is made that "death is preventable and is not supposed to happen to good physicians" (Coombs and Powers, 1975:260). Death is viewed as the enemy, as a failure, and the clinician's reputation and self esteem are at stake (Coombs and Powers, 1975).

The fourth stage posited by Coombs and Powers (1975) is "questioning the medical model." Physicians enter this stage "when they can no longer escape the absurd extremes to which efforts are sometimes taken to keep patients alive" (p. 261). Physicians at this stage see these extremes as "incompatible with good medical practice" and come to realize that "it is unrealistic to expect a cure for everybody" (Coombs and Powers, 1975:263).

The fifth stage, "dealing with personal feelings," is a stage of self examination (Coombs and Powers, 1975).

Coombs and Powers (1975:263) note that the physicians they interviewed were "having a horrible time dealing with death and dying on a personal and professional level," yet

everyone knows that the good doctor is supposed to be calm, with his own feelings under control-- someone on whom the family can rely for steady support, insight and understanding. The doctor who

feels anxiety or fear in the face of death must carefully conceal these emotions.

The physicians at this stage "fault their mentors for giving them such little help with the subjective aspects of death" (Coombs and Powers, 1975:266).

In summary, the findings and assertions with regard to this issue of whether the attitudinal learning that occurs during professional socialization represents a change or maturation in the socializee are contradictory. Whether (1) attitudes change as a result of the professional socialization process, (that is, whether commitment occurs, involving "a personal attachment to certain activities and goals ... (providing)...a basis for consistency and stability in individual behavior in different situations") (Levinson, 1967:258, citing Becker, 1964); (2) changes are temporary situational adjustments; or (3) the socializee simply matures remains unresolved.

This issue appears to be linked to that of the relative importance of the formal educational institution in the professional socialization process. A related issue concerns when this process occurs. The work of Thornton and Nardi (1975) and Coombs and Powers (1975) seems to suggest a developmental process occurring beyond the years of medical school. It seems plausible, however, that the development posited by these researchers could be sped up by effecting changes in the educational process (e.g., by providing

students with opportunities for dealing with the subjective aspects of being a physician, as suggested by Coombs and Powers, 1975).

What Is The Status Of The Socializee During The Socialization Process?

There are two predominant and contrasting views with regard to the status of the socializee during the professional socialization process. These views are enunciated in terms of the professional socialization of physicians by Becker et al. (1961) on the one hand and Merton et al. (1957) on the other. The perspective of Becker et al. (1961) is of the socializee as a subordinate, or a "boy." Merton's (1957b) and Huntington's (1957) position is that socializees comprise a "little society," as Bloom (1979) states, and that as students move through medical school they tend to develop an image of themselves as doctors rather than as merely students (Huntington, 1957).

What Are The Outcomes Of Socialization And How Enduring Are They?

According to Levinson (1967:258):

Perhaps the central question of socialization theory... (is) What kinds of relatively enduring, professionally relevant changes, if any, do students undergo under various socializing conditions (ecological, cultural, structural, processual, and the like)?

This question is related to that concerning whether attitudinal changes undergone by socializees truly represent

changes in commitment that can be attributed to their professional socialization, whether they are simply a function of maturation, or whether they occur as a result of situational adjustment (e.g., to the medical school).

Levinson (1967:258) asserts that:

Socialization theory does involve the premise that the most significant changes wrought in the student are the relatively enduring ones, and that they will exert an appreciable influence on his further professional development even though they may also be modified in the process. In other words, the socializing experience brings about changes in certain personal characteristics; these affect the student's subsequent career and are in turn affected by it. Socialization research thus deals with the interplay of environmental contexts and relatively enduring yet changeable personality structures.

In sum, Levinson (1967) argues that changes that are not enduring are out of the purview of socialization theory and research.

Coombs (1978) notes two divergent approaches evident in previous studies of the professional socialization of physicians: (1) longitudinal designs to trace changes in student attitudes through the course of medical training (e.g., Eron, 1955, 1958), and (2) detailed case studies of the socializing institutions (e.g., by Becker et al., 1961) and their sociocultural milieu. Studies of this latter type, however, tell more about students' adaptation to the medical school culture than about enduring changes undergone by students (Coombs, 1978; Levinson, 1967). Given this, Levinson (1967) asserts that the Kansas group (Becker et

al., 1961) "cannot systematically pursue" what he has termed perhaps the central question in socialization research, that of the enduring outcomes of socialization.

Entwined with this question is that of conformity to the normative role to which the professional is socialized. Waitzkin and Waterman (1976, citing Freidson, 1970) argue that it cannot be assumed that concrete behavior reflects the norms to which the professional has been socialized. As noted earlier, Bloom (1979:32) makes a similar point, asserting that while the concentration of data collection regarding socialization for the professional role has been in the medical school, the "relevance of the findings of such research for behavior in the physician's role has been largely a matter of assumption."

Summary

This section has provided an overview of some of the concepts and issues within socialization theory that have relevance for the present study. The conceptual tools described in this chapter have guided the development of and are incorporated into the conceptual framework for the research. This framework and the specific research questions addressed in the present study are presented in the next chapter.

CHAPTER IV

DESCRIPTION OF THE RESEARCH

In this chapter are presented the conceptual framework that guided this research and the specific research questions and hypotheses that are examined.

CONCEPTUAL FRAMEWORK

The purpose of this conceptual framework is threefold: to designate the areas of inquiry of this research, to clarify the interrelationships of these areas, and to specify the theoretical assumptions underlying the present study. Figure 1 depicts this framework. Each of the various areas, or variables, has been enclosed by a box which is lettered. In the narrative that follows, the letter of the box is given, as well as the name of the variable being described.

As shown in Figure 1, the two principal outcomes of interest, or dependent variables, are the normative (ideal) expectations for the health professional role in the provision of quality terminal care (Box F in the figure), and the long-term viability of hospice care in the U.S. (Box G). A number of factors are conceptualized as affecting these

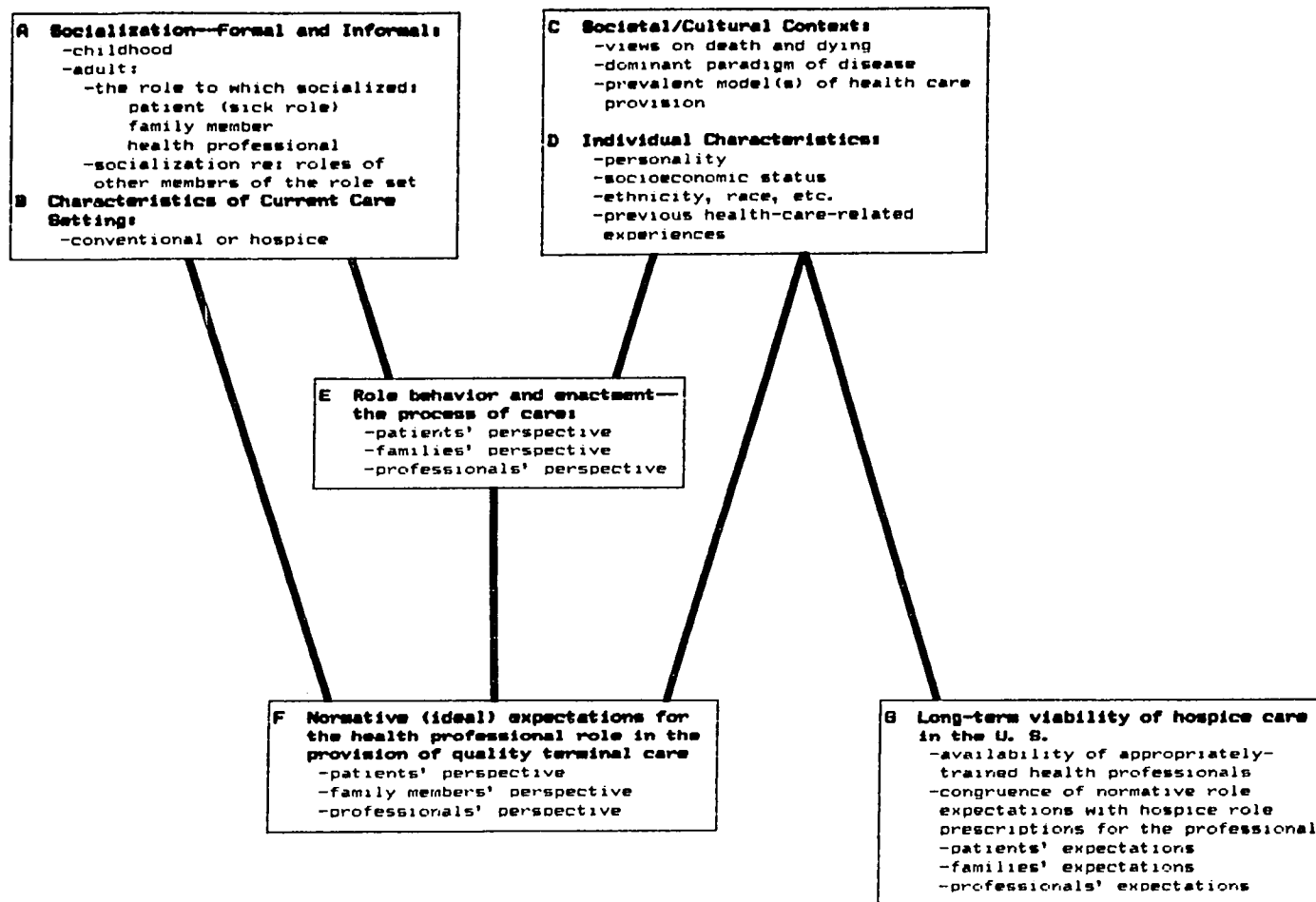


Figure 1. Conceptual framework.

normative role expectations and, ultimately, the viability of hospice care in the U.S.¹

Factors related to the societal/cultural context (A) are conceptualized as a major determinant of individuals' role expectations for the ideal provider of terminal care. Among these factors are societal views on death and dying. As pointed out earlier, ours has been termed a "death-denying society." Death denial may be expected to predispose future professionals toward avoidance of dying patients. Patients and families may be predisposed toward denial of impending death and toward failure to prepare for this eventuality. Such behaviors and attitudes on the part of each group have consequences for the professional-patient, or professional-patient/family relationship, particularly in the areas of communication and patient/family participation in the care.

Another social/cultural context variable is the paradigm of disease that is dominant. Whether the paradigm disease is acute or chronic is seen as likely to affect, through socialization processes, the role expectations for the provider of terminal care. Another such factor is the

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With regard to this last outcome, it should be pointed out that several factors not included here also figure in the feasibility of hospice care, such as the cost of care, but these are beyond the scope of the present study.

model(s) of health care provision that currently is prevalent (i.e., medical or holistic).

Socialization, both formal and informal (C), then, is the next factor conceptualized as affecting role expectations for the ideal provider of terminal care. Of particular importance in this research is adult role socialization, in which individuals learn the expectations associated with a given role, such as the role of the patient, the role of the family member, or, of primary interest here, the role of the professional health provider. In addition, the expectations associated with other members of the role set are learned. The patient, his or her family members, and the professionals involved in the patient's care comprise the role_set in this research. As will be recalled, this concept, developed by Merton (1957a, cited in Huntington, 1957:181), refers to "the complex of role relationships which persons have by virtue of occupying a particular status." Each of the groups in the role set has its own perspective. Expectations for the role occupied as well as expectations for the other members of the role set are learned through socialization processes.

Individual predisposing characteristics (D) are viewed as a third set of factors affecting role expectations for the ideal provider of terminal care. These characteristics include the individual's personality, socioeconomic status, ethnicity, race, and other demographic characteristics, as

well as previous experience with health care professionals and settings

The type of care that is currently being received or provided (conventional or hospice) (B) is a fourth factor seen as likely to influence the expectations for the ideal provider of terminal care. As described momentarily, a tentative hypothesis is advanced that the expectations of patients, families, and providers in conventional care programs are likely to be more similar to the conventional (medical) model of health care than are those of patients, families, and providers in hospice care.

In addition to affecting directly the role expectations held for the ideal provider of terminal care, all of the above factors are seen as affecting role behavior, or the way in which the role is enacted by the individual (E) in the process of giving or receiving care. Role behavior itself, particularly that of the other members of the role set, also directly affects role expectations.

Finally, the above-described factors all indirectly affect the long-term viability of hospice care in the U.S. (G). In addition, three factors are seen as directly impacting the future of hospice care: socialization (C), and particularly the role prescriptions to which health professionals currently are socialized (F) and the societal/cultural context (D).

The conceptual framework employed in this research can be summarized, then, as follows: (1) the dominant social/cultural context is reflected in social and cultural norms concerning roles and role expectations; these norms are transmitted through socialization processes; (2) combinations of roles form role sets, or groupings of roles that intersect; persons who occupy different roles have different perspectives concerning problems and situations by virtue of their contrasting, although complementary, roles; (3) behavior is governed by normative expectations, but not exclusively; individual predispositions and characteristics contribute to behavior as well; (4) the dominant social/cultural context, socialization processes, the particular role occupied, individual predispositions and characteristics, and the characteristics of the care setting in which care is being received or provided are all factors that contribute directly to role behavior and to the normative expectations held for the role of provider of terminal care; these factors contribute indirectly to the viability of hospice care in the U. S. with regard to the availability of professionals capable of providing hospice care, and the acceptability of hospice care to consumers and providers alike.

The conceptual framework described above has guided this research and melds aspects of all three of the dominant sociological perspectives that have been detailed in Chapter

III, Conceptual Tools: the structural-functional, the symbolic interactionist, and the conflict perspectives. Rather than choosing a "partisan" approach, elements of each have been selected in order to lend the greatest amount of understanding to the research problem at hand. Emphasis is given to the structural-functional viewpoint, however, as it affords a logical first step in assessing the role (a structural-functional concept) of the health professional in the provision of terminal care.

The framework employed is consistent with that developed by Bloom (1963, cited in Bloom and Summey, 1976), which has as its central concept the social system. Bloom's model is an extension primarily of the work of Parsons (1937, 1951, 1968), Szasz and Hollender (1956), Spiegel (1954), Kluckhohn (1950, 1958) and Bales (1950) (all cited in Bloom and Summey, 1976). The essential premise of this and all models of the social system is that "social relationships have a pattern based on learned cultural expectations and maintained by the functional homeostatic processes inherent in all systems" (Bloom and Summey, 1976:31).

Bloom's (1963, cited in Bloom and Summey, 1976) model contains the roles of the doctor (A) and the patient (B) and the two important elements of this relationship--(X) "the personalities of the participants, upon which the 'rapport' is dependent" (Bloom and Summey, 1976:26) (an

expressive transaction), and (Y) "the skill of the physician as a 'medical scientist'" (Bloom and Summey, 1976:26) (an instrumental transaction). "Social forces," including the medical profession for the physician and the family for the patient, figure into this model since they affect how the roles A and B are interpreted. Additional "subcultural reference groups" encompassing factors such as "class, race, religion, and ethnicity, which function in particular cases as the significant sources of value-orientation for either or both the doctor and his patient" (Bloom and Summey, 1976:29), also are included. Finally, as these social forces and subcultural reference groups are based in the dominant culture, all of the above elements in Bloom's (1963) model are circumscribed by "the dominant socio-cultural matrix" (Bloom and Summey, 1976:30).

In the present research, the role is the unit of analysis. In particular, this research focuses on the expectations for one role in the patient-family-health professional role set: those for the health professional and the role of the physician and the nurse, in particular. The concept of the role-set, however, is utilized in that the expectations of patients and families are examined, as well as those of health professionals themselves with regard to the role of the health professional in the provision of terminal care. The conflict perspective is enjoined in the assumption that by virtue of the role occupied, role

occupants' perspectives, values, attitudes, and expectations are likely to vary and to be at odds with one another.

The conceptual framework for this research reflects the contributions of both formal and informal socialization agents and processes in the transmittal of normative expectations for roles. A broad definition of professional socialization is employed, encompassing not simply what is taught formally, but also that which is conveyed through commission or omission by formal sources, as well as through informal interaction, such as with fellow students. The impact of individuals' personalities is recognized but not assessed directly, except as emerges in the writings of scholars who have described the values, orientations, and motivations to which physicians and nurses are socialized.

Taken into account in this conceptual framework, then, are many of Freidson's (1961, 1965, cited in Bloom and Summey, 1976) criticisms of Parsons' model of the social system. As summarized by Bloom and Summey (1976), these criticisms include:

1. The Parsonian model views the doctor-patient relationship from the perspective only of the physician, ignoring the expectations of the other members of the role-set, including the patient's family, the nurses, and other persons significant in the treatment process.

2. Expectations are presented by Parsons as the primary influence on behavior, yet expectations actually are only "ideal" standards.

3. Expectations have no influence in themselves; only the position of the person holding them can influence their being met.

4. Parsons' functional model ignores "the necessity of conflict in human relationships," yet, Freidson argues that "conflict exists because each party, the professional and the patient, seeks to gain his own terms from the other" (Bloom and Summey, 1976:31).

The following are the specific research questions that are examined in this study.

RESEARCH QUESTIONS AND HYPOTHESES

Research Questions

The questions investigated in this research are:

1. What are the normative role expectations to which (a) physicians and (b) nurses are socialized, as described in the literature? With which model for the provision of health care, medical or holistic, are these role expectations most congruent?
2. What are the role expectations held by a group of terminally ill patients, family members of terminally ill people, and health professionals currently providing terminal care for the "good" or "ideal"

provider of terminal care? With which model for the provision of health care, medical (conventional) or holistic (hospice), are these role expectations most congruent and how do patients', families', and health professionals' role expectations for the ideal provider of terminal care compare?

3. How do the role expectations of patients, families, and currently practicing professionals for the physician and nurse provider of terminal care compare with the role expectations to which physicians and nurses in training have been socialized?

Research Hypotheses

The research hypotheses are:

- H₁ The normative role expectations to which physicians and nurses are socialized, as described in the literature, will parallel those delineated by Parsons as characterizing the professional role. These expectations typify those prescribed by the medical model of health care provision.
- H₂ The role expectations for the ideal provider of terminal care held by respondents (terminally ill patients, family members of terminally ill people, and currently practicing health professionals) will be most congruent overall with those prescribed by the holistic (specifically, the hospice) model of care.

- H3 The expectations of patients, families, and health professionals for the "good" or "ideal" provider of terminal care will differ from one another.
- H4 The role expectations for the ideal provider of terminal care will be affected by the type of program (conventional or hospice) in which the patient, family member, or health professional is currently receiving or giving care. The expectations of individuals in conventional programs will be most congruent with those prescribed by the medical model.

CHAPTER V

RESEARCH DESIGN AND METHODS

Now that the problem focused upon in this research has been described and other relevant work in the field has been reviewed, specification of the research design and the procedures used in this project is appropriate. The research was conducted in three phases. The first phase involved the development of the analytical model to be used in the research. In the second phase, a systematic review of literature was conducted for the purpose of identifying the role prescriptions and expectations to which physicians and nurses in training are professionally socialized. The third phase consisted of analysis of data gathered in an earlier exploratory study that was designed to identify important factors related to the provision of quality (from the point of view of patients, families, and health professionals) terminal care for the elderly. These data were used to determine the role expectations held by these three groups for the provider of terminal care.

Within this chapter are described the procedures used in each of these three phases, including those to develop the analytical model, to identify in the literature the role expectations to which physicians and nurses in training are

socialized, to select and interview respondents for the earlier exploratory study, and to analyze the data. Also contained are a profile of the study respondents, a description of the instruments used, and a discussion of the quality and the limitations of the data gathered in this earlier study.

PHASE 1: DEVELOPMENT OF THE ANALYTICAL MODEL

In order to characterize: (1) the role expectations to which physicians and nurses in training are professionally socialized, as these are described in the literature, and (2) the role expectations for providers of terminal care that are held by a group of people themselves terminally ill, family members of terminally ill people, and professionals actively involved in the provision of terminal care, an analytical model was needed. A search of the literature for such a model was initiated, and Parsons' (1951:66) "system of types of possible pattern variables of role definition" was discovered. This pattern variable framework consists of five concept-pairs, or polar alternatives, of adjectives for describing particular role expectations. These concept-pairs are: affective neutrality-affectivity; specificity-diffuseness; universalism-particularism; achievement-ascription; and self-orientation--collectivity orientation. These pattern variables are explained in detail in Chapter VI, Analytical Model.

Both an asset and a liability of Parsons' pattern variable framework is its general nature. The pattern variables were developed by Parsons (1951) to be used at the individual, cultural, and societal levels of analysis. Specifically, Parsons (1951) argued that these pattern variables could be used to categorize decisions made by individual actors (the modes of orientation in personality systems), the value patterns of culture, and the normative requirements in social systems (the normative demands on roles).

The broad applicability of Parsons' pattern variables in a variety of contexts, however, creates a difficulty in defining and operationalizing these variables. To aid in their definition and operationalization for the present study, the writings of interpreters of Parsons' work as well as the writings of Parsons himself were examined and the various explications and previous uses of the pattern variables were examined.

Most of the research in which the pattern variables had been used was prospective and involved asking participants to respond directly either (1) to questions designed as specific indices of the pattern variables, (see, for example, Williams' 1959 exploratory study of friendship and social values in a suburban community) or (2) to hypothetical situations constructed to reflect the alternatives of the pattern variables (as in Parks' 1967

work attempting to tie together personality and social role by means of the pattern variables). Most useful for the purposes of this research were the definitions employed of the pattern variables.

Next, the literature pertaining to the two key paradigms for the provision of health care in the U.S., the medical model, and the holistic model (and in this case, specifically the hospice model, which is a holistic model) was scrutinized. Particular attention was paid to areas in which the role expectations prescribed by one model appeared to conflict with those prescribed by the other. The two models were examined in order to identify both general and specific, explicit and implicit role expectations for the health care professional as prescribed within each model.

The original intent was to use Parsons' pattern variables, exclusively, to characterize these role expectations. It became clear, however, that not enough descriptive detail was afforded by the pattern variables themselves; the pattern variables needed to be operationalized.

As a result, based on the descriptions found in the literature pertaining to these two models, a list of content areas, or themes, that appeared to encompass the various role prescriptions for the health professional was formulated. This list of themes, referred to here as "indicators," was modeled after Parsons' pattern variables; that is, each indicator was developed to be comprised of the two opposite

poles of a concept, to be framed in terms of two polar alternatives. In most cases, these poles represented the opposing positions of the medical model versus the hospice model with respect to the concept tapped by a given role expectation. Following development of this list of "indicators," the interviews with terminally ill patients, family members and professional care providers were studied in a preliminary fashion in an attempt to identify any additional relevant content areas or themes, and the list was modified as required.

The last step was to place each indicator under the purview of one of Parsons' pattern variables. This procedure was a somewhat difficult one because of the ambiguity and overlap within the pattern variables. It was, therefore, an admittedly arbitrary process. Given one of the purposes of this research, however, that is, to explore the utility of the pattern variables as a means of describing the various dimensions of role prescriptions for a "good" provider of terminal care, this categorization was both necessary and legitimate. It represents a restatement and elaboration, or operationalization, of the pattern variables. As discussed in the final chapter, future research to determine the validity of these indicators for each pattern variable should be conducted. Such research should involve performance of a factor analysis on responses of a representative sample to a series of questions or

hypothetical situations depicting each indicator developed in this study.

The analytical model developed is presented in Chapter VI.

PHASE 2: IDENTIFICATION OF ROLE EXPECTATIONS LEARNED THROUGH PROFESSIONAL AND WORKPLACE SOCIALIZATION

The second phase of the research involved identification of the role prescriptions and expectations learned through professional workplace socialization by physicians and nurses. In order to do this, a systematic review of pertinent literature was conducted.

Identification Of The Literature

Relevant books and journal articles were identified in three ways: (1) through examination of the Psychological Abstracts, the Sociological Abstracts, and the Social Science Citation Index, (2) through the use of computer searches by key words, and (3) through the application of a "snowball" technique, involving scanning all sources cited in each book/article reviewed and noting, obtaining and reviewing those appearing to be relevant.

The examination of the Psychological Abstracts, the Sociological Abstracts, and the Social Science Citation Index served to identify specific readings of interest.

More important, however, was its function to guide the selection of key words to be used in the computer searches.

Four sets of computer searches were conducted through the Portland State University Library in November of 1983 using Bibliographic Retrieval Services, Inc. (BRS). Two different data bases were searched: NCMH and HLTH.

One search of the NCMH data base queried the base for titles or abstracts containing the words "pattern" or "patterns" and "Parsons" in their titles or abstracts.

A second search, this time of the HLTH data base, was conducted using the words "professional socialization" and "socialization" and ("physician" or "physicians" or "nurse" or "nurses") or <("student" or "students") and ("medical" or "nursing")>.1

A third search of the HLTH data base was made using the words ("terminal care" or "terminal illness") and ("role" or "roles") and ("perceive" or "perception" or "perceptions") and: (1) ("patient" or "patients" or "client" or "clients" or "family" or "families"); (2) ("medical" or "medicine" or "nursing" or "health care"); (3) ("physician" or "physicians" or "nurse" or "nurses"); (4) <("student" or "students") and ("medical" or "nursing")>.

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Parentheses surrounding groups of words denote all the various words that the computer was instructed to search for in combination with the preceding or succeeding group of words.

A fourth search of the HLTH data base was conducted using the words ("terminal care" or "terminal illness") and ("professional" or "professionals" or "professionalism" or "socialization" or "professional socialization") and: (1) ("medical" or "medicine" or "nursing" or "health care"); (2) ("physician" or "physicians" or "nurse" or "nurses") or (("student" or "students") and ("medical" or "nursing")).

Printouts of the titles and abstracts of the books and articles identified were acquired and read. An attempt then was made to obtain copies of those original sources appearing to be most pertinent and to read these in their entirety. Detailed notes regarding statements and findings related to specific role expectations to which physicians or nurses in training are professionally socialized were taken to enable subsequent analysis in terms of the analytical model based on Parsons' pattern variables, as described above and in Chapter VI.

Analysis Of The Literature

The technique employed in analyzing both the literature and the interview data (these data are described in the next section) was content analysis. Broadly defined, content analysis is "a multipurpose research method developed specifically for investigating a broad spectrum of problems in which the content of communication serves as the basis of inference" (Holsti, et al., 1968:597). More

specifically, it is a technique for classifying recording units (e.g., words, sentences, themes, paragraphs, entire documents, open-ended responses to interview questions) into categories on the basis of the judgments of one or more analysts.

Briefly, the steps involved in performing a content analysis of data are:

1. selection of categories or classification schemes into which the documents or responses, or portions thereof (called content units) are to be placed;
2. designation of the size of the units to be coded (e.g., word, theme, sentence, paragraph, etc.);
3. determination of the system of enumeration (e.g., appearance, frequency, or intensity of the attribute);
4. coding of the data; that is, the systematic transformation and aggregation of raw data into units, so as to permit precise description of the content.

The virtue of content analysis is that it allows the researcher to describe systematically the attributes of the message, or response. It "guards against distortion by selective perception" (Bowers, 1979:292), as all relevant data (i.e., both in support of and arguing against research hypotheses) are included.

With regard to the third and fourth steps described above, content analysis is viewed as a quantitative technique. There is disagreement, however, as to the meaning of the term "quantitative." Holsti, et al. (1968) note that while some definitions equate "quantitative" with "numerical," others are less restrictive and include studies in which findings are reported in terms such as "more," "less," or "increasing."

Analyses using exact frequency counts as their system of enumeration are a particular point of contention. The case for such analyses is powerful, especially the argument that such analyses enable conclusions to be stated with more precision. Conversely, some researchers take the position that the equation of content analysis with exact frequency tabulation leads to undue emphasis being placed on precision at the cost of problem significance. Especially in problems of applied social science, inferences drawn on the basis of simple appearance or nonappearance of attributes in messages (sometimes called "qualitative" content analysis) may be more significant than those based on frequency of appearance. This argument is especially valid when a linear relationship cannot be assumed between frequency and importance of attributes (Holsti, et al., 1968).

Given the purposes of this research, the data unit felt to be most meaningful was the theme. For the same reason, the system of enumeration chosen was the appearance

of particular themes in a given document or respondent's interview. The classification scheme for the documents (and the interview responses) is that defined in the analytical framework developed as part of the research, as discussed in the early part of this chapter and described in detail in Chapter VI. That is, the themes, or variables, chosen for analysis are those contained within the analytical model, which is based on Parsons' pattern variables of role definition.

It is the "qualitative" form of content analysis, then, that is used here. It should be noted, though, that the label "qualitative" is somewhat misleading, since data coded in terms of appearance of attributes may be (and is) presented numerically. For example, the percentage of items (e.g., articles, books, interview responses) in which a theme appears may be given (Holsti, et al., 1968).

PHASE 3: IDENTIFICATION OF PATIENTS', FAMILIES', AND HEALTH PROFESSIONALS' ROLE EXPECTATIONS FOR THE PROVIDER OF TERMINAL CARE

The interview data for this research were gathered through an earlier exploratory study that was designed to identify important issues and factors related to the provision of quality terminal care for the elderly. In this study, personal interviews were conducted with individuals having intimate knowledge of the area of terminal care and

comprising the role set (Merton, 1957a), that is, representing the various perspectives from which care can be experienced: terminally ill people, family members of terminally ill persons, bereaved family members, and professional health care providers. The following sections: (1) describe the procedures used to select programs and respondents to be interviewed, (2) profile the programs and the respondents, (3) describe the interview schedules used, and (4) detail the data analysis procedures.

Selection_And_Profile_Of_Participating_Programs_And_Respondents

Given the exploratory nature of the earlier study, it was important to obtain the views of persons representing the various approaches to terminal care and the environments in which terminal care is given. Therefore, a two-step respondent selection design was required. First, programs providing terminal care were selected and second, patients, families, and staff within each program were identified for participation in the study. Appendix A contains an overview of the respondent selection plan.

Selection_Of_Programs. Terminal care may be provided on an inpatient basis (e.g., in a hospital or nursing home) or in the patient's own home. In addition, this care may be either "conventional" or "hospice" care, as discussed in Chapter II, Review of the Literature.

"Conventional" care is that based on the medical model; that is, primary attention is given to patients' medical needs, and care is oriented toward aggressive treatment, with the principal aim being extension of the patient's life. Generally, in conventional care, the emphasis is on inpatient care, and when care is given at home, the home care providers, usually nurses, are staff members of an autonomous organization. In "hospice" care, the holistic model of care is followed, whereby patients' psychological, social, spiritual, and other needs, as well as their physical needs are addressed. Care is provided by a multidisciplinary team, and an attempt is made to provide as much care as possible in patients' own homes. Another feature is that patients' families' needs also are addressed. Hospice care may be given within a hospital, nursing home, or as part of an already existing home care program. This care may also be provided through a separate program in which only hospice care (inpatient and/or home care) is offered.

Therefore, to represent the various terminal care approaches and environments, respondents from 10 different programs were included in the study. Due to budgetary considerations, where possible, programs in the Portland, Oregon, area were selected. These programs were selected purposively on the basis of the researchers' knowledge of the programs providing terminal care in the local community

as well as that of local informants specializing in the area of terminal care who were consulted.

In making the program selections, as well as later in the course of the interviews, it became clear that in practice the distinction between "hospice" and "conventional" programs is not always clear-cut. Some programs claiming to provide hospice care fell short of this goal in terms of meeting all of the characteristics of hospice programs, detailed in Chapter II, that are widely accepted and consistent with the National Hospice Organization standards. Another program was reluctant to designate itself as a hospice because of its location within a hospital and because the patients it served were scattered throughout the hospital. While this model for hospice care is now accepted, at the time of the study there existed a decidedly "purist" hospice faction that considered only autonomous hospice programs as "true" hospices. If a program possessed, at least on paper, all or nearly all of the characteristics of a hospice program as detailed in Chapter II, it was designated a "hospice-like" program.

Profile Of The Programs. Of the 10 programs ultimately selected, five were "hospice-like" and five were "conventional." Nine of the 10 programs were in Portland. One, a freestanding hospice, of which there was none in Portland, was located in another Western state. Three hospitals (two of which were "hospice-like"), four nursing

homes (one "hospice-like"), two home care programs (one "hospice-like"), and one autonomous hospice facility were included in the study. Table 2 briefly describes each program. Appendix A provides detailed information concerning each program.

Selection Of Individual Respondents. Identification of the study participants comprised the second step in the selection process. The study design called for the interviewing of ten people (two terminally ill patients, two family members of terminally patients, two family members of patients who had recently died (referred to here as "bereaved family members"), three health professionals (referred to as "staff" or "staff members"), and the administrator or supervisor) in each of the 10 programs. Of the 100 proposed interviews, 94 were completed.

The administrator or supervisor of each program was first interviewed. He or she then designated three staff persons heavily involved in the care of patients having late stage disease, preferably of different disciplines, such as a nurse, a physician, and a social service provider.

TABLE II

DESCRIPTION OF PROGRAMS PARTICIPATING IN THE STUDY (N=10)

Hospitals (n=3)

1. A teaching hospital selected to represent a traditional inpatient approach to terminal care
2. A private non-profit hospital with a well-established "hospice-like" program for cancer patients
3. A private non-profit hospital with a very recently established "hospice" inpatient unit

Nursing_Homes (n=4)

4. A proprietary skilled nursing facility representing a conventional approach to patient care
5. A non-profit nursing home with skilled and intermediate care beds, specializing in rehabilitation, sponsored by a fraternal organization, representing a conventional approach to care (although planning for a hospice unit had begun)
6. A non-profit nursing home with religious affiliation and both skilled and intermediate care patients, representing a conventional approach to care (but considering specializing in terminal care)
7. A non-profit skilled and intermediate care facility with religious affiliation, providing "hospice-like" services (and planning for a designated hospice unit)

Home_Care_Programs (n=2)

8. A "hospice" home care program under the auspice of a large non-profit, United Way-funded, full service home health agency
9. A small non-profit full service home health agency representing a conventional approach to home care

Autonomous_Hospice (n=1)

10. An autonomous, free-standing hospice program offering both inpatient and home hospice care (located outside the Portland, Oregon, area as no such program had been established locally)

The administrator or a staff person designated by him or her then identified two terminally ill patients meeting the following criteria, which were modified from those used by Hinton (1979):

- a. at least 60 years of age;
- b. willing and able to be interviewed;
- c. having a prognosis of six months or less to live;
- d. having received care in the program at least one week;

The final criterion was that one patient was to be one for whom staff felt care "was going well," and the other was to be one for whom care was "not going so well" for some reason. This criterion was applied to maximize the range of perspectives and opinions that patients would bring to bear on the nature of "quality" terminal care.

Similarly, two family members of older (age 60 or over) terminally ill patients being cared for in the program were identified by the administrator or staff persons. Family members could be related to the patients interviewed or they could be family members of patients not interviewed. The stipulation made was that they should be first order family members or members who were close to the patient.

Finally, two family members whose loved ones had died within the last six months (bereaved family members) were identified and interviewed.

For both the bereaved family members and the family members of patients currently ill, the selection criterion of "care going or having gone well"/"care not going or not having gone so well" was applied. That is, one family or bereaved family member was to be one for whom the patient's care was going or had gone well, and the other was to be one for whom the patient's care was not going or had not gone so well.

Profile Of The Respondents. The following paragraphs profile the characteristics of the respondents by group. Appendix A contains additional detail.

Patients. A total of 17 of the proposed 20 patients (two in each of the 10 programs) were interviewed. In one program, no patients were interviewed because the program's start-up date was delayed and because no patients meeting the study criteria had been served by the close of the interviewing period of the project. In another program, which was quite small, only one patient could be interviewed. Only three of the patients who were served in this program while interviews were being conducted met the study criteria, and the nursing supervisor reported that two of those declined to participate when she approached them.

Nine of the 17 patients interviewed were women and eight were men. Ages ranged from 57 to 86, with 75 as the median age. Although the man who was 57 did not fit the age criterion for the study, he was included because (1) he and

the other patient interviewed in that site were the only two patients who were otherwise eligible to participate, and (2) more important, he expressed enthusiasm for the study and a desire to be interviewed when he learned about the study.

Fifteen of the 17 patients had a primary diagnosis of cancer. One patient was diagnosed with amyotrophic lateral sclerosis, and another had experienced a severe cardiovascular accident (CVA) and had a very limited prognosis. The time since the diagnosis or since the first episode of illness ranged from three weeks to over seven years. Five people reported being ill for one year or less, five others had been ill one and a half to two years prior to the interview, and the remaining seven from three to seven and one-half years.

In most cases, the individual's prognosis was "guarded," "uncertain," or "unclear," reflecting providers' reluctance to estimate specific amounts of time left to live. At least three patients had outlived their original prognoses, two by over a year; one man was especially delighted about "surprising the experts." Most patients knew about their disease and stated to the interviewer that they were "living on borrowed time" or "couldn't expect to survive this too long." One person did not know her prognosis, one either did not know or did not wish to speak of

it, and one had been told, according to staff, yet denied it.²

Most of the patients with whom the researchers spoke had been cared for in a variety of settings. Of the eight people who were interviewed in the hospital or their homes, only one had ever been a patient in a nursing home. In contrast, respondents interviewed in nursing homes generally reported several episodes of hospitalization as well as home care.

Family Members Of Terminally Ill Patients. Eighteen family members of patients who were currently terminally ill were interviewed for the study. It should be noted again that the family members interviewed were not necessarily those of patients who were interviewed.

There was only one patient and one family member available to be interviewed from one home care program, and in the program which was quite new, no patients and, consequently, no family members, fit the study criteria. In one of the nursing homes, staff enthusiastically recommended a third family member in addition to the two called for in the respondent selection plan. This person was interviewed both

2

As noted earlier, awareness of the prognosis was not a criterion for participation. Patients and families were interviewed "for research into caring for people with a serious illness," as the research team did not want to risk divulging previously unknown or denied information, and because such awareness was not central to the purpose of the study.

in order to compensate for the lower number of family members from the other programs and because the staff member already had contacted the family, and they were very much interested in taking part. The staff person also indicated that this family had presented a problem for the staff in the past and, therefore, fit the criteria of a family member where care had not gone well.

The group of family members interviewed contained 15 women and three men who ranged in age from 30 to over 80. Included were a nephew, a niece, a sister, seven wives, six daughters, and two husbands. In 13 cases, their ill relative was also interviewed for the study. In three of the five remaining cases, interviews were conducted with the family members in anticipation that their ill relatives would be interviewed as well, but the patients subsequently became too ill to be interviewed. The fourth family member was interviewed in place of the wife of one of the patients because the patient had requested that she not be interviewed. In the fifth case, a patient having no family was interviewed, so a family member of another patient (who was too ill to be interviewed) was asked to participate.

The terminally ill relatives of the family member respondents ranged in age from 57 to 84. Of the two whose ill relatives were under the age of 60 and so did not meet study criteria, the reason for including one, and thus his family member, is described in the profile of the patients

interviewed. The second was a family member of a patient 58 years of age; this individual was included at the program staff's insistence because of their reported difficulty in identifying respondents who met all criteria.

Fifteen of the respondents' relatives had some form of cancer, two had suffered strokes, and one had amyotrophic lateral sclerosis. Length of illness or time since diagnosis ranged from five and one-half months to six years. The functional status of the patients about whom family members spoke varied. Two patients, while quite seriously ill, were ambulatory and apparently were continuing many of their normal activities. Four of the patients were very close to death at the time their family members were interviewed; one man died only hours after his wife's interview.

The degree of involvement of family members in the patient's care varied as well, although most of the family members interviewed seemed to provide considerable support. The least involved was a man who visited his uncle every week and took care of his finances. This man was the patient's closest relative. Some of the other family members interviewed had come from out of state to be with their ill relatives in their last days. Of those who were spouses of terminally ill people, all were or had been heavily involved in providing care at home. Many were themselves in poor health. The role for several of the

daughters appeared to be that of advocate and information-gatherer. One daughter had quit her job to take over her father's business.

Twenty bereaved family members (two in each of the 10 programs) were interviewed. These family members included daughters, husbands, wives, one cousin, one daughter-in-law, and one brother. The respondents ranged in age from their late 20s to 86 years of age. Seventeen of the 20 family members' terminally ill relatives had had some form of cancer, including cancer of the colon, breast, or lung, leukemia, and multiple myeloma. One man had had cirrhosis of the liver and two women had had a severe stroke. Many had been ill for several years before they died, but some for only a few weeks. The median length of the relative's illness was 20 months; the mean length was about 30 months.

Most of the family members had been bereaved for just one or two months, although one person had been bereaved for only 10 days, and another for nearly two years. The recollections of this latter respondent remained quite vivid, and the program staff had felt that her interview would make a strong contribution to the study.

All of the bereaved family members had been very heavily involved in the care of the relative who had died. With two exceptions, all had cared for their relatives at home at some point during the course of the person's illness. One, a brother, had not, but he had visited his

sister daily, both when she was in her own home and when she was in the hospital. Another respondent's sister had cared for their ill mother in her home, with the respondent providing other types of support. This respondent was one of the several of the respondents who had played the role of advocate for the terminally ill patients, which involved gathering information, seeking explanations, and spending nights in the hospital or nursing home with the patient to make sure that they received the necessary services.

Health Professionals. A total of 39 health professionals, (referred to variously as "staff," "care providers," "health professionals," or "professional care givers" throughout this document), including the administrators or supervisors of the 10 programs, were interviewed for the study. In one site, only three providers were interviewed since the fourth became ill and unable to participate.

Of the 10 administrators or supervisors interviewed, seven had training in a field in addition to that of administration: five were nurses, one was a social worker, and one was a physician. In one program, administrative responsibility for the program was shared by two individuals. The person who was most involved in day-to-day supervision was designated as the administrator for the purposes of the study.

Included among the remaining 29 respondents in this sub-group were 14 nurses (including a geriatric nurse practitioner and a mental health nurse), seven social workers, four physicians, four home health or nurse aides, and one chaplain.

The length of time the health professionals interviewed had been working in their current positions ranged from one month to 23 years. The median length of time was one year.

Description Of The Interview Schedules

The instruments developed for use in this earlier study were designed to elicit the views of the respondent groups concerning issues surrounding the definition, provision, and assurance of quality terminal care. Guiding their development was a preliminary conceptual model, with the design based on a review of relevant literature. This model contained those elements asserted in the literature as factors affecting or indicating the quality of care. The intent was to structure the interviews so that the important dimensions of quality terminal care, from the perspective of all pertinent groups, would be identified and explicated. With this goal in mind, while standardized for each respondent group, questions were open-ended to promote free expression of experiences, thoughts, and concerns. The interviews were conducted face-to-face, both because of the

personal and sensitive nature of the questions and to facilitate probing where clarification or elaboration was necessary. Five schedules (one each for patients, families, bereaved families, program staff, and administrators) were designed. The schedules for patients, families, and bereaved families were virtually the same, with appropriate wording changes, as were those for program staff and administrators. Copies of the patient and the staff interview schedules appear in Appendix B. In general, the instruments used with patients, families, and bereaved families asked questions regarding:

- a. the needs of terminally (or "seriously," for those possibly unaware of the prognosis) ill people;
- b. the needs and concerns of families of incurably (or "seriously") ill people;
- c. characteristics of staff that enhance provision of "good" care;
- d. things liked and disliked about the various settings in which care had been received; and
- e. the definition of "quality" terminal care (or "care for seriously ill people").

The schedules used with program staff and administrators contained questions concerning:

- a. the needs of terminally ill persons and their families;

- b. characteristics of staff that enhance provision of "good" care;
- c. factors (e.g., policies and practices) hindering and facilitating provision of "good" care;
- d. the definition of "quality" terminal care;
- e. recommendations for assuring provision of "quality" terminal care;
- f. indicators of "quality" terminal care; and
- g. (for administrators only) characteristics of the program in general and of service recipients.

Questions of a general nature regarding these issue areas were asked as well as some employing a version of the critical incident technique. This latter method involved asking staff to think of three specific cases in which care had gone well, and then three in which care had not gone as well as they would have hoped, and to describe the circumstances in each of those six cases. Similarly, patients and families were asked to recall three care providers they had especially liked and three they had not liked. One example of general questioning came near the close of the interview, when all respondents were asked to describe what they thought "good care for people who are seriously ill consists of" (or "terminally ill", for providers and those patients and families aware of the prognosis).

Content Analysis Of The Interview Data

The technique employed in analyzing the interview data was a form of content analysis. Traditionally, applications of content analysis have not involved the direct questioning or observing of people. Instead, already existing written material is examined (Kerlinger, 1973). Increasingly, however, this technique has been applied to data, or messages, generated in the research process, such as responses to open-ended questions in survey research. In fact, the coding of open-ended questionnaires may be considered to fall under the rubric of both content analysis and survey research; some researchers use the terms "content analysis" and "coding" interchangeably (Holsti, et al., 1968).

As noted in the discussion of the analysis of the literature on the socialization of physicians and nurses, content analysis allows systematic description of the message, or response, and eliminates distortion caused by selective perception. As Holsti, et al. (1968:603) observe, this is especially important in research such as that reported on here:

To analyze...open-ended questionnaires, the social scientist often requires information of a subtlety or complexity which renders casual scrutiny inadequate, even if undertaken by a skilled and sensitive reader.

Given the purposes of this research, the data unit felt to be most meaningful was the theme. The system of

enumeration chosen was the appearance of particular themes in a given document or respondent's interview. As a result of the open-ended nature of the questions, an attempt had to be made in analyzing the data so as not to weight the responses of some participants more than others due to their loquaciousness. This attempt took the form of analyzing the data by appearance or nonappearance of a given theme rather than an exact frequency tabulation.

The classification scheme for the interview responses (as well as for the socialization literature) was that defined in the analytical framework developed as part of the research, as discussed in the early part of this chapter and described in detail in Chapter VI. That is, the themes, or variables, chosen for analysis are those contained within the analytical model, which is based on Parsons' pattern variables of role definition.

In sum, a thematic analysis of the views of the three groups of respondents (patients, families, and health professionals) with regard to the characteristics and behaviors they felt a provider of quality terminal care should possess and exhibit was conducted. As described in the preceding section, Description Of The Interview Schedules, a number of questions pertinent to the research problem were asked in these open-ended, structured interviews with terminally ill patients, family members, and health professionals currently providing terminal care.

Instead of selecting for analysis only certain questions asked in the interviews, however, a decision was made to read all interviews in their entirety, and to note and code all comments relevant to the research problem. These comments were recorded as to their position with regard to each of the pattern variables as operationalized in the analytical model (see Chapter VI).

The decision to analyze the interviews in their entirety was made for two reasons: (1) because of the appearance of comments relevant to respondents' role expectations for the provider of quality terminal care throughout the interviews, and not just in response to particular questions, and (2) because of a desire on the part of the researcher not to take interviewees' comments out of context. As a result of the freedom of response allowed through the open-ended response format, interviewees occasionally would answer a question prior to its being asked. To avoid the boredom and impatience which would result from asking respondents to repeat themselves later in the interview, these out-of-sequence responses were noted by the interviewer and the question was not asked except when clarification or elaboration was felt to be necessary or desirable. The reverse of this situation occurred as well: interviewees frequently remembered things that they should have mentioned earlier, or a thought came to mind and they wished to express it then, regardless of its relevance at

that time. Also, sometimes the response given to one question was actually much more pertinent to another.

After all respondents' relevant comments were coded, they were aggregated by respondent group: patients, families (including families whose relatives were living at the time of the interview as well as those whose relatives had died within six months prior to the interview), and health professionals (the administrators and the program staff were combined to form one group).

Quality And Limitations Of The Interview Data

The interview data brought to bear on the questions posed in this study are exceedingly rich in detail and breadth, providing the perspectives of providers actively involved in the provision of terminal care as well as those of terminally ill patients and family members of gravely ill or recently deceased patients. The quality and the limitations of the data generated in this study are related to the (1) respondent selection, (2) instrumentation and data collection, and (3) analytical procedures used. Specifically, caution is required in interpreting the findings and generalizing from them due to the non-random nature of the respondent selection process, the use only of verbal self reports of the respondents and the lack of behavioral data, and the open-ended format of the instruments.

Respondent Selection. Both the limited time frame of the study and cost considerations precluded the use of random selection procedures either for programs or for individual respondents (patients, families, and providers). Random selection of patients and families was not feasible because of the relatively short time frame within which interviews were to be conducted and the small number of patients in a program at any give time likely to fit the study criteria. Random selection of family members who had been recently bereaved was deemed too time consuming. The representativeness of the respondents interviewed, therefore, cannot be assured.

The respondent selection procedures chosen, however, did attempt to maximize the likelihood of identifying a range of individuals with a wide variety of perspectives concerning the provision of quality care for terminally ill older people. Professionals of various disciplines who were involved in the provision of terminal care (physicians, nurses, aides, social workers, and clergy) as well as patients and families (some who had had relatively positive and others who had had negative care-related experiences), were to be interviewed. Furthermore, inclusion of the "care had gone well/care had not gone well" criterion was felt to be a more useful and practical approach to obtaining views of "quality" terminal care which would be based both on

positive and negative experiences than a random selection procedure.

Nonetheless, there was a possible bias toward persons least likely to be critical of care in a given program, in that respondents were to be identified by the program administrators because of their knowledge of the staff persons most involved in providing terminal care and of the patients and families who would meet the criteria. For the most part, though, having the administrator or their designee select the respondents did not seem to result in only favorable comments about the care; providers and recipients of care (patients and families) alike seemed quite candid and willing to relate shortcomings as well as positive aspects of care. There were cases in which each of the two patients, family members with ill relatives, and family members whose relative had recently died of a terminal illness seemed to be persons whose care-related experiences appeared, on the whole, relatively positive, or, conversely, negative. Rather than being an intentional disregard of the study criterion of one respondent for whom care had gone well and one for whom care had not gone so well, more often this deviation seemed to have occurred because of an attempt to satisfy the other criteria. Even those were not rigidly adhered to, with the most obvious example being the identification of patients or family members of patients younger than 60 years of age,

particularly in programs which provided care to a very small number of terminally ill patients.

Another problem with having respondents selected and approached initially by the program administrator or staff is that the exact number of persons who were considered but not approached for some reason, or who were approached but who refused to participate, is unknown. The selectors did not indicate difficulties in obtaining agreements to be interviewed once individuals were asked, but again, those who might have refused may not have been approached. In a few cases, we were referred to potential respondents without their having been apprised of the study; these persons were a bit apprehensive at the outset, especially about signing the form indicating their informed consent to participate in the research.

It should also be pointed out that, as would be expected in research in which very ill people are to be interviewed, some interviews which had been arranged with patients had to be rescheduled or another patient selected because the first became unable to respond due to a serious deterioration in condition or, in a few cases, death.

Most of the patients who were interviewed or whose care was described by a family member had a primary diagnosis of cancer. In that the designation "terminally ill" usually is applied to victims of cancer, however, and most programs being developed specifically to serve the

"terminally ill" are targeted toward persons having cancer, this is not viewed as a limitation of the study.

No special efforts were made to maximize demographic differences among respondents and no socioeconomic data were gathered formally for any of the respondent groups; however, a fairly broad range of financial statuses, levels of education, and occupations seemed to be represented among the participants. With the exception of some respondents who were Jewish, however, no members of ethnic or racial minorities were interviewed. Thus, the results with respect to the role expectations held for health professionals providing terminal care may be somewhat culture-bound.

Two final respondent selection issues should be noted. First, the data were gathered with the quality of terminal care given principally to the elderly (persons age 60 and older) in mind. This is not viewed as a serious limitation, however, as the greatest proportion of deaths in the U.S. (approximately four-fifths) are of persons over the age of 65 (Halper, 1979). Second, only programs providing terminal care in urban areas were included. Again, as the bulk of health care, especially specialized health care, is provided in urban settings, this is not viewed as a limitation of the study.

In general, the persons with whom we spoke were very open and willing to describe their experiences and feelings about the various care settings and providers. Most of the

patients were aware of their limited prognosis and many discussed this with the researchers. Patients and bereaved families in particular seemed surprisingly comfortable with the researchers and often shared past events. Patients did tire easily and answered questions more briefly than the other groups. Some patients and family members were very matter-of-fact about their or their relative's condition and their care experiences; others were close to tears many times. Interviewees volunteered two primary reasons for their willingness to participate in the study: a hope that the care given to others could be strengthened and improved through their descriptions of their feelings and experiences throughout their or their relative's illness, and a desire to express gratitude for care which had been received.

Bereaved family members seemed particularly willing to talk in detail with the researchers. This may have been due in part to a therapeutic value in reviewing these events, but also because of their having seen their loved one through to the end of his or her life and the broadened perspective that afforded.

Data_Collection. The primary limitation related to the collection of the data was that respondents' verbal reports were relied upon. The accuracy of these reports, and especially the extent to which selective recall (due to repression or suppression) affected respondents' comments, cannot be estimated, although family and bereaved family

members' accounts of the various experiences with care they or their relative had had usually were quite vivid and appeared to be fairly comprehensive.

Some professionals commented that they wished they could have had more time to consider their responses; for these persons, a mail questionnaire might have been more suitable. A loss of completeness and clarity, as well as a lower number of responses, might have resulted, however, had the questionnaire been mailed. Also, the value of personal communication and presence in the care setting cannot be overstated in research of this type.

The use of the open-ended question format generally seemed to be appreciated by all respondents, although some people did remark that certain questions were "hard." This format was viewed by the research team as that most appropriate and useful given the exploratory nature of the study, but it did pose some problems both in terms of conducting the interview itself (questions were sometimes answered before they were asked) and in analyzing the data, as discussed below.

Finally, the instrument did contain a "checklist" which listed various statements concerning the provision of care to seriously ill people and asked respondents to rate how much each item "mattered." Unfortunately, the checklist as a whole proved to have a number of deficiencies. First, it was too long. Second, it was biased toward the hospice

model of care; that is, all items contained wording consistent with hospice principles. Third, it asked respondents to indicate the importance of each item (how much each mattered), which was a somewhat confusing format. Should such a checklist be used in the future, it could be much improved through decreasing the number of items, wording some statements to be consistent with the medical model orientation to health care, and asking respondents to indicate the extent to which they agreed with each statement. Fourth, certain items, or statements, posed problems in that they contained words that were interpreted differently by the various respondents, such as one which referred to "services."

Despite the deficiencies of the checklist, it did serve to elicit some interesting and enlightening comments. Therefore, a decision was made to use in the analysis only those pertinent explanatory remarks made in response to the item on the checklist, not the ratings of importance assigned by respondents to the various items.

Data Analysis. The primary difficulty associated with open-ended questioning is the reliability of the analysis. As detailed previously, the analytic method chosen for the purposes of this study was content analysis. In content analysis, the reliability of a study is a function of both the judge(s) or coder(s) and the categories into which data must be classified. Affecting the reliability of the

coder(s) is the type of units designated to be coded. When these units are "natural," (e.g., a word or a paragraph), few problems arise; when the units are themes, as in this study, coding is more difficult because of the lack of physical guides to distinguish one unit, or theme, from another.

The second step in content analysis, and the second area in which reliability can be problematic, is the decision concerning the category into which the unit is to be placed. As Holsti, et al. (1968:658), point out:

Reliability of classification is largely a function of category definition and the types and numbers of discriminations to be made...fine discriminations between categories often result in a high incidence of disagreement. After pretesting, the investigator may aggregate such categories, but this approach is applicable only if the fine distinctions are not of major theoretical significance.

They go on to say that, paradoxically, "As categories and units of analysis become more complex, they are likely to become both more useful and less reliable" (Holsti, et al., 1968:660).

The validity of the data also should be discussed here. Holsti, et al. (1968) state that normally, if the data serve as a direct answer to the research question, as is the case at least partially in this research, rather than as indicators of characteristics to be inferred, and if the purpose of the research is a purely descriptive one, content, or face, validity is sufficient. Content validity

usually is established through the informed judgment of the investigator. In that the findings appear to be plausible and in keeping with what might have expected, they are felt to have content validity.

Summary. In sum, there are certain drawbacks in the methodological procedures used in this study, including the fairly small number of cases (N=94), the respondents not having been selected randomly, a few instances in which the selection criteria were not rigidly adhered to, the use of self-report rather than behavioral data, and the use of open-ended questions and the performance of content analysis. At the same time, the research was exploratory in nature, and the design employed yielded data very rich in detail, from persons receiving or giving terminal care in a range of urban programs. It is felt that the data are exceedingly rich and provide a reasonably comprehensive view of the types of role expectations held by patients, families, and health professionals for the ideal provider of quality terminal care.

CHAPTER VI

ANALYTICAL MODEL

The analytical model developed as part of this research is derived from and comprised of Parsons' (1951) pattern variables, which were first referred to in Chapter III and then discussed briefly in the first section of Chapter V, Research Design and Methods, Phase I: Development of Analytical Model. As mentioned earlier, these pattern variables offer a framework for viewing the role expectations associated with the health professional role in the provision of quality terminal care. A description of the pattern variables is presented below. An elaboration of the analytical model developed for this research then follows.

Parsons' Pattern Variables: A Framework for Viewing Role Expectations

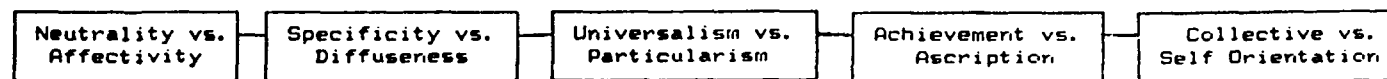
One framework for viewing the expectations associated with a role is that developed by Parsons (1951). His "system of types of possible pattern variables of role definition" (Parsons, 1951:66) consists of five concept-pairs or polar alternatives. The five concept-pairs are:

(1) affective neutrality--affectivity; (2) specificity--diffuseness; (3) universalism--particularism; (4) achievement-orientation--ascription--orientation; and (5) collectivity-orientation--self-orientation. (See Figure 2.)

Parsons views the pattern variables as being interrelated and not as simply constituting a list. He states that the concept-pairs revolve about an axis which has two poles: motivational orientation and cultural (value) orientation. Two of the pattern variables (universalism-particularism and achievement-ascription) are of particular relevance to the value-orientation pole; two are of particular relevance to the motivational-orientation pole (specificity-diffuseness and neutrality-affectivity); and the fifth is "neutral" between them (collective-self orientation) (Parsons, 1951:102). There are 32 possible combinations of polar values of the five variables. These variables enable categorization of the normative demands on roles.

Turner's (1974:36) description of Parsons's pattern variables and their meaning is a particularly clear one and is reproduced below:

1. Affectivity-affective neutrality concerns the amount of emotion or affect that is appropriate in a given interaction situation. Should a great deal or little affect be expressed?
2. Diffuseness-specificity denotes the issues of how far-reaching obligations in an interaction



Figure_2. Parsons' pattern variables.

situation are to be. Should the obligations be narrow and specific or should they be extensive and diffuse?

3. Universalism-particularism points to the problem of whether evaluation and judgment of others in an interaction situation is to employ standardized and agreed-upon criteria or subjective standards. Should evaluation be performed in terms of objective, universalistic criteria or in terms of more subjective, particularistic standards?
4. Achievement-ascription deals with the issue of how to assess an actor, whether in terms of performance or on the basis of inborn qualities, such as sex, age, race, and family status. Should an actor treat another on the basis of achievements or ascriptive qualities that are unrelated to performance?
5. Self-collectivity denotes the extent to which action is to be oriented to self-interest and individual goals or to group interests and goals. Should an actor consider his personal or self-related goals over those of the group or larger collectivity in which he is involved?

Parsons (1951) has applied his pattern variable framework to the role of the physician. As he states, this role belongs to the general class of "professional" roles, a sub-class of the larger group of occupational roles:

As an occupational role it is institutionalized about the technical content of the function which is given a high degree of primacy relative to other status-determinants. It is thus inevitable both that incumbency of the role should be achieved and that performance criteria by standards of technical competence should be prominent...

In common with the predominant patterns of occupational roles generally in our society it is therefore in addition to its incorporation of achievement values, universalistic, functionally specific, and affectively neutral. Unlike the role of the businessman, however, it is collectivity-oriented not self-oriented...

There is an intrinsic connection between achieved statuses and the requirements of high technical competence, as well as universalism and competence...

High technical competence also implies specificity of function. Such intensive devotion to expertness in matters of health and disease precludes comparable expertness in other fields (Parsons, 1951:434-435).

With regard specifically to the pattern variable affectivity-neutrality, he asserts that:

The physician is expected to treat an objective problem in objective, scientifically justifiable terms. For example whether he likes or dislikes the particular patient as a person is supposed to be irrelevant, as indeed it is to most purely objective problems of how to handle a particular disease (Parsons, 1951:435).

Concerning the physician's collectivity orientation, Parsons (1951:435) notes:

The "ideology" of the profession lays great emphasis on the obligation of the physician to put the "welfare of the patient" above his personal interests, and regards "commercialism" as the most serious and insidious evil with which it has to contend...The "profit motive" is supposed to be drastically excluded from the medical world.

In sum, the role of the professional, which includes the role of physician and that of nurse, is, according to Parsons and in terms of the pattern variables, characterized by affective neutrality, specificity, universalism, achievement, and collectivity orientation.

For the purposes of this research, these pattern variables have been operationalized through the identification of one or more "indicators" of each of the five pattern variables, as described in the first section of

Chapter 5, Phase I: Development of Analytical Model. As noted earlier, these indicators were developed through a review of the literature describing the medical and the hospice models of care. Parsons' (1951) application of the pattern variables to the role of the physician, as an example of the general class of professionals, which is a sub-class of the larger groups of occupational roles, resulted in the characterization of the role of the physician as affectively neutral, specific, universalistic, achievement-oriented, and collectivity oriented. It is this last quality that, Parsons (1951) asserts, differentiates the professional from other occupational roles.

Descriptions of the role prescriptions and expectations for the professional within the medical model parallel Parsons' characterization of the medical practitioner (or, in general, the professional) role; that is, the role of the professional in the medical model is affectively neutral, specific, universalistic, achievement oriented, and collectivity oriented.

The professional role within the hospice model of care can be seen to differ dramatically in pattern variable terms from that within the medical model. Based on the principles of hospice care as described in Chapter 2, the hospice professional role would have tendencies toward the following characteristics in pattern variable terminology: affectivity, diffuseness, particularism, ascription

orientation, and collective orientation. In other words, the professionals within the two models appear to differ in all aspects of their roles except in their collective orientation, which is the one characteristic that Parsons argued differentiated professionals from other occupational roles.

Table III depicts the role dimensions, or the poles of each pattern variable, as prescribed by (1) the medical model, and (2) the hospice model. Again, it should be remembered that Parsons sees the pattern variable alternatives as polar concepts denoting extreme points of variation along a continuum. It is appropriate, therefore, to speak of a role with expectations having tendencies toward affective neutrality, universalism, specificity, achievement, or collective orientation, for example. As explained by Parks (1967), the role expectations prescribe the norms of choosing certain pattern variable alternatives, that is, of choosing these alternatives in a significant proportion of the situations encountered in that role. This characterization of the role of the hospice professional, especially, however, may be too simple. A more accurate description requires elaboration and modification of Parsons' pattern variable framework. Specifically, "indicators" in which the pattern variables are operationalized to have particular meaning in this research problem are required.

TABLE III

THE MEDICAL MODEL VERSUS THE HOSPICE MODEL:
CATEGORIZATION BY PARSONS'
PATTERN VARIABLES

<u>Medical Model</u>	<u>Hospice Model</u>
Affective Neutrality	Affectivity
Universalism	Particularism
Specificity	Diffuseness
Achievement	Ascription
Collective Orientation	Collective Orientation

In addition, within this elaborated framework, both polar extremes of one of the pattern variables may be viewed as descriptive of the role expectations of the hospice professional. This variable is achievement-ascription. In hospice care, there is a clear role for lay people, including the patient and the family, who participate by virtue of their ascribed role or status, and volunteers, who may or may not have extensive professional training. At the same time, the hospice physician or nurse is credentialed and has achieved his or her role through specialized education and training. Furthermore, this professional is expected to achieve a goal: comfort and enhanced quality of life for the patient. This goal, while different from the goal of

the professional providing care within the medical model (life prolongation), is, nonetheless, a goal requiring sophisticated technical skill; as such, it may be viewed as representing an achievement orientation.

On the next several pages, the analytical model which was developed as part of this research is presented. The model is presented first in tabular form in Table IV. Table IV depicts: (1) each of Parsons' pattern variables (numbered and in capital letters); (2) the simplified name used to refer to this pattern variable (in parentheses); (3) the name of the indicator developed (numbered and lettered); and (4) the two opposite poles of the indicator (left=1, right=2). Generally, for both the pattern variable alternatives and their indicators, pole 1 represents the role prescription for the doctor or nurse under the medical model (and also those alternatives stipulated by Parsons as those indicating the role expectations for the "professional" role). Pole 2 represents the role prescription under the hospice model. Exceptions to this are noted by an asterisk and are explained in detail in the following narrative description of each indicator, which follows Table IV. In this description, each of Parsons' (1951) pattern variables is listed, followed by a description of the operational indicators, or variables, developed as a part of the present study specifically for definition of the role of the health professional in the provision of terminal care.

TABLE IV

ANALYTICAL MODEL: INDICATORS OF PARSONS' PATTERN VARIABLES
AS THEY PERTAIN TO ROLE EXPECTATIONS FOR THE
PROFESSIONAL PROVIDER OF TERMINAL CARE

1. AFFECTIVE NEUTRALITY---AFFECTIVITY
(Referred To As Affectivity Variable)
 - 1A: Affective Involvement:
 1. Neutral Affect/No Emotional Involvement
 2. Positive Affect/Moderate Emotional Involvement.
2. SPECIFICITY--DIFFUSENESS
(Referred To As Diffuseness Variable)
 - 2A: Scope Of Care
 1. Provision Of Physical Care
 2. Provision Of Holistic Care
 - 2B: Unit Of Care
 1. Patient Is Unit Of Care
 2. Patient And Family Are Unit Of Care
 - 2C: Availability Of Care
 1. Limited Availability
 2. Unlimited Availability
3. UNIVERSALISM--PARTICULARISM
(Referred To As Particularism Variable)
 - 3A: Care Approach
 1. Generalized Care
 2. Individualized Care
4. ACHIEVEMENT-ORIENTATION--ASCRPTION ORIENTATION
(Referred To As Ascription Variable)

Provider's Orientation Toward Patient

 - 4A: Goal Of Care
 1. Goal Is Life Prolongation
 2. Goal Is Comfort, Quality Of Life*

(Continued)

TABLE IV, Continued

- 4B: Pain Control Practices
 1. Drugs Given As Needed (Intermittently)
 2. Drugs Given At Regular Intervals

- 4C: Patient Involvement
 1. Patient Not Involved
 2. Patient Is Involved

- 4D: Family Involvement
 1. Family Not Involved
 2. Family Is involved

- 4E: Volunteer Involvement
 1. Volunteers Not Involved
 2. Volunteers Involved

Patient's Evaluation Of Health Professional*

- 4F: Criteria For Evaluating Health Professional*
 1. Performance Criteria Used
 2. Ascribed Characteristics Used

5. SELF-ORIENTATION--COLLECTIVITY ORIENTATION**
 (Referred To As Collectivity Variable)

Relationship With Patient

- 5A: Motivation Of Health Professional
 1. Professional's Welfare First
 2. Patient's Welfare First

Relationships With Other Providers

- 5B: Interprofessional Communication, Collaboration
 1. Separate Professionals, Minimal Communication
 2. Professionals Communicate, Collaborate As Team

- 5C: Interprofessional Decision-Making
 1. Hierarchical Decision-Making And Relationships
 2. Egalitarian Decision-Making And Relationships

* Indicates left-hand pole (pole 1) may represent the role of the health professional under the hospice model, instead of the medical model

** Indicates both models' role prescriptions may be right-hand pole (pole 2).

Description Of The Analytical Model And Its Indicators

The Affectivity Variable.

1A: Affective Involvement: (1) Not Affectively Involved (2) Affectively Involved. This indicator combines Parsons' (1951) Affectivity pattern variable and Williams' (1959) notion of emotional commitment. The affectivity pattern variable concerns the extent to which it is appropriate for the physician or nurse to express emotion or affect in his or her role, such as in interaction with the patient or family (Turner, 1974). Another way of conceptualizing this is offered by Olsen (1978), who states that actors who are affective attend to their own and to others' feelings, and the interaction is on a personal basis. The interaction between actors who are affectively neutral is on an impersonal basis.

Williams (1959) states that the affectivity pattern variable represents a role expectation as to the expression of affect. He argues that neither this pattern variable nor any of the other four covers the aspect of affective involvement, marked by strong emotional commitment.

It should be noted that Parsons himself later added an additional pattern variable to his original scheme: instrumental-expressive (Parsons, 1953, "Some Comments on the State of the General Theory of Action," American Sociological Review, 18 (December 1953): 618-631). As Olsen (1978:83) writes, this pattern variable describes:

the nature of the goal they (actors) are seeking through interaction. Instrumental interactions are means to the attainment of some other end, as when a store clerk sells merchandise to a customer or several community agencies join forces in a fund-raising drive. Expressive interactions, in contrast, are valued for their own sake regardless of the outcome, as in a casual chat between friends or a religious ceremony.

Williams' (1959) notion of emotional commitment could conceivably be considered within this instrumental-expressive variable, but Parsons himself, in his later writings, seems to have abandoned the concept as constituting a pattern variable. Instead, he employed it in his broader "theory of action" framework (see, for example, Parsons, 1960, "Pattern Variables Revisited: A Response to Robert Dubin," American Sociological Review, August, 1960, 25,4, 467-483). Furthermore, no empirical applications of the pattern variable framework which used this sixth variable could be found.

In the opinion of this author, the concepts "expression of affect" and "emotional involvement" do not represent separate dimensions of role expectations, requiring, in essence, a sixth pattern variable. Rather, they represent a continuum of affect. For the purposes of the present research, therefore, the two concepts of affectivity and emotional involvement were combined.

Also important to note is the fact that while Parsons' pattern variable framework generally consists of a left and a right pole which are diametrically opposed to one another,

this particular indicator, even as conceived by Parsons, differs from that model. The affectivity pattern variable has as its left pole (pole 1) not negative affect but neutrality. This deviation is easily understood both in this context of expectations for the health professional role as well as expectations for other roles. Logically, negative affect probably would be undesirable on the part of a professional or nonprofessional.

The Diffuseness Variable. As Turner (1974) describes it, the specificity-diffuseness pattern variable concerns the issue of whether obligations in the interaction situation should be narrow and specific or extensive and diffuse. Three indicators of specificity-diffuseness were identified as relevant expectations associated with the role of the professional provider of terminal care.

2A: Scope Of Care: (1) Provision Of Physical Care (2) Provision Of Holistic Care. This indicator expresses whether the provider attends only to the patient's physical care needs or whether he/she attends to the broader emotional, psychosocial, and spiritual needs of the patient as well as the physical needs.

2B: Unit Of Care: (1) Patient Is Unit Of Care (2) Patient/Family Is Unit Of Care. Determined here is whether the provider gives care just to the patient or whether the needs of the patient's family also are addressed.

2C: Availability Of Care: (1) Limited Availability (2) Unlimited Availability. This indicator identifies the extent to which the provider is available and accessible to the patient. While most physicians can be reached by telephone, the degree of difficulty and the rapidity with which this is accomplished can vary considerably and contribute to a perception either of accessibility or inaccessibility. Included in this category is the expectation concerning how much checking on or visiting of the patient is done (whether the patient is in an institutional setting such as a hospital, nursing home, or inpatient hospice, or at home with the aid of a home health program) and how often the patient is seen by the primary provider (usually the physician).

The Particularism Variable. The role expectation which is "universal" is generalized, where ego (the actor) has no particular relationship with alter (the object) (Parsons, 1951). Olsen (1978) differentiates the poles of this pattern variable in terms of whether the interaction follows a standard pattern (universal orientation) or is unique to that specific situation (particular orientation). In other words, this pattern variable examines the degree of reflection of existing norms and practices; if standard norms and practices exist and are followed, regardless of the object's specific situation (needs, individuality) this is a universalistic orientation. Generalized, or standard,

care (universalistic orientation) is the norm for professional behavior (Parsons, 1951).

3A: Care Approach: (1) Generalized Care (2) Individualized Care. This indicator examines the role expectation with respect to whether the treatment given to one patient is expected to be essentially the same as that given to all patients (generalized care) or whether the expectation is that the care be tailored to meet the various particular needs of each patient (individualized care).

The Ascription Variable. As Parsons (1951:63) notes, three of the pattern variables (affective neutrality-- affectivity, self- collectivity oriented, and universalistic-particularistic) refer "to ego as actor," in this case, the physician or nurse provider of terminal care. One (specificity- diffuseness) specifies the "scope of ego's 'interest' in the object," and the fifth (achievement- ascription orientation) describes the "characteristics of social objects themselves, that is, from ego's point of view of the alter in the complementary role-orientation structure or to ego himself as an object" (Parsons, 1951:65 and 63). In other words, this pattern variable concerns not only the physician's or nurse's view of the patient, but also the patient's view of the physician or nurse.

Turner (1974:36) points out that the achievement- ascription pattern variable deals with the issue of how an object (the health professional, here) is to be assessed,

that is, in terms of (1) his or her performance or (2) on the basis of inborn qualities. Mayhew (1968) and Parsons himself (1951) would probably take exception to the adjective "inborn." Parsons defines ascription in terms of what the object is, including being "a physician" (Parsons,; 1951:64). They argue that this pattern variable refers to classification of the treatment of other actors (like universalism-particularism): when the other is treated entirely with reference to his or her fixed position in an established social structure, (i.e., being a doctor or a nurse) or when he or she is categorized in terms of his or her qualities, this is an ascription orientation. As Parsons (1951:64) puts it:

The major focus of a particular role-expectation... may be what the object is in this sense, e.g., that he is ego's father, that he is a physician, or that he is over six feet tall...This (quality) may be the criterion for differentiation of treatment and of expectations of his behavior.

Alternatively, an orientation that focuses on the actor's performance (past, present, or future), that is, what the actor did, does, or will do, is an achievement orientation (Mayhew, 1968). Expectations are oriented to the actor's effectiveness or success in achieving particular goals or performances (Parsons, 1951).

In sum, the "actor" or "object" in this situation may be either ego (physician, nurse) or alter (patient) (Parsons, 1951:64). An achievement (or performance)

orientation can refer to the performance either of the physician or the nurse, or of the patient or the patient and the family. Similarly, an ascription (or personal qualities or characteristics) orientation can refer to the characteristics of either ego or alter.

And herein lies one source of confusion with regard to this pattern variable. The role expectation may be examined from the perspective of the physician or nurse focusing on the patient, or from the perspective of the patient focusing on the physician or the nurse. The difference between the two perspectives, then, is whether the focus is on alter, the other (the patient) and how he or she is to be treated, or on ego, the role incumbent, (the physician or nurse) and how he or she is evaluated.

The simplest way to define and operationalize this pattern variable, and the most consistent with the focus of the other pattern variables, is in terms of how the physician or nurse is expected to treat the other actors in the interaction (the patient, the family, volunteers). The first five indicators of the achievement-ascription pattern variable demonstrate this perspective. The sixth and last indicator demonstrates the second perspective, how the physician or nurse is evaluated by the patient.

Provider's orientation toward treatment of the patient.

4A: Treatment Goal: (1) Goal Is Life Prolongation (2) Goal Is Quality Of Life, Comfort. Is the patient to be treated with a goal of life prolongation in mind, or with the patient's comfort and quality of life in mind? These different goals can be looked at as representing the two opposite poles of this pattern variable, or simply as different aspects or possibilities within one pole. An argument is made here for viewing them as two opposite poles.

Treatment of a patient as though it is possible that he or she could or should, with proper treatment, live through the illness implies an achievement orientation toward the patient on the part of the provider. The expectation is that the patient will perform, will respond to treatment, and at least maintain the current level of health, if not get better. The treatment is aggressive and cure-oriented, and the goal is life prolongation.

Treatment of a patient with an eye toward life quality rather than life prolongation implies an acceptance of the disease as a terminal one, and as a quality, or attribute, of the patient. The patient who is terminally ill will not, by definition, regain his or her health. Rather than expecting the patient to do so (achievement orientation), the terminal illness comes to be seen as an

attribute of that patient, and the provider is expected to treat the patient on this basis. This implies an ascribed orientation. At the same time, this terminal status is not viewed with an attitude of there being "nothing more to do." What is to be done, the treatment goal, simply is different: comfort and quality of life.

It could be argued, then, that in both the hospice and the medical model, the professional role is achievement-oriented, that one difference between the expectations for this role in the two models is simply the existence of different goals. However, because the basis for this difference in treatment goals is the patient's quality, or ascribed status, of being terminally ill, depiction of the hospice model's prescription for the role of the provider of terminal care as having a tendency toward ascription, at least in this indicator, seems most accurate.

4B: Pain_Control_Practices: (1) Drugs_Given_As_Needed, Intermittently_Upon_Request (2) Drugs_Given_At_Regular_Intervals. This indicator represents one way in which the provider's treatment orientation (life prolongation versus quality of life) is manifest. Because of the number of references to pain medication practices, both in the literature on care of the dying and in the interviews with patients, families, and providers, this was included as a separate indicator.

Pain medication may be given on an as needed basis, that is, as is felt necessary by the nurse or as requested by the patient (pole 1, medical model). Alternatively, it may be given regularly, such as every four hours (pole 2, hospice model). Providers subscribing to the medical model for care often feel the latter practice leads to narcotic addiction and are reluctant to give pain medication on this basis. These providers generally are concerned with prolonging their patient's life (Indicator 4A: Treatment Goal). Other providers (i.e., hospice professionals), guided by their treatment of the patient's terminal illness as an ascribed quality and their concern for the patient's comfort and quality of life, administer pain medication regularly so as to control the patient's pain adequately, enabling him or her to function as normally as possible and enhancing the patient's quality of life.

4C: Patient Involvement: (1) Patient Not Involved (2) Patient Is Involved. Involvement of the patient in care-related decisions implies treatment of the patient from an ascribed orientation, as the patient is involved not as a result of his or her competence or performance as a provider of health care but instead, because of his or her ascribed status as a patient, and as one directly affected by this care.

The opposite pole, no involvement of the patient in care-related decisions, implies an achievement orientation.

The professional provider "knows best," and it is in the patient's best interest to let that provider administer all treatments he or she believes to be effective and to make all care-related decisions.

An important factor enabling and indicating patient participation or nonparticipation in the care is communication. Is the patient informed, for example, of his or her prognosis and of the provider's treatment plans?

4D: Family Involvement: (1) Family Not Involved (2) Family Is Involved. The explanation of this indicator is the same as that for the above indicator of patient participation or non-participation in the care.

4E: Volunteer Involvement: (1) Volunteers Not Involved (2) Volunteers Involved. Acceptance of volunteer involvement in the care implies an ascription-oriented role expectation. Volunteers may or may not have professional training, but are involved because of some personal attribute such as desire to help. Nonacceptance or nonutilization of volunteers in the care implies an achievement orientation: no one but the health professional is seen as capable or qualified to provide this care.

Patient's Evaluation Of Provider.

As detailed earlier in this subsection describing the indicators of this pattern variable, achievement-ascription, the second perspective within this pattern variable is that of the patient and how he or she evaluates the provider.

4E: Criteria For Evaluation Of The Health

Professional: (1) Performance Criteria Used (2) Ascribed Characteristics Used. Does the patient evaluate the provider in terms of the provider's performance (achievement orientation) or in terms of his characteristics or qualities (ascribed orientation)? That is, are the providers evaluated as "competent," "good," or "knowing what they're doing," (achievement orientation) or are they evaluated on the basis of personal characteristics or status, such as being the doctor ("he's the doctor"), being "male," "female," or "physically strong" (ascription orientation)?

As discussed earlier, the sick role, in which the patient is expected to accept and comply without question to the health professional's orders and decisions, is the corollary of the professional role in the medical model. It would seem that, as a result of this unquestioned compliance, evaluation by the patient of the professional in the medical model would be ascribed, based on who the health professional is, the characteristics of the health professional. Alternatively, the hospice model would appear to prescribe an achievement orientation: the health professional being evaluated by the patient in terms of the professional's performance, not simply his or her position as a doctor or nurse. In sum, the poles on this indicator seem to be reversed for the medical and the hospice models

with regard to the role expectations prescribed for the health professional.

The_Collectivity_Variable. The fifth and last pattern variable concerns the permissibility of the actor's:

pursuing any interests "private" to himself as distinguished from those shared with the other members of the collectivity in which he plays a role...A role, then, may define certain areas of pursuit of private interests as legitimate, and in other areas obligate the actor to pursuit of the common interests of the collectivity. The primacy of the former alternative may be called "self-orientation," that of the latter, "collectivity-orientation" (Parsons, 1951:60).

With regard to the problem of role expectations for the provider of quality terminal care, there are two aspects of this pattern variable. The first concerns the provider's relationship with the patient. The second relates to the relationship of the provider with other providers.

This pattern variable represents a somewhat different level of analysis, and it has frequently been dropped in empirical research concerning the pattern variables (e.g., Williams, 1960). It is useful here, though, as the distinction seems possible, even though both models are sometimes on the same pole.

Relationship_With_Patient.

5A: Motivation_of_Health_Professional:__(1)

Professional's_Welfare_First_(2)_Patient's_Welfare_First.

This is the indicator in which the norms of both the medical model and the hospice model appear to prescribe that

professionals have a collective orientation. Thus, both models fall on the collective-oriented pole. It may be, however, that the medical model is less collective-oriented than the hospice model.

Providers who are concerned primarily with their patients' welfare, who are dedicated to serving their patients, have a collectivity, or service, orientation. Those who consider their own self interests before those of their patients have a self orientation (e.g., those who are members of the profession for profit motives, or simply because "it is a job").

Relationships With Other Providers.

5B: Interprofessional Communication: (1) Separate Professionals, Minimal Communication (2) Professionals Communicate, Collaborate as Team. Providers who consider themselves as part of a team and who communicate with other providers involved in their patient's care are collectivity-oriented. Providers who are separate, individual practitioners who do not consider themselves as part of a care-giving team and who do not communicate with other providers who may be involved in the patient's care may be considered to be self-oriented.

5C: Interprofessional Decision-Making: (1) Hierarchical (2) Egalitarian. Providers who consider the input of all team members equally demonstrate a collectivity orientation. Those who observe a hierarchical chain of

command and communication among providers may be said to be self-oriented.

Summary

This chapter has described the analytical model that was developed for use in this research. This model, an elaboration or operationalization of Parsons' (1951) pattern variables of role definition, was created for two purposes. First, it was to be used in classifying the role expectations to which physicians and nurses, specifically, are socialized, as these are described in the literature. Second, it was to be employed as the scheme for categorizing the role expectations held by a sample of terminally ill patients, family members, and professional providers of terminal care who were interviewed in an earlier exploratory study of the definition of quality terminal care. In the following chapter, the findings of the research are presented using this analytical model.

CHAPTER VII

RESULTS

In this chapter are presented the findings of the study. The three research questions are addressed separately and in sequence in three major sections. Providing the structure for the analysis are the indicators developed for the purposes of this research. As detailed in Chapter VI, Analytical Model, these indicators were derived from and elaborate on Parsons' (1951) pattern variable framework for the analysis of role expectations.

RESEARCH QUESTION 1: WHAT ROLE EXPECTATIONS ARE LEARNED BY PHYSICIANS AND NURSES THROUGH PROFESSIONAL AND WORKPLACE SOCIALIZATION, AND WITH WHICH MODEL FOR THE PROVISION OF HEALTH CARE, MEDICAL OR HOLISTIC, ARE THEY MOST CONGRUENT?

This question was addressed through a thematic content analysis of literature in the area of socialization for the role of physician or nurse. The specific methods used for identifying the literature are detailed in Chapter V, Research Design and Methods. Particular attention was paid to literature focusing on the role expectations to which

physicians and nurses are socialized with respect to care of the dying.

As described above, providing the structure for this thematic content analysis of the literature are the indicators of role expectations that were developed as part of this study. The role expectations which are learned and held, first by physicians, then by nurses, as these are reported in the literature, are presented with respect to each indicator.

To aid in the summarizing of the role expectations noted by the various sources reviewed, two tables, one describing the role expectations reported to be learned and/or held by physicians, and one describing the role expectations reported to be learned and/or held by nurses, have been prepared for each indicator. Included on each table are four columns: (a) the author(s) and the date of the publication; and descriptions of (b) any normative role expectations reported to be learned through professional socialization; (c) any role expectations said to be learned and/or held by the physician or nurse in the workplace; and (d) the ideal role expectations in this domain from the perspective of the author(s).

One additional piece of information is included in each of the last three columns. As explained in earlier chapters describing Parsons' pattern variables and the analytical model developed for this study, each indicator is

comprised of two poles. One pole, generally the left pole (or the "1" in this case), represents the normative expectation consistent with the medical model of care. The other pole, generally the right pole (or the "2"), represents the role expectation consistent with the holistic model of care. In each of the last three columns (b, c, and d), then, a number representing the pole of the expectation described by each particular source is included. A key to the meaning of each number ("1" or "2") is at the head of each table. The presence of both numbers ("1-2") in a column means the source indicated a conflict in this role expectation. The absence of an entry in a column means the source did not directly address that topic. Explanatory notes under the numbers are included where sources made particularly interesting points.

Finally, two master tables, one relevant to socialization for the physician role (Table XXXI), the other to socialization for the nurse role (Table XXXII), were prepared. These tables list all of the sources reviewed down the left side of the page and each of the indicators across the top of the page. "X's" indicate which sources addressed which indicators. These tables are useful as overviews and are discussed in the summary of this section.

Affectivity Variable, Indicator 1A: Affective Involvement

This indicator combines Parsons' (1951) affective neutrality--affectivity pattern variable, and Williams'

(1959) notion of emotional commitment, which was discussed in Chapter VI, Analytical Model. Upon examination both of the literature reviewed and of the responses of the patients, family members, and health professionals interviewed (Research Question 2), it became clear that these two concepts are closely intertwined empirically. It seems that affect as it is expressed often conveys the degree to which the health professional is emotionally or personally involved with the patient or the patient and the family.

This indicator, then, examines the literature with respect to the role expectations for the degree of affective, or personal, involvement on the part of the health professional toward the patient or the patient and the family. Neutral affect and no personal involvement exemplify the medical model position (pole 1) on this indicator. The right pole (pole 2) is positive attention to the interpersonal relationship with the patient and at least some personal involvement and represents the holistic approach.

Expectations For The Role Of Physician. As shown on Table V, the sources reviewed consistently pointed out that physicians in their professional socialization receive little instruction in interpersonal relations with patients and in fact learn to be emotionally detached (pole 1). Workplace ("actual practice") socialization is similar.

TABLE V

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
AFFECTIVITY VARIABLE, INDICATOR 1A:
AFFECTIVE INVOLVEMENT

Author(s), Date	1 = Neutral Affect/ No Personal Involvement		2 = Positive Affect/ Personal Involvement	
	Professional Socialization Process	Actual Practice	Ideal Practice	
Becker et al. (1961)	1 Taught value of impersonal way of viewing events.		1 Spare the professional the anxiety, discomfort the lay perspective suggests, esp. in death.	
Bloom (1979)	1	1 Emphasis is placed on cognitive aspects of performance.	2 Physician needs inter- personal skills, esp. the ability to communicate (cites research).	
Coombs (1978)	1 Relatively small amount of formal instruction is devoted to interpersonal aspects of patient welfare; students are moved from initial idealism to detached concern; develop protective shield, suppression.		2 Fully rounded physician is sorely needed BUT emotional detachment is necessary, no matter how sympathetic clinician may be. At the same time, long range suppression is not always healthy.	
Coombs & Powers (1975)	1 Medical teaching model glorifies science of medi- cine at expense of art of medicine; not taught to relate warmly, meaningfully. Students start with layman's attitude (2), evolve to (1): "calm, objective rationality and full control of emotion." Taught to be analytical, non-emotional. "The educa- tional processes which foster empathy & compassion are not clearly visible."	1-2 Physicians are at different developmen- tal stages.	2 Must treat patient and family with "gentleness and sympathy;" patients need "warm sensitivity and understanding concern". BUT, cannot take personally; must retain composure, not sob over favorite patient; not a doctor, then.	

(Continued)

TABLE V, Continued

Lasagna (1968)	1		2
	Once in medical school, students become increasingly emotionally detached.		Decrease in emotionality is disturbing.
Levinson (1967)	1		
	Citing others, argues students become emotionally detached.		
Lief & Fox (1963)	1-2		
	Students in medical school are trying to find a balance of detachment and concern.		
Mullaly & Osmond (1979)	1	1	1
			To become emotionally involved could be harmful.
Rosenberg (1979)	1	1	
	Several theories for this presented; argues for theory of conflicting demands placed on students. Asserts growth in cynicism and apathy results.	Apparently alienated, cold, & self-serving professional.	
Schulz & Aderman (1976)		1	2
		Doctors resort to styles of interaction characterized by detached concern.	
Scurry et al. (1979)		1-2	1-2
		Their research indicates "women physicians may form better relationships with dying patients"	This might have "implications for the vulnerability of the female house officer to feelings of sadness & other emotions when the patient dies."
Searle (1981)	1	1	2
	As medical skills improve, social skills often atrophy due to total immersion in medicine.		Patients want doctors who talk to them.

Sources were less clearly in agreement in terms of their ideals. Some were disturbed by the lack of emotionality on the part of physicians, while others advocated this due to the "harmful effects" such emotionality can have. Many strongly advocated increased positive attention to the interpersonal aspects of care, arguing that it is essential that physicians be "well-rounded" and relate warmly and humanly with their patients. They cautioned, nonetheless, that physicians should not become emotionally involved.

Expectations For The Role Of Nurse. A review of Table VI reveals a great deal of ambiguity in the role expectations to which nurses are socialized with respect to their interpersonal relationship with patients. In general, according to these sources, nurses appear to learn some basic communication skills, but also to develop professional distance (poles 1-2). Some disengage from dying patients due to a fear of overinvolvement (pole 1); others do not but later suffer stress (pole 2). The general consensus was that nurses should possess good interpersonal skills and should be "authentic interpersonally," but they should not become "overinvolved."

TABLE VI

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
AFFECTIVITY VARIABLE, INDICATOR 1A:
AFFECTIVE INVOLVEMENT

Author(s), Date	1 = Neutral Affect/ No Personal Involvement		2 = Positive Affect Personal Involvement	
	Professional Socialization Process	Actual Practice	Ideal Practice	
Germain (1980)		1-2 The death of a patient is one of the most emotionally devastating problems faced by nurses, even when the "appropriate level of professional distance for sound clinical judgment has been maintained."	1-2 Give of themselves, share, listen, receive, respond with human authenticity; BUT still acknowledge the defenses of professional caregivers.	
Myers (1982)		1-2 Found in her case study that some nurses initiated condolences upon the death of a patient; others did not; some avoid, use euphemisms.		
Quint (1967)	1 Little attention is given to interactional problems associated with dying, or to communication skills. Trainees learn to minimize time spent with dying patients, to change the subject, to make nonspecific comments, to refer questions to an authority. The conversational aspects of nursing are presented in general rather than specific terms. Trainees learn composure & self control are highly valued & learn to talk to patients in "professional manner."	2 Assignment to a dying patient has tremendous emotional impact.	1-2 A broader base in behavioral science content is needed. Interaction with dying patients is critical, BUT becoming personally involved with the dying patient is not good.	

(Continued)

TABLE VI, Continued

Rosenthal et al. (1980)	1-2 Ambiguity found in nursing school: nurses are taught to be cheerful, reassuring, but at the same time, they develop a definition of professional behavior which includes dignity, distance.	1-2 The appropriate extent of emotional involvement is ambiguous in school & on the job.	1-2 Competence in interpersonal skills is essential for achieving an understanding of the patient. BUT nurses should not become over-involved.
Ross (1978)		1 Because of a fear of overinvolvement, nurses may disengage, withdraw from patient.	
Thrush et al. (1979)		1 There is direct avoidance & minimizing of interpersonal contacts with the terminally ill.	2 The ideal is the nurse who "dares to care."
Vachon (1978)		2 Because of various motivations for working with the dying, notes that some staff become over-involved, overidentify with patients.	1-2 Notes stress of over-involvement.
Williams (1982)		1 The death of a patient arouses psychological trauma; often the response is isolation, neglect of dying patients.	2

Diffuseness Variable, Indicator 2A: Scope Of Care

This indicator examines sources' assessment of the role expectations to which health professionals are socialized with respect to the scope of care to be given. "Scope of care" refers to whether only the physical care needs of patients (pole 1) or patients' psychosocial needs as well as their physical needs (pole 2) are addressed. This latter option is termed "holistic care," and is consistent with the hospice model of terminal care. The former, "physical care," represents the medical model approach to health care.

Expectations For The Role Of Physician. Table VII summarizes the findings of the analysis of the literature on this issue. With the exception of two sources from the late 1950's (who note that physicians are, or were then, being socialized to provide comprehensive, or holistic, care) and one current source who asserts students are exposed to both approaches, all others state that there is nearly exclusive attention to the physical aspects of care, both in their professional socialization and in actual practice (pole 1). Even one of those two sources (Fox, 1957) noted that while comprehensive care was being taught, many students felt "social problems" were beyond the scope of the doctor's work.

There was similar consensus, with one exception, that physicians should, ideally, attend to patients' psychosocial

TABLE VII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
DIFFUSENESS VARIABLE, INDICATOR 2A:
SCOPE OF CARE

1 = Physical Care Only 2 = Psychosocial Care Also

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Becker et al. (1961)	1 Patients should be "really" sick, not psychosomatically.		
Bloom (1979)		1-2 Discusses the "new humanism of medical ethics. At the same time, notes that the bulk of the physician perfor- mance literature focuses on technical, not inter- personal, processes.	2 Professional socialization should include concern about emotional, social factors in patient's illness; should teach such skills, knowledge.
Coombs (1978)	1 Training is disease- centered.	1 Emotions, feelings of patients often over- looked.	2 Must deal openly with subjective features of medical care: the emotions, feelings of patients, families.
Coombs & Powers (1975)	1 "The clinician learns to view dying patients not as people with feelings, but as medical entities, speci- mens, or objects of scientific interest...the old scientific fragmentali- zation method."		2
Field (1953)		1-2 Concentration is on the sick organ.	2 Emphasis should be on the intrinsic worth of the patient as a person, not just as a disease; notes this concept is not new; possibly is older than Roman Empire.

(Continued)

TABLE VII, Continued

Fox (1957)	2	1	
	School teaches comprehensive care, but many students feel solution of "social problems" is beyond the scope of the doctor's work.		
Harman (1971)	1		2
	Few respondents had any education for the social-psychological care of dying patients.		Recommends discussion groups re: problems of social-psych. care of dying patients be held for medical students.
Lasagna (1968)	1		2
	Orientation in medical school is to the medical problem, not the patient.		Need new curriculum that is patient-oriented from the beginning.
Merton (1957b)	2	1	2
	There is a renewed emphasis on the patient as a whole person.	This renewed emphasis on the patient is "a conception more honored in the breach than the observance."	Argues for "social medicine" and cites many physicians who feel similarly.
Mullaly & Osmond (1979)	1	1	1
			General medical practice & psychotherapy are not compatible. Argues against courses in death & dying: students may not WANT knowledge in the psychotherapeutic area; there may not be enough time; may not be consistent with contemp. practice of medicine.
Robinson (1974)		1	
		Some doctors feel emotional, psychological, social problems are out of the sphere of medical competence.	

(Continued)

TABLE VII, Continued

Rosenberg (1979)	1 & 2	1	
	There is conflicting socialization; there is exposure to the role of specialist AND an orientation to the total patient.		
Salber (1975)	1	2	
	Doctors are trained in clinical rather than social aspects of medicine.	Need to learn the patient's life circumstances in order to treat effectively; these influence seeking of care, presentation of symptoms, acceptance of medical assessment & intervention.	
Schulz & Aderman (1976)	1	2	
		Medical schools need to focus on socialpsychological aspects of dying to eliminate avoidance behavior.	
Searle (1981)	1	2	
	Doctors are socialized to total immersion in medicine, medical problems.	Patients seem to want a doctor who has time to listen to their problems, talk to them.	
Simpson (1976)		1	2
		Prevalent lack of concern for patients' psychological state; there is isolation and abandonment.	New philosophy calls for awareness of patients' psychological needs.

needs as well as their physical needs (pole 2). The exception, Mullaly & Osmond (1979), argued that such attention is not appropriate: that students may not want knowledge in the "psychotherapeutic" area, there is likely not enough time, and that attention to psychological needs may not be consistent with the contemporary practice of medicine.

Expectations For The Role Of Nurse. As seen in Table VIII, only one source (Lurie, 1981) argued definitively that nurses are socialized to provide psychological support to patients (pole 2), while one source asserted they definitely are not socialized to address patients' psychological needs (pole 1). The remaining several others noted ambiguity and conflict in nurses' professional socialization, pointing out deficiencies in actual training and continued separation, rather than integration, of behavioral and biological components of care. Most agreed that in the work setting, provision of physical care supersedes the giving of psychosocial care (pole 1). The ideal of all sources was inclusion of the psychosocial dimensions of care within the realm of nursing care (pole 2).

TABLE VIII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
DIFFUSENESS VARIABLE, INDICATOR 2A:
SCOPE OF CARE

1 = Physical Care Only 2 = Psychosocial Care Also

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Germain (1980)	1-2 Nurse educators prior to 1969 (influence of Kubler-Ross) attempted to expand the physical focus of care of the dying to a more holistic patient and family focus. While the nursing literature is replete with references to Kubler-Ross, training is inadequate.	1 What holistic knowledge is learned is only infrequently translated into practice.	2
Krant (1978)		2 Nurses usually have more skills in relating to the physical and often psychological relief of suffering.	2 Physical and psychological factors go hand in hand.
Lurie (1981)	2 Nurses are socialized to give psychological support to patients.	1 Citing work of several authors, states that nurses tend to respond to patients' talk of dying with avoidance behaviors.	
Myers (1982)	1-2 Resocialization toward the social rather than the medical model for nurses is being scrutinized.		2 Social as well as medical aspects of death and dying must be respected.

(Continued)

TABLE VIII, Continued

Quint (1967)	1-2	1	2
	During the 50's there was growing emphasis on psychological nursing care, but a general silence about dying. Nurses are taught to care for patient's body, not to interact. Also, not all curricula emphasize psychological aspects. The directive to provide psych. care is vague, subject to different interpretations and methods of implementation.	Technical (physical) activities take precedence. Social & psych. aspects of patient care are not explicitly built into hospitals' accountability systems.	Patients need help with human problems. BUT communication with dying patients can become a new kind of ritual.
Rosenthal et al. (1980)	1-2	1	2
	Giving emotional support (talking, listening) is given high priority in professional training; at the same time, there is continued influence of the biomedical model, with its emphasis on physiologic responses. Most nursing textbooks separate biological & behavioral components of care; also, behavioral components usually are associated with psychiatric nursing.	The provision of emotional support is given low priority in the job setting.	The true ideal for the patient is provision of holistic care, BUT the authors caution that emphasis on psychosocial care may provide a new avenue for increased control over problem clients; this occurred in their study. They recommend integration of the behavioral & social sciences into the nursing curriculum.
Schulz & Aderman (1976)	1	1	2
			Nursing schools need to focus on socialpsychological aspects of dying to eliminate avoidance behavior.

(Continued)

TABLE VIII, Continued

Simpson (1976)

1

Little attention is
given to the patient's
emotional needs.

2

Nurses should have an
awareness of psychological
needs.

Thrush et al.
(1979)

1

Nursing education tends
to support the purely
"biological-technical
approach to patient care;
psychosocial aspects
of death & dying are
relatively neglected.

1

Nurses sometimes resort
to avoidance behaviors--
this obscures the psycho-
social aspects of care.

2

Death & dying have
psychosocial dimensions.

Diffuseness Variable, Indicator 2B: Unit Of Care

Examined here are sources' views concerning what unit of care--solely the patient (pole 1), or the family as well as the patient (pole 2) physicians and nurses are socialized to address. Specifically of interest is whether or not any mention was made of the expectation that health professionals address the needs of the family in addition to those of the patient.

Expectations For The Role Of Physician. As shown in Table IX, only five sources addressed this issue, and only one source referred to families and their needs in the context of physicians' professional socialization. This source stated that students are not prepared to meet the needs of families. All sources agreed that families' needs generally are not addressed by the physician (pole 1), but that the focus of treatment should, ideally, be the family unit (pole 2).

Expectations For The Role Of Nurse. Table X reveals a similar lack of attention to this role expectation for nurses by the sources examined. One source stated that the patient and the family are the clients (pole 2). Another asserted that the needs of families frequently are overlooked (pole 1). Others noted that the family focus is only sometimes apparent (poles 1-2). All implied that such a focus is desirable (pole 2).

TABLE IX

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
DIFFUSENESS VARIABLE, INDICATOR 2B:
UNIT OF CARE

	1 = Patient Only	2 = Patient and Family	
Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Coombs (1978)		1 Emotions, feelings of patients & their families are often overlooked.	2
Coombs & Powers (1975)	1 "The developmental personality changes which result from medical socialization ...are not conducive to preparing the doctor emotionally so that he can meet the needs of dying patients and their families in the depersonalized hospital setting."	1	2
Field (1953)		1	2 There is a need for focus on the family as the unit of treatment; experience has demonstrated that illness of one member has repercussions on entire group.
Krant (1978)		1 Citing others, notes needs of patient's spouse often are not met.	2 There is a need to help the family.
Rosenberg (1979)		1 Medical politics & hostility dominate over the needs of patients & families.	

TABLE X

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
DIFFUSENESS VARIABLE, INDICATOR 2B:
UNIT OF CARE

1 = Patient Only 2 = Patient and Family

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Germain (1980)	1-2 Prior to 1969 and the influence of Kubler-Ross, there was some evidence in the literature of a patient & family focus. Now nursing literature is replete with references to Kubler-Ross, but there is a lack of adequate training.		
Krant (1978)		1 Argues that hospital policy may fail to meet the needs of patients' spouses; families' needs frequently are overlooked.	2 Families should be assisted, as well as the patients.
Myers (1982)		1-2 Found in her case study that some nurses talked to the family (bereaved) and some did not.	
Rosenthal et al. (1980)		2 Both the patient & the family are clients.	

Diffuseness Variable, Indicator 2C: Availability Of The Health Professional

This indicator identifies sources' perspectives of the role expectations concerning the availability and accessibility of health professionals to the patient or the family, in terms of time and physical presence.

Expectations For The Role Of Physician. Table XI summarizes the findings of the analysis of the literature. Most of the relevant comments made by sources addressed the issue of avoidance by physicians of patients who are dying. All indicated that either during their professional socialization or in the workplace, dying patients frequently are avoided (pole 1). One source noted that medical students learn about "the preciousness of time" as a result of their professional socialization experiences. Two sources offered their ideals that dying patients not be avoided (pole 2).

Expectations For The Role Of Nurse. Nurses, too, are seen by the nursing socialization sources as avoiding dying patients, as shown on Table XII. One source addressed the issue of 24-hour availability, noting that while nurses maintain continuous coverage, their schedules are more rigid than those of physicians; therefore, they tend to be less available. The ideal role expectation was stated overtly by only one source; this ideal was for non-avoidance (2).

TABLE XI

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
DIFFUSENESS VARIABLE, INDICATOR 2C:
AVAILABILITY OF THE PHYSICIAN

1 = Limited Availability 2 = Unlimited Availability

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Coombs & Powers (1975)		1 Until doctors reach Stage 5 (of the developmental stages of coping with death), avoidance is often used as a coping technique.	
Harman (1971)	1 Found considerable avoid- ance of dying patients by medical students.		2 Dying patients should not be avoided.
Rosenberg (1979)	1 Through the socialization process, medical students become concerned about the preciousness of time.		
Schulz & Aderman (1976)		1 Dying patient is avoided due to discomfort with death.	2
Scurry et al. (1979)		1 Their research shows likely unconscious avoidance of dying patients.	

TABLE XII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
DIFFUSENESS VARIABLE, INDICATOR 2C:
AVAILABILITY OF THE NURSE

1 = Limited Availability 2 = Unlimited Availability

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Lurie (1981)		1 Citing several authors, states that nurses tend to respond to patients' talk of dying with avoid- ance behaviors.	
Myers (1982)		1-2 Nurses in general maintain continuous coverage, but nurses' work schedules are far more temporally rigid than doctors'.	
Ross (1978)		1 Nurses sometimes disen- gage, withdraw from dying patients due to fear of overinvolvement.	
Schulz & Aderman (1976)		1 Nurses sometimes avoid dying patients.	2
Thrush et al. (1979)		1 There is direct avoidance & minimization of inter- personal contacts with dying patients by nurses.	
Williams (1982)		1 There often is isolation & neglect of dying patients by nurses due to their inability to deal with death.	

Particularism Variable, Indicator 3A: Care Approach.

As described in Chapter VI, Analytical Model, this indicator examines whether the role expectation to which health professionals are socialized is for care to be generally or individually oriented; that is, whether, the treatment given to a patient by a health professional is to be essentially the same as that given to all patients (pole 1, generalized care) or tailored to meet the particular needs of each patient (pole 2, individualized care).

Expectations For The Role Of Physician. Table XIII summarizes the findings of the analysis of the literature as they relate to this indicator. Only one of the sources indicated that the approach to which physicians are socialized is the individually oriented approach (Freidson, 1970a). All others asserted that professional socialization imparts a generalized approach to students, whereby students become disease-centered and dehumanized in their approach (pole 1). Those sources who stated their ideal expectation advocated the individualized approach (pole 2).

Expectations For The Role Of Nurse. Only four of the sources examined commented with regard to role expectations for the appropriate care approach, as shown on Table XIV. The one making reference to the professional socialization of nurses on this issue (Rosenthal et al., 1980) noted that students learn to replicate the known approach for dealing

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
PARTICULARISM VARIABLE, INDICATOR 3A:
CARE APPROACH

1 = Generalized Care 2 = Individualized Care

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Blumenfield et al. (1979)	1 Students surveyed expressed little uncertainty & made broad generalizations to dying patients, specifically re: whether patients should be told about their terminal illness.		2 Each patient should be evaluated on an individual basis.
Coombs (1978)	1 Medical students learn to depersonalize the patient.		2
Coombs & Powers (1975)	1 Students learn depersonalizing techniques to cope with the death of patients; the primary one learned is to deny the subjective features, view patients as entities, specimens, objects of scientific interest, not as persons with feelings.		2
Freidson (1970a)	2 "Clinical experience" is one of the two basic values of the medical profession.	2 Decisions are based on the uniqueness & uncertainty of each case.	

(Continued)

TABLE XIII, Continued

Harman (1971)	1	2
	During medical school, trainees become disease-centered & relatively dehumanized in their patient-care attitudes.	In medical education, stress individualization of care, but also educate re: typical dying trajectories so students learn generalities on which individualization is based; teach skills needed for finding the most appropriate death for a patient.
Lasagna (1968)	1	2
	"Professors tend to...reduce everything to fundamental chemical and physical cellular processes, unaware of the sterility of this ambition."	"The doctor must respect simultaneously the general & the individual."
Rosenthal et al. (1980)	1	
	Cite other authors who note that decisions are based on typologies of patients and their conditions rather than on viewing each patient as a unique individual.	

TABLE XIV

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
PARTICULARISM VARIABLE, INDICATOR 3A:
CARE APPROACH

Author(s), Date	1 = Generalized Care 2 = Individualized Care		Ideal Practice
	Professional Socialization Process	Actual Practice	
Quint (1967)		1 Rough handling of the patient (depersonalized treatment of his/her body) is one way used to cope with the dying patient.	
Rosenthal et al. (1980)	1-2 While nurses' training & philosophy urge them to treat each patient as an individual rather than a "case," students learn to replicate the known approach for dealing with problems, to categorize patients according to presenting problems; many instructors are not comfortable dealing with uncertainty.	1 Job experience of the nurse leads to a view that the nurse's main goal is to foster the work of the organization & that the pursuit of this goal is the key to career advancement. Too, generalization counteracts "overinvolvement."	1-2 Individualized care should be the professional goal; but the categorization of patients and health services is a necessary condition for efficient, effective delivery of health care—does lead to fragmentalization, though.
Simpson (1976)		1 Little attention is given to the patient's personality.	
Thrush et al. (1979)		1 The dying patient is discussed as the "colostomy" or the "coronary" in Bed 2.	2 Education about death that teaches the patient is a person is a valuable asset to the nurse & the patient.

with problems and to categorize patients according to their presenting physical problem (pole 1), despite the training they receive indicating that nursing's philosophy is to treat each patient as an individual (pole 2). Each of the four sources reported that in actual practice, the generalized, depersonalized approach predominates (pole 1). Of the two sources stipulating their ideals, both cast their votes for the individualized approach, although Rosenthal et al. (1980) were ambivalent, pointing out that categorization of patients is necessary for efficient, effective delivery of health care.

Ascription Variable. Indicator 4A: Treatment Goal

Examined in this indicator are the expectations concerning the goal of the treatment received by the terminally ill patient: whether the patient is to be treated with (pole 1) a goal of life prolongation or (pole 2) a goal of the patient's quality and comfort of remaining life in mind. At issue is whether health professionals are socialized to meet a goal requiring that all attempts to treat (cure) the patient right up to the very end be made (pole 1), or to shift the goal to one of comfort and quality of life for the patient who is terminally ill (pole 2).

Expectations For The Role Of Physician. This indicator received more attention than any of the others by the sources consulted in this analysis of the physician

socialization literature. Two themes relevant to socialization with respect to the goal of care are evident. First, as revealed in Table XV, in general, sources assert that physicians are cure-oriented, are socialized to a highly technological approach to medicine, and are taught to use their technical skills to prolong life, as death is seen as the antithesis of good medical practice (pole 1). Second, the lack of formal education of physicians concerning death and treatment of dying patients is pointed out (pole 1).

There appears to be a conflict in role expectations as enacted in actual practice. Some sources report that physicians rely on the criterion of "quality of life" to aid them in their decisions concerning treatment, and/or the philosophy that no extraordinary measures should be taken with the terminally ill (pole 2). Other sources assert that physicians generally continue to adhere to the position that death should be avoided at all costs (pole 1).

There is a similar conflict in the ideals of the sources examined: some assert that the physician's goal should be to prolong life, while others argue that patients should not be kept alive solely for the purpose of prolonging their lives: that quality of life is the primary consideration. Most sources would seem to agree that useless treatments should be avoided and patients' symptoms should be relieved; the ambiguity lays in the definition of

TABLE XV

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
ASCRPTION VARIABLE, INDICATOR 4A:
TREATMENT GOAL

1 = Life Prolongation 2 = Life Quality & Comfort

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Becker et al. (1961)	1 Students view patients who can be cured as "better" than those who cannot.		1 The true work of the physician is saving endangered lives.
Coombs (1978)	1 Death is seen as the antithesis of good medical practice.		2 The higher developmental stage is beyond objecti- fying and combatting death. The medical teaching model is questioned, then personal feelings are dealt with.
Coombs & Powers (1975)	1 In clinical pathology rounds, the assumption is made that death is preven- table, not supposed to happen to patients of good physicians.		1-2 Doctor's main job is to cure if possible, but he must also relieve and comfort.
Dickenson (1976)	1 There is a lack of formal education re: death & care of dying patients in U.S. medical schools.		
Epstein (1974)	1 Students learn the Hippocratic dictum, to prolong life, not to decide what, if any, life is not worth living.		1 Defends the Hippocratic dictum; useless treatments, no, but feels it is better to err on the side of life. It is undignified to cooperate with death.

(Continued)

TABLE XV, Continued

Karoti (1975)	1	2
	The "militant concept" opposes death at all costs. Ethicists themselves do not agree re: distinction between extraordinary & ordinary means.	Physician judgments must respect life, but not necessarily prolong it.
Lasagna (1968)	1	
	The internist in training is taught more about dramatic acute illnesses than problems of chronic disease, & is given no preparation for problems connected with death.	
Liston (1973)	1	
	Lack of formal education in U.S. medical schools re: death & care of the dying.	
Morison (1974)	1-2	2
	What is "extraordinary" is debated; estimates of patient's future quality of life are sometimes used. Cultural norms will not allow sanction of euthanasia.	Need to assure death with dignity.
Mullaly & Osmond (1979)	1	2
	Cite others who argue that dying persons are being treated in the sick role.	Doctors must ensure proper transition from sick role to dying role, to ensure relatively painless & timely death.
Schram et al. (1978)	1-2	
	Note recent court decisions have rejected "quality of life" as valid criterion, yet Scurry et al. (1979) found this factor ranked most important by house officers in their decisions to use the "no code" designation.	

(Continued)

TABLE XV, Continued

Schulz & Aderman (1976)	1	Argue that research shows dying patient is considered a deviant, and that death is associated with disappointment & failure by physicians, who cope by avoiding death.	
Scurry et al. (1979)	1-2	Their research shows that while house staff admit discomfort with dying patients, they say they do not avoid dying patients. Authors note incompatibility of responses.	2 Agree strongly with "no code" designation.
Searle (1981)	1	Physicians are socialized to a highly technological approach to medical practice; may lead to over-diagnosis, over-treatment. Error of omission is learned to be greater than error of commission, so do everything possible for patient.	
Simpson (1976)	1	The role of the physician recedes to that of the nurse in terminal care.	1-2 Extension of life remains first priority, but remission of symptoms also a major goal.
Veatch & Tai (1980)	2	In the 1960's, chronic disease suddenly became the socially dominant disease; prior, it was aggressive, acute infection.	
Williams (1982)	1	Argues average physician is still unprepared to assist the dying patient.	

"useless" and in the timing of the physician's transition to treating patients within the dying, as opposed to the sick, role.

Expectations For The Role Of Nurse. The role expectations concerning the appropriate goal of care for nurses appear to be in even greater conflict than those for physicians. Table XVI show that several sources argue that the domain of nursing is related to "care" functions, which include an emphasis on patients' physical and psychological comfort (pole 2). At the same time, nurses are reported to be highly influenced by the treatment orientation of physicians and to place a high value on recovery (pole 1). Some sources note the lack of adequate education for nurses in death and dying (pole 1). All sources agree that the ideal goal for care of the terminally ill should be the provision of comfort. While relating more to Indicator 5C, Interprofessional Decision-Making, an interesting thread running through the work of several sources should be pointed out here, as well, as it frequently surfaced in the context of expectations with regard to the goal of care. This thread was a belief that in the care of the terminally ill, the role of the nurse should become dominant over that of the physician.

TABLE XVI

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
AScription VARIABLE, INDICATOR 4A:
TREATMENT GOAL

1 = Life Prolongation 2 = Life Quality & Comfort

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Germain (1980)		2 Asserts that the primary aim of nursing is "care."	2
Krant (1976)		2 More input by nurses is provided in late-stage disease.	2 More input by nurses is necessary in late-stage disease.
Lurie (1981)	2 One of the central values common to all nursing is the emphasis on "care" functions (which include necessary nursing proce- dures as well as the pro- vision of psychological support, health counseling, and education) as opposed to being physicians' sub- ordinates & performance of maintenance or "core" functions.	1-2 There are conflicts be- tween nursing & medicine re: "core," "care," & "cure" functions.	
Myers (1982)		1-2 Found in her case study that nurses preferred to spend time with neonates who were getting better rather than worse; yet their goal was day-to- day comfort.	

(Continued)

TABLE XVI, Continued

Quint (1967)	1	2
	Little attention is given to preparing nurses to cope with problems associated with dying; nurses are prepared to take care of only the body. Textbooks show concern mainly for life-saving or technical matters re: death, such as body preparation. High value is attached to recovery. Also, preparation for death is not standardized.	Care and comfort are needed.
Rosenthal et al. (1980)	1-2	1-2
	Nurses are socialized to believe that physicians "cure" & deal with complicated medical problems; nurse practitioners "care" for all patients & "cure" simple problems. Nurses delegate to others "core" functions—keeping track of medications, etc.	Ideally, nurses prefer patients who leave the hospital "cured." But the goal can shift when cure is not possible; a patient who is dying is not seen automatically as a problem. The "caring" process is difficult for some.
Simpson (1976)		2
		In terminal care, the physician's role recedes, & the nurse's role takes its place.
Thrush et al. (1979)	1	2
	The preservation of life is the foremost goal of the medical professions.	
Veatch & Tai (1980)		2
		The nurse is seen as providing "care," the physician as providing "cure."

(Continued)

TABLE XVI, Continued

Williams (1982)	1-2	1	2
	Nursing theorists see domain of nursing as related to "care;" yet while there is increasing discussion of death, the average nurse still is unprepared to assist patients who are dying.	Only recently has the curative emphasis become possible & dominant. By inclination or socialization within the hospital system, most nurses identify with the treatment-oriented philosophy of the physician: dying patients violate norms by their failure to respond & by their eventual death. Death is viewed as a treatment failure. This results in burnout, isolation, & neglect of patients, intra-staff conflict, & patient-staff conflict.	The domain of nursing is care & support. The A supportive role is appropriate for the care of the dying.

Ascription Variable, Indicator 4B: Pain Control Practices

Role expectations with respect to pain control practices to be followed by health professionals in the care of terminally ill people are examined in this section. As discussed in Chapter VI, Analytical Model, expectations concerning appropriate pain and symptom control may be either that pain and symptoms should be controlled only as they arise and are experienced by the patient (pole 1), or that pain and symptoms should be eliminated if possible, generally through the administration of medication at regular intervals so they are not experienced (pole 2). This latter view is consistent with the treatment goal of quality of life. The former perspective is related to the treatment goal of prolonging life and the potential adverse effects connected with regular administration of medication.

Expectations For The Roles Of Physician and Nurse.

As seen in Tables XVII and XVIII, only one of the sources analyzed (Krant, 1978) addressed this indicator. He commented both on the role of the physician and the nurse, arguing that physicians receive inadequate education in pain and symptom control (pole 1), and that nurses generally have better skills in this area (pole 2). From his perspective, pain and symptom control through the administration at regular intervals of medication is ideal (pole 2), as this enables the patient to be comfortable and to be able to plan and communicate with family members.

TABLE XVII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
ASCRPTION VARIABLE, INDICATOR 4B:
PAIN CONTROL PRACTICES

1 = Medication As Needed 2 = Medication Regularly

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Krant (1978)	1 Inadequate education in pain & symptom control, palliation		2 Need pain, symptoms controlled so patient & family can plan, communicate.

TABLE XVIII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
ASCRPTION VARIABLE, INDICATOR 4B:
PAIN CONTROL PRACTICES

1 = Medication As Needed 2 = Medication Regularly

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Krant (1976)		2 Nurses usually have more skills in relating to physical and psychological relief of symptoms.	2 Pain & symptom control is essential.

Ascription Variable, Indicator 4C: Patient Involvement

Role expectations to which health professionals are socialized with respect to involvement of patients in treatment-related decisions are examined here. An achievement orientation is implied by an expectation for no involvement of patients in treatment-related decisions (pole 1); this orientation sees the professionals as "knowing best," due to their specialized training. Involvement of patients (pole 2) implies an ascription orientation, since patients are involved not as a result of their competence or performance as providers of health care, but instead, because of their ascribed status as patients, and as those directly affected by the care they receive.

As noted in Chapter VI, certain conditions serve as enabling factors for patient involvement, or participation, in care-related decisions. Particularly, information about the patient's diagnosis and prognosis, treatment options and resources, as well as a willingness on the part of the health professional to allow patients some say or input into treatment-related decisions are likely to be required. Both of these enabling factors are visible in the relevant statements made in the literature consulted.

Expectations For The Role Of Physician. Most of the sources making statements relevant to this indicator commented on the provision of information to patients, as described in Table XIX. Of the two sources who discussed

TABLE XIX

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
ASCRIPTION VARIABLE, INDICATOR 4C:
PATIENT INVOLVEMENT

1 = Patient Not Involved 2 = Patient Is Involved

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Becker et al. (1961)	1 Students learn that patients should be cooperative, submissive.		
Beverly (1976)		1 Asserts that the general consensus among physi- cians is that the whole truth should not be told.	2 Patients want to know, so physicians should communicate information using a tentative approach.
Blumenfield et al. (1979)	2 Found socialization had no effect—students same as house staff: patients should be told of their terminal illness. Authors note this represents a change from the 1970's.		1-2 "The patient must be viewed as a distinct indi- vidual who is dealing with an extremely important life event." Student should look beyond own needs and "what may seem to be the cultural themes of today."
Freidson (1970a)	1 Each doctor has ultimate responsibility for his own patient; this is one of two basic values of the medical profession: "medical responsibility." This affects willingness to involve patients in decisions.		

(Continued)

TABLE XIX, Continued

Harman (1971)	1 Physicians are not learning a preference for, or receiving support for open awareness contexts (informing patients of their illness).	1 Few physicians surveyed used or supported patients' preferences re: receiving information.	2 Patients should be helped to reach death in the way they desire. They need information for this to occur.
Haug (1979)		1-2 Notes challenges to physician authority are occurring (as evidenced by self-care and right to information movements) except by older people.	2 Since self-care is inevitable, public needs training on appropriate utilization & limits of self-care.
Krant (1978)		1 Asserts physicians are more likely to tell males than females of their terminal illness.	2 Acknowledgement & communication are very important for "easeful death" of the patient.
Lasagna (1968)		1 States various studies indicate 70-90% of doctors do not inform patients they are facing a terminal illness. Also, the image of doctor as father, omniscient leads to belief that doctor is not to be disobeyed.	2 Studies indicate that 77-89% of patients would wish to be told if they were dying.
Rosenberg (1979)	1-2 There are conflicts in socialization; students learn both that they need to be leaders and to work with a team and that they need to be authority figures.		1-2 The physician needs to be able to decide which decisions one must make & which must be left to the patient and the family.
Schulz & Aderman (1976)		1 Argue that in many cases, doctors do not reveal the nature of the terminal illness to their patients.	2 Patients desire and need information.

(Continued)

TABLE XIX, Continued

Scurry et al. (1979)	<p>1-2</p> <p>Found 83% of house officers responded that they thought it "essential to tell a dying patient of his prognosis, only 57% believed they did not avoid telling a patient directly that he is dying." Such responses are not entirely compatible; indicate likely unconscious avoidance of patients.</p>	<p>2</p> <p>Disclosure is ideal.</p>
Searle (1981)	<p>1</p> <p>Due to obsessive-compulsive role of physician to be thorough, complete, & the strong sense of responsibility felt, physicians are not inclined toward patient participation in decision-making.</p>	<p>2</p> <p>Patients want more responsibility for their health care, want someone who is candid about the limits of his knowledge and that of medicine in general.</p>
Szasz & Hollender (1956)	<p>1</p> <p>Posit several models of the doctor-patient relationship, with most common one being physician guidance, patient cooperation.</p>	<p>2</p> <p>Imply preferred model is mutual participation, esp. where patient is terminal, as physician does not know what's best, cannot cure.</p>
Veatch & Tai (1980)	<p>1-2</p> <p>Assert there is a change occurring: was "do no harm," (paternalism, therapeutic privilege); now it is patient autonomy & self-determination (pro-truth cultural mood). Also, lay population is increasingly sophisticated.</p>	

the provision of information in the context of professional socialization, one (Blumenfield et al., 1979) reported that students felt patients should be told of their terminal illness (pole 2), while the other source (Harman, 1971) found that physicians were not learning to inform patients (pole 1).

Those sources discussing the actual practice of physicians indicated, with one exception, that physicians do not reveal the terminal nature of patients' illness to their patients (pole 1). Scurry et al. (1979) found that over four-fifths of the house officers they surveyed viewed the provision of information as essential to patients; however, only just over half believed that they did not avoid telling patients they are dying.

The sources which addressed this issue of provision of information generally felt that, ideally, patients should be told if they are dying. Blumenfield et al. (1979), however, caution that the physician should examine the case of each individual patient; not all patients should be told.

Several sources approached the subject of patient involvement in more general terms, particularly as it related to the norm of "medical responsibility." In general, earlier (publication dates prior to 1979) sources indicated that it is this norm to which physicians are socialized (pole 1); they argue that physicians are socialized to believe that the patient's welfare is the

physician's responsibility; therefore, the physician should make the treatment decisions and patients should be cooperative and submissive. Most newer sources (1979 and more recent) note the cultural changes currently taking place, such as the consumer rights and the self-help movements (pole 2), and the increasing challenges to physician authority. Especially important for the present research, however, is Haug's (1979) finding that older people are much less likely to question their physician and/or to wish to participate in their own care.

Exceptions were Searle (1981), who points out the obsessive-compulsive role to which physicians are socialized and their reluctance to allow patient participation in decision-making, and Rosenberg (1979), who asserts that physicians in training receive contradictory messages (poles 1-2) with respect to who, physician or patient and family, should make treatment decisions.

Rosenberg (1979) indicates that the ideal is a situation in which the physician decides which decisions should be made by whom. All other sources feel increased patient involvement is desirable and/or inevitable, and the ideal role expectation is for the physician to facilitate appropriate decision-making.

Expectations For The Role Of Nurse. As shown in Table XX, the sources in the literature examined point out that while some attention is devoted to the concept of "involving

TABLE XX

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
ASCRIPTION VARIABLE, INDICATOR 4C:
PATIENT INVOLVEMENT

1 = Patient Not Involved 2 = Patient Is Involved

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Quint (1967)		1 Patients who cooperate are preferred. Patients often are not informed of their prognosis.	2 Open awareness is ideal; however, author seems to assume it is the doctor's responsibility to provide this information.
Rosenthal et al. (1980)	1-2 "Involve the patient" is a phrase bandied about in the literature, education & practice without exploration of its meaning or implica- tion.	1-2 The basis of professional authority is being eroded as patients become better educated; yet patients who are perceived as demanding, noncompliant are "problem" patients, may be isolated. Uncer- tainty and loss of control are threatening to health professionals, including nurses. Re: the provision of information: traditionally the responsibility of the physician, but his failure to provide makes nurse's management of the patient more difficult.	1 Ideally, from the nurse's perspective, the patient should follow eagerly and exactly the therapeutic program, be pleasant, uncomplaining, and fit into the hospital routine.
Schulz & Aderman (1976)		1 Nurses tend to avoid the subject of death.	2 The patient needs & wants to know.

(Continued)

TABLE XX, Continued

Veatch & Tai
(1980)

1-2

The nurse looks more favorably to disclosure, but traditionally has felt obliged to say the matter should be discussed with the physician; now there is more active patient involvement.

2

Active patient involvement & self-care are ideal.

Williams (1982)

1

There is a failure to share accurate information with the patient.

2

Information should be shared so the patient can fulfill the dying role, whereby the patient is no longer dependent on medical authority, is more independent & autonomous.

the patient," little concrete training in implementation methods is provided (pole 1-2). Also, the loss of control inherent when patients participate in decision making is threatening to nurses and other health professionals. With respect to the provision of information specifically concerning the nature of the patient's illness and prognosis, there appears to be consensus that nurses do not provide such information (pole 1). Rosenthal et al. (1980) note that the provision of information traditionally has been the responsibility of the physician. All but one source feel that patient involvement and the provision of information to patients to facilitate involvement (pole 2) is ideal. Rosenthal et al. (1980) present the nurses' ideal as being one in which the patient is cooperative, pleasant, and uncomplaining (pole 1).

Ascription Variable, Indicator 4D: Family Involvement

This section examines sources' reports of expectations to which health professionals are socialized with respect to involvement of families. Just as involvement of patients in their own care and in care-related decisions implies an ascription orientation on the part of the health professional, so does involvement of the patients' families (pole 2). Expectations that health professionals not involve patients' families, that the professionals "know best," are achievement-oriented (pole 1).

Expectations_for_the_Role_of_Physician. Only three sources reviewed commented on expectations for physicians pertaining to the involvement of families (see Table XXI). Rosenberg (1979) asserts that physicians' socialization is conflicting: that physicians learn both that they should be authority figures (pole 1), and that they should allow patients and families to be involved (pole 2).

In terms of actual practice, Coombs and Powers (1975) point out that families are whisked out of the patient's room when the patient is actively dying, they are not allowed to be involved (pole 1). Rosenthal et al. (1980) cite studies finding that families were at least more likely than patients to obtain information (poles 1-2).

Coombs and Powers' (1975) ideal is that families should be involved (pole 2). Rosenberg (1979) argues that patients and families should be allowed to make some decisions, but that the physician needs to make others (poles 1-2).

Expectations_For_The_Role_Of_Nurse. Three of the sources addressing the socialization experiences of nurses comment with regard to expectations for the involvement of patients' families, as seen in Table XXII. The assessments made by these sources are not consistent. One states that families are involved (although they are involved by the physician, not the nurse, through the provision of information). Another asserts that the family often is

TABLE XXI

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
AScription VARIABLE, INDICATOR 4D:
FAMILY INVOLVEMENT

1 = Family Not Involved 2 = Family Is Involved

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Doombs & Powers (1975)		1 Family is not allowed to be present during final moments of patient's life.	2
Rosenberg (1979)	1-2 Conflicting socialization: be authority figure vs. be team player with patients and families.		1-2 Physician must decide decisions physician should make & which ones must be left to the patient & the family.
Rosenthal et al. (1980)		1-2 Cite studies showing families are more likely to obtain information than patients.	

TABLE XXII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
AScription VARIABLE, INDICATOR 4D:
FAMILY INVOLVEMENT

1 = Family Not Involved 2 = Family Is Involved

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Myers (1982)		2 Found in case study that parents were involved in discussion of treatment options; however, medical doctors initiated discussions.	
Rosenthal et al. (1980)	1-2 The phrase "involve the family" is prevalent in the literature, educa- tion & practice, yet its meaning and implications are not explored.	1-2 The conventional strat- egy is to maintain control over families; there is struggle, con- flict between nurses and families. When the pa- tient is dying, though, visiting rules often are relaxed. Conferring the role of patient upon the family is more common than conferring that of worker. The provision of infor- mation is traditionally the responsibility of the physician.	1-2 Families can be a problem; the patient's domestic problems may follow him. While family involvement is consistent with nursing philosophy (which emphasizes the importance of patient's support systems), it threatens nurses' author- ity & autonomy. At the same time, it can cut down on nurses' work, let them spend less time, not get emotionally involved, although with terminal patients, the nurse who delegates may feel guilty.
Talcot-Porsonby (1973)		1 Modern medicine often excludes the family.	2 The family should be kept fully informed. Every- thing should be explained, including the nursing care & how the family can help. Family should be encouraged but not forced to become involved.

excluded. A third notes that visiting rules frequently are relaxed for families of dying patients, but that families generally are not included as workers, helpers, or team members, and that any information provided to them usually is given by the physician.

Talcot-Ponsonby (1973) argues that, ideally, families should be kept fully informed and advised as to how they can help (pole 2). Interestingly, this author cautions that families should not be forced to become involved. Rosenthal et al. (1980) appear to have mixed feelings concerning their ideal expectations for family involvement. They point out that families can be a problem, particularly in situations in which the patient and the family do not have a positive relationship. At the same time, families can aid in reducing nurses' work and decreasing the possibility of nurses' becoming emotionally involved with the dying patient.

Ascription Variable, Indicator 4E: Volunteer Involvement

None of the sources analyzed made mention of role expectations learned through socialization by either physicians or nurses that addressed involvement of volunteers in the care of dying patients.

Ascription Variable, Indicator 4F: Criteria For Evaluating
The Health Professional

As noted in Chapter VI, Analytical Model, this last indicator of the achievement-orientation--ascription orientation pattern variable differs in perspective from the previous six. Instead of ascertaining how the health professional is expected to treat or evaluate the patient or other members of the role set, this indicator examines the expectation concerning how the patient and other members of the role set evaluate or assess the health professional.

Under scrutiny in this indicator is whether the role expectation to which the health professional is socialized is that the professional be evaluated in terms of (pole 1) his or her effectiveness, competence, skills and capacities (pole 1, performance orientation) or his or her sex, age, intelligence, physical characteristics, or group membership (e.g., M.D., R.N.) (pole 2, ascriptive or ascribed orientation).

In Chapter VI, Analytical Model, it was stated that in the medical model, since the patient is expected to comply unquestioningly with the health professional, evaluation of the professional likely would be ascribed, based primarily on the health professional's position as a doctor or a nurse, or on other personal ascriptive characteristics. Alternatively, in the hospice model, since the patient is expected to take a more active role in his or her care, it

was posited that the health professional would likely be evaluated on the basis of performance capacity, not simply position as a doctor or nurse or other ascriptive characteristics, such as sex or age. In this indicator, then, the poles descriptive of the medical and the holistical models are reversed.

Expectations For The Role Of Physician. As depicted in Table XXIII, there was no consensus with regard to whether physicians are socialized to expect to evaluate themselves or to be evaluated by patients on the basis of ascriptive qualities or their performance. A considerable number of the sources noted that physicians are reluctant to criticize each other's performance (pole 2), that physicians are viewed as omniscient by virtue of their positions as physicians (pole 2), and that physicians learn the need to protect this image and to never make a mistake. At the same time, some sources note that physicians are aware of instances of incompetent performance (pole 1), they learn to be self-critical (pole 1), and they are socialized to high standards and an obsessive-compulsive workstyle (pole 1).

Notable among sources' ideals are the comments of Fox (1957), who points out that doctors who do not present themselves as all-knowing evoke criticism and alarm on the part of patients, and those of Searle (1981), who argues the opposite position: that patients want doctors who are self-critical. The lack of agreement among sources appears to be

TABLE XXIII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
ASCRIPTION VARIABLE, INDICATOR 4F:
CRITERIA FOR EVALUATION

1 = Achievement Criteria 2 = Ascription Criteria

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Coombs (1978)	1 Medical students say good doctors must be techni- cally competent.		
Fox (1957)	2 Students are socialized to be "savant."	2 The doctor is regarded as an expert.	2 The doctor must act like a savant; otherwise, evokes criticism & alarm.
Harman (1971)	2 Trainees are reluctant to make negative judgments of colleagues' professional conduct.		1
Lasagna (1968)	2 Medical students are un- questionably superior, intellectually, to the "average man."	1-2 The image of the doctor is one of father, diety, priest, omniscient, yet the doctor "knows how fallible he often is."	
Mullaly & Osmond (1979)	1		1-2 Doctors need sufficient natural sensitivity & empathy.
Robinson (1974)		1-2 Any practitioner is as- sumed qualified to perform any ordinary duties, but the work of each is also seen as a creation of his personality and exper- ience. Merit is evaluated based on both formal training & experience.	

(Continued)

TABLE XXIII, Continued

Rosenberg (1979)	1-2	1
Learn the need to protect the image of medicine, of colleagues (2) yet know of instances of incompetence (1); learn the need to be self critical (1) versus the need never to make a mistake (2).		Medical politics & hostility dominate over the needs of patients & families.
Searle (1981)	1-2	1
Are socialized to high standards, hard-work, obsessive-compulsive role (1), which leads to vain attempt to be perfect, omniscient, omnipotent (2). There is an abundance of Type A personalities in medical school and the medical profession.		Patients want doctors who are candid about the limits of their knowledge.

related to sources' perspectives with respect to the appropriateness and desirability of patient involvement in treatment-related decisions.

Expectations For The Role Of Nurse. A similar lack of consensus of opinion was found for the sources addressing expectations for the role of nurse (see Table XXIV). Some sources noted that certain ascriptive qualities such as femininity and being a woman were valued, while others focused on performance-related criteria, such as empathy, compassion, assertion, ability to cope with uncertainty, no repressed fears of death. Ross (1978) felt that nurses who were sensitized to their personal death concerns were ideal for the treatment of dying patients.

Collectivity Variable, Indicator 5A: Motivation

This indicator, the first of those related to Parsons' self-orientation--collectivity-orientation variable, concerns the health professional's relationship with the patient. Specifically, it addresses the issue of whether the health professional's welfare (self orientation, pole 1) or the patient's welfare (service or collectivity orientation, pole 2) is paramount.

As noted in Chapter VI, Analytical Model, both the medical model and the hospice model appear to prescribe that professionals have a collective orientation; that is, both models fall on the collective-oriented pole: pole 2.

TABLE XXIV

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
ASCRPTION VARIABLE, INDICATOR 4F:
CRITERIA FOR EVALUATION

1 = Achievement Criteria 2 = Ascription Criteria

Author(s), Date	Professional Socialization Process	Actual Practice	Ideal Practice
Jacox (1974)	2 Some nursing instructors explicitly tell their students that their femininity is an important asset to be used when relating to physicians.	2 There is a predominance of women in the ranks.	
Lurie (1981)	1 Pre-socialization: describes the importance of selecting the right candidate with the right characteristics, including empathy, compassion, assertion, less bureaucratic, more psychosocial, better able to cope with uncertainty.		
Myers (1982)	2 The school-based ideal is that the nurse does not make a mistake, responds clearly.	1 Observes that nurses do make mistakes, do not always respond clearly and quickly.	
Quint (1967)	1 The avoidance of errors in practice is taught as extremely important, and is related to concerns of personal negligence.		
Ross (1978)		1 Found some nurses were sensitized to death, some had repressed personal fears of death.	1 Nurses sensitized to their personal death concerns are helpful in the treatment of dying patients.

Expectations For The Role Of Physician. As seen in Table XXV, in general, most sources seem to feel that socialization is to the service orientation (pole 2), but pressures related to the need to protect colleagues and to gain and protect position also are learned (pole 1). As expected, several sources expound the ideal of the service orientation (pole 2, patient's welfare first). Two sources, however, (Searle, 1981 and Coombs, 1978) argue that one important method for serving the patient involves meeting the needs of the physician first (pole 1), including needs to talk about subjective feelings and to be emotionally and physically fit.

Expectations For The Role Of Nurse. With respect to the socialization of nurses, a change in the role expectations to which nurses are socialized appears to be underway. Motives other than a humanistic calling to sacrifice oneself for the sick (pole 2) are becoming acceptable, including personal fulfillment and social status (pole 1), as described in Table XXVI.

The ideals of the sources range from the expected service ideal (pole 2) to implementation of various strategies to protect the nurse from stress (pole 1, although again, this is seen as having benefits for patients and families, as well as the nurse) to a mixed ideal, whereby both a wish to meet patients' needs and a desire for personal fulfillment are seen as acceptable (poles 1-2).

TABLE XXV

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
COLLECTIVITY ORIENTATION VARIABLE,
INDICATOR 5A: MOTIVATION

Author(s), Date	1 = Provider's Welfare First	2 = Patient's Welfare First	Ideal Practice
	Professional Socialization Process	Actual Practice	
Coombs (1978)	2 Medical students state that a good doctor must be dedicated to the patient's welfare.		1 & 2 Author argues that quality of care would be improved if students' needs (espe- cially those for talking about their subjective feelings) were met through structured opportunities.
Harman (1971)	1 Reports that seniors were less patient-centered than freshmen and intern/resi- dent samples. Also notes that trainees are reluctant to make negative judgments of colleagues' professional conduct; this would be an infraction of the consen- sually defined ethics of physicians.		2
Robinson (1974)	2 A service orientation is inherent in the definition of a professional.		2 A collectivity or service orientation is essential.
Rosenberg (1979)	1-2 Students learn the need to protect the image of medicine & colleagues but are aware of instances of incompetence. Also learn the need to be self-critical, yet at the same time, to never make a mistake.	1 The professional apparently cares more for his or her authority than for the needs of the patient & the family. Medical politics & hostility occur among practitioners.	

(Continued)

TABLE XXV, Continued

Searle (1981)	2	1	1-2
	Socialization is to the "service ideal."	Actual commitment is to the occupational role of physician.	The physician needs to be attuned to his/her own welfare (decrease use of drugs, alcohol; improve marital relations; get more sleep) to best be able to serve the patient.
Shuval (1975a)		1	
		Cites vested interests, territorial competition among disciplines & their domains.	
Veatch & Tai (1980)		2	2
		Refer to Parsons (1951) "collectivity orientation" and note two changes: patient welfare has expan- ded to include patient autonomy, and the "collec- tivity" has changed to include several profes- sional roles.	

TABLE XXVI

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
COLLECTIVITY ORIENTATION VARIABLE,
INDICATOR 5A: MOTIVATION

Author(s), Date	1 = Provider's Welfare First	2 = Patient's Welfare First	Ideal Practice
	Professional Socialization Process	Actual Practice	
Alutto et al. (1971)	2 Found no difference in orientation among nursing students in three educa- tional structures (asso- ciate, diploma, bacca- laureate); all had a service orientation.		
Germain (1980)		1-2 Cites Vachon's (1978) reasons for wanting to work with dying patients, only one of which is a sense of humanitarian calling. States that ideal nursing performance is impeded by professional- bureaucratic role demands.	
Jacox (1974)	2 Are socialized to have a willingness to serve others.	2	
Myers (1982)		1-2 The old nurse values said nurses follow a calling to care for the sick & poor through sacrifice of self for others. Emerging nurse values say nurses select a social status and follow personal goals first and respond to a high, sacrificial calling last.	

(Continued)

TABLE XXVI, Continued

Quint (1967)	1	1-2
	A high value is placed on protecting self from negligent performance.	Other reasons for doing a good job of caring for the dying, as well as service orientation, are acceptable, including personal worthwhileness & fulfillment.
Rosenthal et al. (1980)	1-2	2
	Nurses want to alleviate suffering and to participate in the process of caring for or curing the sick, but professional-bureaucratic role demands impede ideal nursing performance.	The ideal is the humanitarian, or service concept/ orientation of nursing.
Vachon (1978)	1-2	1
	Describes possible motivations of staff for caring for dying patients, including accidents or convenience; desire to do the "in" thing; intellectual appeal or desire to gain control over pain or illness; religious or humanistic "calling;" previous unresolved grief; suspicion one might develop the disease.	Because of these various motivations, unexpected stress can be encountered & pose problems for patients, other staff, families. Advocates recognition that staff have needs, motivations, & stress & urges that staff develop insight into own needs; maintain balance between work & outside life; guard against too great a need to be needed (a team approach is crucial); maintain support system at work & outside; have ongoing support of counselor, therapist.

Collectivity Variable. Indicator 5B: Interprofessional Communication

Examined in this indicator is the role expectation with respect to the need for health professionals to: (pole 1) function separately, individually; or (pole 2) coordinate their efforts, to communicate, to work together, and/or to be a "team." Health professionals who coordinate their efforts and are supportive of one another are viewed as being collectivity oriented. Health professionals who function separately and independently are seen as self oriented.

Expectations For The Role Of Physician. As shown in Table XXVII, only three of the sources reviewed specified how physicians are socialized with respect to this issue. Rosenberg (1979) notes that physicians receive conflicting messages (poles 1-2) in their professional socialization, including those to be an authority figure, but also to work with a team. This author asserts that in practice, however, the tendency is to "go it alone" (pole 1). Each of the other sources, as well, point out competition and poor communication among professionals in actual practice (pole 1).

Expectations For The Role Of Nurse. Among the sources discussing socialization for the role of nurse (see Table XXVIII) there was a general consensus that while nurses may receive some training in how to work with certain other

TABLE XXVII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
COLLECTIVITY ORIENTATION VARIABLE,
INDICATOR 5B: INTERPROFESSIONAL
COMMUNICATION

Author(s), Date	1 = Not Team Oriented; Autonomous	2 = Team Oriented; Cooperative	Ideal Practice
	Professional Socialization Process	Actual Practice	
Rosenberg (1979)	1-2 Conflicting socialization: be a leader, be responsible, work with a team, be an authority figure.	1 Tendency is to "go it alone."	
Shuval (1975a)		1 Notes competition between disciplines & their domains.	
Veatch & Tai (1980)		1 What is dominant now is the hospital, rather than the isolated physician. The hospital, if not a team, is at least a health care bureaucracy. Communica- tion within the staff is often less than ideal.	

TABLE XXVIII

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
COLLECTIVITY ORIENTATION VARIABLE,
INDICATOR 5B: INTERPROFESSIONAL
COMMUNICATION

Author(s), Date	1 = Not Team Oriented, Autonomous		2 = Team Oriented; Cooperative	
	Professional Socialization Process	Actual Practice	Ideal Practice	
Jacox (1974)		1 Cites others who note problems of teamwork & interpersonal communi- cation.	2 Argues that an inter- disciplinary model is essential for optimal care of the dying.	
Lurie (1981)		1 Cites work of others who found problems of poor inter-professional communication.	2 All health professionals need to "keep their stories straight."	
Quint (1967)	1-2 Students are not taught to work effectively with physicians. They do learn, though, to use clergy; referral to a minister can take the pressure off the nursing staff.	1 There are communication problems between physi- cians and nurses; these stem directly from male- female norms.	2 Need better communication, cooperative planning.	
Rosenthal et al. (1980)	1-2 Nurses may learn to be team-oriented, but they are not skilled at negotiating with other health professionals.	1-2	1-2 The nurse needs to learn how to work in & lead professional & inter- professional teams, but also have the ability, authority to make deci- sions independently, autonomously, as well as in collaboration.	
Williams (1982)		1 Conflict in cure vs. care philosophy leads to intrastaff conflict.		

professionals such as clergy, they are not skilled at negotiating with other health professionals (Quint, 1967; Rosenthal et al., 1980). In addition, there are problems in the workplace of poor inter-professional communication and cooperation (pole 1).

The ideal expectation is for the nurse to be a capable team member, communicating and collaborating with the other professionals involved (pole 2). Rosenthal et al. (1980) feel that the nurse should have the ability and authority to make decisions independently and autonomously, as well as in collaboration (poles 1-2).

Collectivity Variable. Indicator 5C: Interprofessional Decision-Making

Closely interrelated with Indicator 5B (Inter-professional Communication) is this indicator of the role expectations concerning the status relationship between health professionals. Examined is the question of whether the decision-making structure is hierarchical, with one professional making the decisions (pole 1) or egalitarian, with all disciplines having equal input in decisions (pole 2). This indicator looks at those sources that deal specifically with this question of decision-making and authority.

Expectations For The Role Of Physician. Table XXIX shows that four sources make comments in this area

TABLE XXIX

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF PHYSICIAN
COLLECTIVITY ORIENTATION VARIABLE,
INDICATOR 5C: INTERPROFESSIONAL
DECISION-MAKING

Author(s), Date	1 = Hierarchical	2 = Egalitarian	Ideal Practice
	Professional Socialization Process	Actual Practice	
Robinson (1974)		1	1 The activities of other occupations who work in relation to health & illness are derived from those of the medical profession. Even if the medical professional does not perform these activities, he or she does control & have final responsibility for them.
Rosenberg (1979)	1-2 Conflicting socialization: medical students learn to be leaders, be responsible, yet at the same time, to be team members & to check everything with a superior.		
Shuval (1975a)		1 There are status differentials among health professionals.	2 These differences should be attenuated to enable collaboration as a team.
Veatch & Tai (1980)		1-2 Traditionally, the doctor-nurse relationship has been hierarchical (doctor higher). Increasingly, nurses are developing a sphere of role autonomy & responsibility.	

concerning the socialization, professional and workplace, of physicians. Three note traditional status differentials (pole 1), especially between doctors and nurses, and the fourth reports that physicians receive conflicting messages in training with respect to whether they are to be the leader and be responsible, or whether they are just one member of a team (poles 1-2). Two sources express ideals, one of whom (Robinson, 1974) accepts as a given the higher status of the physician and believes this hierarchy is appropriate (pole 1), while the other asserts that team collaboration (pole 2) is the ideal approach.

Expectations For The Role Of Nurse. This issue appears to be quite a salient one with respect to the role of the nurse. As seen in Table XXX, the majority of the sources comment on this issue of interprofessional decision-making. Most of these sources assert that nurses are socialized to hold expectations for hierarchical decision-making (pole 1). Two opposite forms of hierarchical structure are described, however: one in which the physician is at the pinnacle making decisions, the other in which the nurse holds this position of autonomy and authority. Some sources argue that nurses are socialized to obey physicians, and that nursing is subordinated to medicine; others argue that nurses learn autonomous decision-making skills in their professional socialization, and that particularly in the care of terminally ill

TABLE XXX

RESULTS OF REVIEW OF LITERATURE CONCERNING PROFESSIONAL
SOCIALIZATION FOR THE ROLE OF NURSE
COLLECTIVITY ORIENTATION VARIABLE,
INDICATOR 5C: INTERPROFESSIONAL
DECISION-MAKING

Author(s), Date	1 = Hierarchical		2 = Egalitarian	
	Professional Socialization Process	Actual Practice	Ideal Practice	
Alutto et al. (1971)	1 Found a predisposition to authoritarianism, greatest among nurses in associate degree pro- grams, then diploma, then baccalaureate.			
Freihofer & Felton (1976)		1 Found hierarchical rela- tionships in their exploratory research (physician first).	1 Argue the nurse, due to the amount of contact with the patient & family, is in a most favorable posi- tion to assist individuals cope with death & dying.	
Germain (1980)	1 Socialization imparts autonomous decision- making skills.			
Gliebe (1977)	1 Autonomy, independence, & flexibility are learned.			
Jacox (1974)	1 Nurses are socialized to be "obedient," not auto- nomous, not to exercise professional judgment.		1 Autonomy, independence, & willingness to take risks are ideal.	
Krant (1976)		1 In late stage disease, nurses have more input.	1 More input by nurses is necessary in late stage disease.	

(Continued)

TABLE XXX, Continued

Lurie (1981)	1-2	There are collegial relations between nurses & physicians, yet hierarchical relationships between nurses (who are on top) & other health care workers.
Myers (1982)	1	Nurses are socialized to see the nurse as a leader.
Quint (1967)	1	2 The physician is perpetuated as being in the sole authority position. Nurses need to break old established patterns of dealing with physicians; need to do more than just carry out doctors' orders.
Rosenthal et al. (1980)	1	2 Nursing is subordinated to medicine—a female-dominated one to a male-dominated one; the roots of this are in sexism (cites several sources). The physician is at the pinnacle; the nurse is expected to support physician's decisions (e.g., re: provision of information). The professional socialization of nurses might be improved to develop a cadre of nurses who are more assertive than is at present customary, & more skilled in negotiating with other health professionals in a team setting.
Simpson (1976)	1	1 In terminal care, the role of the physician recedes, shifts to the nurse. Nurses should have the pre-dominant role in the provision of terminal care.
Wessell (1979)	1	1 The nurse presently plays a major role in the management & execution of care of the terminally ill at home. The nurse should document & expand this role.

patients, actually have more input than physicians. All sources argue that ideally, nurses should at least be equal members of the health professional team (pole 2), and several sources assert that nurses should play the dominant role in the provision of care to the dying (pole 1).

Summary

Tables XXXI and XXXII depict the indicators addressed by each of the sources reviewed with regard to expectations which each asserts are learned and held by physicians and nurses, respectively. These tables are useful for pointing out the types of role expectations to which the most attention was devoted in the literature reviewed.

Indicators receiving the greatest amount of attention in the literature on socialization of physicians included: 4A (Treatment Goal), 2A (Scope of Care), 4C (Patient Involvement), and 1A (Affective Involvement). Those mentioned most often among the sources reviewed in the literature on socialization of nurses included: 5C (Interprofessional Decision-making), 4A (Treatment Goal), 2A (Scope of Care), and 1A (Affective Involvement), in that order. If prevalence of appearance in the literature can be assumed to indicate salience, this analysis reveals considerable commonality of focus on particular issues in socialization for these two health professional roles. Not mentioned in either of the socialization literatures was the

TABLE XIII
 DESCRIPTIONS OF SOCIALIZATION FOR THE ROLE OF PHYSICIAN:
 INDICATORS MENTIONED BY EACH SOURCE REVIEWED

AUTHOR(S) AND DATE	INDICATOR(S) MENTIONED												COLLECTIVITY		
	AFFECTIVITY:			DIFFUSENESS			PARTICULARISM:			ASCRPTION					
	1A	2A	2B	2C	3A	4A	4B	4C	4D	4E	4F	5A	5B	5C	
Becker, Geer, Hughes, & Strauss (1961)	X	X				X		X							
Beverly (1979)								X							
Bloom (1979)	X	X													
Blumenfeld, Leve, & Kaufman (1979)					X			X							
Coochs (1978)	X	X	X		X	X					X	X			
Coochs & Powers (1975)	X	X	X	X	X	X			X						
Dickenson (1976)						X									
Epstein (1974)						X									
Field (1953)		X	X												
Fox (1957)		X									X				
Freidson (1970a)					X			X							
Hicks (1970)															
Harman (1971)		X		X	X			X			X	X			
Haug (1979)								X							
Kanoti (1975)						X									
Krant (1978)			X				X	X							
Lasaona (1968)	X	X			X	X		X			X				
Levinson (1967)	X														
Lief & Fox (1963)	X														

(Continued)

(Continued)

TABLE XIII. Continued

TABLE XIII. Continued	INDICATOR(S) MENTIONED													
	AFFECTIVITY: 1A	DIFFUSENESS 2A 2B 2C			PARTICULARISM: 3A	ASCRPTION 4A 4B 4C 4D 4E 4F						COLLECTIVITY 5A 5B 5C		
Author(s) and Date														
Liston (1973)						X								
Norton (1957b)		X												
Horison (1974)						X								
Mullaly & Osmond (1979)	X	X				X					X			
Robinson (1974)		X									X	X		X
Rosenberg (1979)	X	X	X	X				X	X		X	X	X	X
Rosenthal, Marshall, Macpherson & French ((1980)					X				X					
Salber (1975)		X												
Schram, Kane, & Roble (1978)						X								
Schulz & Adelman (1976)	X	X		X		X		X						
Scurry, Bruhn, & Bunce (1979)	X			X		X		X						
Searle (1981)	X	X				X		X			X	X		
Shoval (1975)												X	X	X
Simpson (1976)		X				X								
Szasz & Hollender (1956)								X						
Veatch & Tai (1980)						X		X				X	X	X
Williams (1982)						X								
Number Of Sources Mentioning Indicator	12	16	5	4	7	16	1	13	3		7	6	3	4
Percentage	33%	44%	14%	11%	19%	44%	3%	36%	8%	0%	19%	17%	8%	11%
Pole Most Frequently Mentioned *	1	1	1	1	1	1	1	1-2	1-2		1-2	2-1	1-2	1-2

* Pole 1 = medical model normative role expectations
Pole 2 = holistic/hospice model normative role expectations EXCEPT for
indicators 4F (where poles are reversed), and 5A (where both
models prescribe the norm of collectivity orientation (pole 2)).

TABLE IIIII
 DESCRIPTIONS OF SOCIALIZATION FOR THE ROLE OF MURDER:
 INDICATORS MENTIONED BY EACH SOURCE REVIEWED

AUTHOR(S) AND DATE	AFFECTIVITY: 1A	DIFFUSIONNESS		PARTICIPATIONNESS		AScription						COLLECTIVITY		
		2A	2B	2C	3A	4A	4B	4C	4D	4E	4F	5A	5B	5C
Alutto, Hershinsk, & Alonso (1971)														
Freshofer & Felton (1976)														
Gershin (1980)														
Glaser (1977)														
Jacob (1974)														
Krant (1976)														
Lurie (1981)														
Myers (1982)														
Quint (1967)														
Rosenthal, Marshall, Nacheraun & French (1980)														
Poss (1978)														
Schulz & Adrean (1976)														
Simonon (1976)														
Talbot-Fonsomby (1979)														
Thrush, Paulus, & Thrush (1975)														
Vachon (1978)														
Veatch & Tai (1980)														
Wessells (1979)														
Williams (1982)														

(Continued)

(Continued)

TABLE XIII. Continued

	INDICATOR(S) MENTIONED														
	AFFECTIVITY:		DIFFUSENESS		PARTICULARISM:		ASCRPTION						COLLECTIVITY		
	1A	2A	2B	2C	3A	4A	4B	4C	4D	4E	4F	5A	5B	5C	
Number Of Sources Mentioning Indicator	8	9	4	6	4	10	1	5	3	0	5	7	5	12	
Percentage	42%	47%	21%	32%	21%	53%	5%	26%	16%	0%	26%	37%	26%	63%	
Pole Most Frequently Mentioned *	1-2	1-2	1-2	1	1	1-2	2	1-2	1-2		1-2	2-1	1-2	1	

- * Pole 1 = medical model normative role expectations
 Pole 2 = holistic/hospice model normative role expectations EXCEPT for
 indicators 4F (where poles are reversed), and 5A (where both
 models prescribe the norm of collectivity orientation (pole 2)).

issue of volunteer involvement in the care (4F). Noteworthy also is the lack of attention to the issues of pain control practices (4B) and family involvement (4D).

Tables XXXI and XXXII also contain a row specifying, for each indicator, which pole, 1 or 2, best represents the reports of the majority of the sources reviewed with regard to the specific role expectations that the physician or nurse is socialized to hold. It should be recalled that pole 1 is associated with the medical model of health care provision and pole 2 with the holistic model, with the exception of Indicators 4F (Criteria for Evaluation of the Health Professional), in which the poles are reversed, and 5A (Motivation of the Health Professional), in which pole 2 represents the norms of both models.

As depicted in Table XXXI, this analysis of the literature on socialization for the role of physician reveals that, as hypothesized, the role expectations which are learned and held by physicians generally appear to be congruent with the norms of the medical model. At the same time, there appear to be some issues with respect to which socialization for the role of physician is (a) conflicting and/or (b) seems to be moving toward the norms associated with the holistic model. These issues include patient and family involvement (4C and 4D), criteria of evaluation of the health professional (4F), interprofessional communication (5B), and interprofessional decision-making (5C).

With respect to professional and workplace (actual practice) socialization for the role of nurse (see Table XXXII), there was very little consensus concerning the role expectations to which nurses are socialized. The field of nursing appears to be in quite a state of flux; based on this analysis of the literature, nurses appear to receive a considerable number of conflicting messages with respect to the role expectations which they are expected to hold.

These conflicting messages come both from within nurses' professional socialization and between their professional and their workplace socialization. The areas in which conflicting messages derive from within nurses' professional socialization with respect to expectations for affective involvement (Indicator 1A), the appropriate scope of care (2A), the appropriate unit of care (2B), the appropriate care approach (3A), and desirable interprofessional communication skills (5B). Nurses' professional socialization appears to conflict with norms and values held in the workplace with regard to issues including: the goal of care (4A), where, as co-workers with physicians, nurses are influenced by those norms associated with the medical model; and, where professional and bureaucratic demands surface, the areas of patient and family involvement (4C and 4D) (the nurse's job is easier without such involvement); and motivation (5A) (as noted by Myers, 1982, emerging nurse values are that nurses follow personal goals first and

service orientation second). Particularly interesting is the apparent emphasis in both the professional and workplace socialization of nurses on hierarchical decision-making (pole 1, Indicator 5C), with either the physician or the nurse serving in the dominant role.

In sum, based on the literature reviewed, the role expectations learned and held by physicians appear to be generally congruent with the medical model of health care provision, although there is some evidence of conflict and change in these expectations. With respect to the role expectations learned and held by nurses, it is very difficult to categorize these as belonging to either the medical model or the holistic model; the values and role expectations of nurses appear to be in a state of considerable change and flux.

Caution is required in generalizing from these findings, however, as much of the literature that was reviewed consisted of essays and assertions based on the authors' personal experiences and observations and/or their interpretation of the work of other scholars. There is a need for systematic empirical study of the current socialization experiences of physicians and nurses.

In addition, several years of literature were covered. Many of the more recent sources seemed to reflect some movement toward the holistic model, at least in certain areas of role expectations.

RESEARCH QUESTION 2: WHAT ARE THE ROLE EXPECTATIONS HELD BY A SAMPLE OF TERMINALLY ILL PATIENTS, FAMILY MEMBERS OF TERMINALLY ILL PATIENTS, AND HEALTH PROFESSIONALS FOR THE PROVIDER OF QUALITY TERMINAL CARE, AND WITH WHICH MODEL FOR THE PROVISION OF HEALTH CARE, MEDICAL OR HOLISTIC, ARE THESE EXPECTATIONS MOST CONGRUENT?

The findings with respect to each of the fifteen indicators are reported in this section. A summary is included at the end of the section.

Indicator 1A: Affective Involvement

Based on an empirical analysis of the comments of respondents relevant to this dimension, a dichotomous, left-right pole categorization scheme, "no, the health professional should not be affectively involved"/"yes, the health professional should be affectively involved," was determined to be simplistic and not as descriptive of the data as these data merited. A continuum represented by four "levels" of affective involvement seemed more appropriate.

As noted earlier, this variable has as its left pole not negative affect but neutrality. In fact, respondents did describe attitudes and behaviors representing negative affect which they viewed unfavorably, such as health professionals who were "uncaring," "callous," or "discourteous." To minimize the confusion which would likely result from having descriptors viewed favorably and

unfavorably, the attitudes and behaviors which were viewed negatively were reversed to their positive form, such as "caring," "sensitive," and "courteous," and classified according to the scheme developed.

The four levels of affect were derived through: (1) reading all comments of respondents that concerned the affective relationship between the health professional and the patient or patient/family; (2) developing a preliminary categorization scheme based on this reading; (3) classifying responses according to this scheme; (4) reading the responses that had been grouped within each category to assess the degree to which they "fit" together; (5) consulting Webster's Collegiate Thesaurus to determine synonym groupings; (6) discussing the categories with colleagues; (7) refining the categories; and (8) repeating this process various times. The scheme described below represents that ultimately settled upon.

The first category (A) is one which contains responses indicating "neutral" affect, in which the health professional is courteous, polite, and respectful, but reveals little, if any, of him/herself. Duties are performed responsibly, but routinely; there is no evidence of emotional involvement.

The second category (B) is one in which the health professional is pleasant, congenial, cheerful, and projects

some personality. The health professional still is not emotionally involved, or only minimally so.

The third category (C) is one in which the health professional is warm, kind, caring, compassionate, and interested. He or she is, or seems to be, personally involved, although not intimately or completely.

The fourth category (D) is one in which the health professional treats the patient as he or she would treat a family member: as someone very special, with love, with 100 percent emotional involvement, with deep concern and intimacy. Table XXXIII contains examples of the types of responses classified within each of the four categories.

TABLE XXXIII

WORDS AND THEMES COMPRISING EACH OF THE FOUR CATEGORIES OF
INDICATOR 1A: AFFECTIVE INVOLVEMENTA. Affect: Neutral/
Personal Involvement: None

courteous, polite, civil, respectful, nonjudgmental, treats patient with dignity.
NOT demeaning.

B. Affect: Pleasant, Cheerful/
Personal Involvement: Minimal

friendly, saying hello, congenial, pleasant, charming, sweet, nice, good-natured, with a relaxed attitude, calm, mellow, informal, cheerful, convivial, lighthearted, good bedside manner, projecting personality, outgoing, interesting, positive attitude, happy, always smiling, teasing, joking, sense of humor, laughing.
NOT cross, dreary, dull.

C. Affect: Warm, Caring/
Personal Involvement: Moderate

warm, warm personality, considerate, compassionate, kind, human, humanness, thoughtful, thoughtfulness, empathy, empathic, sympathy, sympathetic, understanding, concerned, showing concern, being people rather than professionals, relating humanly, sharing how they as staff feel, showing emotion, allowing patient to be human, acting like they like the patient, soft-spoken, patient, patience, hugging, affectionate, touching, talking--showing they care, someone with feeling, having a heart.
NOT callous, indifferent, cold, abrupt, distant, reserved, professional, all business, impersonal, inconsiderate, impatient, rough.

D. Affect: Loving, Treating Like Family/
Personal Involvement: High

Loving, treating patient like part of their family, like a mother, father, sister; emotionally involved, personally attached, very close, very personal.

Table XXXIV contains a summary of respondents' responses. It should be noted that because respondents gave multiple responses, the n's and percentages do not total properly. As shown on Table XXXIV, all but two of the 17 patients in the sample volunteered comments in the course of their interviews that were pertinent to this indicator. This indicator, then, with responses from 88% of the patients, was one of the most frequently mentioned by patients. Similarly, all but one of the family members (97%) made some relevant comment, as did all but four (three in conventional programs, one in a hospice program), or 90%, of the health professionals.

The patients in conventional programs as well as those in hospice programs mentioned category B (pleasant and cheerful) most often, followed by category C (warm and caring). Family members in each of the types of programs mentioned category C most frequently, and then category B. A few patients mentioned category D (loving, emotionally involved) as did several of the family members. More families than patients also mentioned the desirability of being courteous, polite, and respectful (category A). Somewhat higher numbers of families in conventional programs mentioned each of the categories of affective involvement than did families in hospice programs.

The responses of health professionals in conventional programs and as well as those in hospice programs varied

TABLE XXXIV
INDICATOR 1A: AFFECTIVE INVOLVEMENT
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

DEGREE OF AFFECTIVE INVOLVEMENT	PATIENTS							FAMILIES							HEALTH PROFESSIONALS						
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)			Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)			Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)		
	n	%	n	%	n	%		n	%	n	%	n	%		n	%	n	%	n	%	
A. Courteous/No Involvement	1	11%	0	0%	1	5%		3	15%	1	6%	4	11%		2	11%	0	0%	2	5%	
B. Pleasant/Minimal Involvement	6	67%	7	88%	13	76%		14	70%	10	56%	24	63%		3	16%	3	15%	6	15%	
C. Warm, Caring/Moderate Involvement	6	67%	5	63%	11	64%		20	100%	16	89%	36	95%		16	84%	19	95%	35	90%	
D. Loving/High Involvement	2	22%	3	38%	5	29%		8	40%	5	28%	13	34%		7	37%	9	45%	16	41%	
NO RELEVANT COMMENT IN ANY OF THE ABOVE	2	22%	0	0%	2	12%		0	0%	1	6%	1	3%		3	16%	1	5%	4	10%	
# of Categories Mentioned	15	Avg.** 2.14	15	Avg. 1.88	30	Avg. 2.00		45	Avg. 2.25	32	Avg. 1.88	77	Avg. 2.08		28	Avg. 1.75	31	Avg. 1.63	59	Avg. 1.69	

* Responses do not always sum to n, N, or 100% due to multiple responses.

**Average is based on # of categories mentioned divided by
n - # of respondents who made no relevant comment.

from those of patients and families. The categories mentioned most frequently by both sets of health professionals were C, followed by category D, although two more hospice staff than conventional staff mentioned this latter category. Also, two conventional staff noted the desirability of professionals with category A attitudes and behaviors (being courteous, respectful, and polite) compared to none of the hospice staff.

In addition to noting the categories mentioned most frequently by each group, however, it is important to point out that comments were made by some patients, family members, and health professionals concerning instances in which one or more of the four categories could not be endorsed by them. That is, each of the categories of affective involvement has its drawbacks or risks as well as its benefits.

In Category A, for example, four family members indicated that health professionals who were courteous and polite, and who "just did what's necessary," seemed distant; these health professionals were not deemed satisfactory or desirable as providers of terminal care. In other words, health professionals whose attitudes and behaviors were classified in Category A were not adequate, as far as these family members were concerned. For these family members, health professionals who were "warm" (Category C) were desired. It is noteworthy that each of these family

members' relatives was being, or had been, cared for in hospice programs.

With respect to Category B, three family members (two hospice, one conventional) felt that health professionals sometimes could be too cheerful and overly optimistic. Similarly, two family members (both of hospice programs) noted that professionals could be too bubbly, too talkative, or kid around too much--that some patients do not like this.

The only cautionary note with respect to Category C was offered by one health professional and one family member, both of whom indicated limits to the desirability of health professionals' sharing information about themselves and their lives with the patient. The health professional pointed out that while personal sharing of one's self and life with the patient or the patient and the family was desirable, the health professional must take care not to burden the patient and the family; that is, the health professional should not share too much. The family member commented that health professionals should not be "full of their own problems."

Category D received the greatest number of cautionary comments. These comments centered around the dangers of the health professional's becoming too involved and too close to the patient. Two family members and seven health professionals made comments of this nature. One of the

family members, a daughter, was concerned that a nurse was becoming too close to her father, spending her time off with him. The daughter seemed to feel that this was not professional.

The other family member noted that health professionals should not become too involved with their patients because then they themselves will get sick. This comment, as did most of the comments of health professionals themselves, related to the danger of "burnout" due to the emotional trauma that accompanies overinvolvement and/or overidentification with the patient. Overidentification was mentioned as a risk particularly with patients who were young.

Other relevant comments of health professionals addressed (a) the difficulty of remaining objective (n=1, conventional) and (b) the concern that there is only so much time, and if the health professional becomes emotionally involved with a patient, the time spent with the other patients is likely to be diminished (n=2). This latter concern reflects the "universalistic" treatment norm of the medical model of care, and indeed, the two individuals who mentioned it worked in two of the conventional programs in the sample.

In sum, patients' expectations centered around professionals being pleasant and cheerful and being warm and caring. Families' expectations, too, concentrated in these

two categories, but the pattern of response was different: the desirability of being warm and caring was mentioned more often than was being pleasant and cheerful. In addition, a greater percentage of families mentioned the desirability of professionals who would treat patients as though they were family members, who would give them love, and who would get emotionally involved. Families' expectations, then, were for somewhat more affect and emotional involvement than were patients'. Health professionals' expectations for professionals in the role of provider of terminal care were for even greater emotional involvement. The average number of categories mentioned by families was highest of the three groups, followed by patients and then by health professionals. Expectations by subgroup (conventional compared to hospice) did not appear to differ significantly. Finally, it should be remembered that each of the categories of affective involvement has its drawbacks or risks as well as its benefits, as pointed out by some patients, family members, and health professionals.

Indicator 2A: Scope Of Care

This indicator represents respondents' views with respect to the scope of care which they expect to be given ideally by health professionals who are providing terminal care. "Scope of care" refers to whether only the physical care needs of patients or patients' psychosocial needs as well as their physical needs are addressed. This latter option is termed "holistic" care, and is consistent with the hospice model for the provision of terminal care. The former, "physical" care, represents the medical model approach to health care.

The data analyzed with respect to this indicator consisted of relevant responses volunteered throughout the course of the interviews with respondents, including any explanatory remarks made in response to one of the checklist items (item c), in which respondents were asked how much they felt it mattered that "Doctors and nurses sit, talk and listen, as well as attend to patients' physical needs." For reasons explained earlier (see Chapter V, Research Design and Methods, Phase III, Content Analysis of the Interviews), only comments respondents volunteered were analyzed; the ratings assigned were not. Table XXXV summarizes the responses of respondents as they related to this indicator.

It should be noted that within the category of "holistic" care were included a few responses that addressed

TABLE XXXV
INDICATOR 2A: SCOPE OF CARE
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

SCOPE OF CARE	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional		Hospice		TOTAL		Conventional		Hospice		TOTAL		Conventional		Hospice		TOTAL	
	(n=9)		(n=8)		(N=17)		(n=20)		(n=18)		(N=38)		(n=19)		(n=20)		(N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Physical Care Only	1	11%	2	25%	3	18%	3	15%	3	17%	6	16%	0	0%	0	0%	0	0%
Holistic Care (Both)	5	56%	3	38%	8	47%	17	85%	14	78%	31	82%	19	100%	20	100%	39	100%
No Relevant Volunteered Comment	3	33%	3	38%	6	35%	0	0%	1	6%	1	3%	0	0%	0	0%	0	0%

* Percentages may not sum to 100% due to rounding error.

the psychosocial aspects of care only. These comments were relatively rare, though (patients: n=2 (both hospice); families: n=3 (two conventional, one hospice); health professionals: n=2 (both conventional)).

It should also be pointed out that spiritual needs of patients, while theoretically a part of the concept of "holistic care," were not included in this analysis unless the respondent specified that these needs could or should be met, or were met, by the health professional. Comments that focused on visits that were made, or ideally would be made, by rabbis, ministers, or other clergy were not classified here. Given this study's focus on the role of the health professional, and specifically the role of the physician or nurse provider of terminal care, it was not felt appropriate to include comments related to provision of spiritual support by other than a health professional.

Turning now to the data presented in Table XXXV, several results are noteworthy. First is the relative lack of relevant comments made by patients; only 65% commented compared to 97% of the families and to 100% of the health professionals. Second, excluding from the analysis all respondents who did not make relevant comments, it is clear that patients were somewhat more likely to comment only on physical care needs (27%) than were families (16%) or health professionals (0%).

The amount of missing data for patients combined with this result could indicate the greater salience for patients of their physical needs and/or patients' lack of awareness of the possibility of getting their non-physical needs met by the health professional. One patient commented, for example, "The nurses are wonderful--they attend to all your <physical> needs: they feed you, they clean your bed, and they give you your pills if you're in pain. What else is there to say?" It is clear from the comments of several of those who mentioned physical care needs only, however, that there is "physical care" and then there is "physical care;" specifically, these respondents noted the need for physical care with compassion, physical care that is done gently. One patient reported, for example, that "some toss you around like a piece of wood...The treatment I got this morning was rough..."

One patient whose comment was classified as advocating a holistic approach explained that he felt it was very important for doctors and nurses to talk with patients:

It helps you out a lot, the doctors and nurses both. Especially if the doctor sits down and talks to you a few minutes; that gives you quite a bit of relief, you know. You feel like you're close to him, you know.

Another patient felt that health professionals could not be expected to meet patients' psychosocial needs, but this would be nice in an ideal sense: "Oh, we can't expect them to do that--they have too much to do; it's appreciated if

they do. Once in awhile, they stop in if they have time..."

Common within the responses of families, as well as some of the patients whose comments were classified as advocating a holistic approach, was the emphasis on "encouragement" of patients, the belief that health professionals should "encourage" the patient.

A third interesting result is the fact that literally all health professionals noted that the provision of holistic care for terminally ill patients is ideal. What should be pointed out, though, is that holistic care appears definitely to be only an ideal, not an accomplished fact. Comments by several health professionals included statements noting that nursing is oriented to the provision of physical care and is task-oriented, that nurses are not trained to talk to patients, and that there is a need for health professionals to learn that physical care is not the most important thing: that physical care is important for comfort, but there is a need to recognize patients' social, emotional, and spiritual needs.

Fourth, the data summarized in Table XXXV reveal that there appears to be little relationship between the type of program (conventional or hospice) the respondent represents and whether he or she is more or less likely to note the need for health professionals to address psychosocial needs as well as physical needs of terminally ill patients.

Finally, a note is necessary concerning those respondents who made comments which were classified as indicating an expectation for holistic care but which focused not on both physical and psychosocial care needs of patients, but only on psychosocial care needs. The patients and families who made such comments were not experiencing physical pain or other physical symptoms which could have been controlled. As one family member noted, her mother did not at that time need physical care; she needed someone to talk to. This family member was frustrated that this need alone could not be met: "I understand that in (home care program), you can't have just a social service person unless there's also nursing care going on, and I don't think that's fair; she doesn't need nursing care at this point." This comment appears to illustrate that this respondent (a) drew a clear division in role responsibilities between nurses and social workers, and (b) had a lack of expectation, or understanding, that nurses as well as social workers can meet patients' psychosocial needs. This same respondent, however, noted that the nurses in the hospital had special training in meeting some of the family's needs, such as those for emotional support and for information. Two health professionals, both in conventional programs, also noted only psychosocial needs. It seems likely that these persons assumed patients' physical needs would be met, but wanted to focus attention on the psychosocial needs of patients.

Indicator 2B: Unit Of Care

The data with respect to this indicator were analyzed at two levels. The first level examined patients', family members', and health professionals' interviews to determine who respondents felt should constitute the unit of care: solely the patient (left pole, or pole 1), or the family as well as the patient (right pole, or pole 2); that is, whether or not any mention was made of the desirability (in an ideal or actual sense) for health professionals to address any of the needs of the family in addition to those of the patient. The second level of analysis examined the particular types of family members' needs that were mentioned. The categories of needs were determined empirically through scrutiny of the relevant individual responses.

The rationale for employing the second level of analysis derived from a curiosity about the results from the first level of analysis, particularly with regard to the health professionals' responses. As will be described below, nearly all health professionals espoused the desirability of treating the family as the unit of care (e.g., "dealing with families," or "meeting families' needs, too"). The responses of health professionals working in hospice programs versus those of professionals working in conventional programs, however, appeared to differ considerably in detail.

The data for this indicator were those received in direct response to a particular question about the needs of families ("What would you tell a group of medical and nursing students about the needs of the family of people who are very sick?") as well as other comments volunteered throughout the course of respondents' interviews. One item of the checklist administered at the close of the interview pertained to this issue as well. This item asked respondents to indicate how much it mattered to them that "services be provided for families as well as for patients." Unfortunately, the term "services" confused a number of respondents, especially patients and families. "Services" appeared to connote financial aid or assistance, for example, to some lay people, who then qualified their answer, saying such services should be provided "only if necessary," or "only if they're down and out." Only those explanatory remarks to this checklist item that clearly pertained to an expectation that families' needs either be met or not be met by the health professional were classified here.

Respondents who listed needs of families that they felt health professionals had met or should have met were classified as indicating the family as the unit of care. Respondents who specified that only the patient's needs should be attended to were counted as indicating the patient as the unit. Respondents who made no relevant comments

either way were placed in the "no relevant comment/missing" category.

Concerning the second level of analysis performed, as indicated earlier, several types of needs of family members with terminally ill relatives were identified.

Specifically, eight types of needs were identified, including the needs for:

- (1) emotional support, including talking, listening, hugs, being there, comforting and encouraging the family, helping them to accept, adjust to and cope with the patient's death, helping them to accept the patient's care situation and not feel guilty (especially if the family felt they could no longer afford to keep the patient at home and had placed him or her in a nursing home or hospital);
- (2) resolution of family conflicts, including opening up communication channels between the patient and the family, or between one family member and another, so they can be a support to each other;
- (3) information on the patient's condition and treatment, and instruction as to how to help the patient physically;
- (4) information on and/or assistance with practical matters and available resources, such as making funeral arrangements, getting financial help,

getting needed equipment, helping the family make decisions;

(5) acknowledgement of the family's presence, showing of some interest in and concern for the family;

(6) respite care, rest, a break, to take time for themselves to assure optimal physical functioning;

(7) bereavement care, followup support (after the patient has died);

(8) general "help" (and other comments too general to classify, such as "the family is included," "the family is treated," "the family is as important as the patient").

The following paragraphs report the results by respondent group: patients, families, and health professionals. Table XXXVI presents the results in tabular form.

Patients' Responses. As noted in a previous section, many of the patients interviewed as part of this study were in the very final stages of their illness and were extremely weak. As a result, some questions were not asked. Among the questions typically not asked when patients were tiring were this one about the needs of families and the several items comprising the checklist. Of the nine patients in conventional programs, eight had missing data for this indicator: three patients were not asked this question,

TABLE XXXVI

INDICATOR 2B: UNIT OF CARE
SUMMARY OF RESPONSES
BY RESPONDENT GROUP

UNIT OF CARE	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Patient As Unit Of Care	0	0%	1	13%	1	6%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Family As Unit Of Care	1	11%	5	63%	6	35%	15	75%	17	94%	32	84%	17	89%	20	100%	37	95%
No Relevant Comment	8	89%	2	25%	10	59%	5	25%	1	6%	6	16%	2	11%	0	0%	2	5%
TYPES OF FAMILY NEEDS * DESCRIBED	n	Adj %**	n	Adj %	n	Adj %	n	Adj %	n	Adj %	n	Adj %		Adj %		Adj %		Adj %
Emotional Support (1)	1	100%	2	40%	3	50%	8	53%	12	71%	20	63%	16	94%	17	85%	33	89%
Conflict Resolution (2)	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	1	6%	5	25%	6	16%
Info. On Patient (3)	0	0%	0	0%	0	0%	7	47%	5	29%	12	38%	2	12%	6	30%	8	22%
Info. On Resources (4)	0	0%	0	0%	0	0%	5	33%	8	47%	13	41%	4	21%	8	40%	12	31%
Interest, Concern (5)	0	0%	3	60%	3	50%	4	27%	8	47%	12	38%	1	6%	1	5%	2	5%
Respite, A Break (6)	0	0%	1	20%	1	17%	4	27%	2	12%	6	19%	2	11%	6	30%	8	21%
Bereavement Support (7)	0	0%	0	0%	0	0%	1	7%	3	18%	4	13%	1	6%	11	55%	12	32%
Help In General (8)	1	100%	2	40%	3	50%	2	13%	7	41%	9	28%	11	65%	11	55%	22	59%
# Of Categories Mentioned	2	Avg 2.00	8	Avg 1.67	10	Avg 1.67	31	Avg 2.07	45	Avg 2.65	76	Avg 2.38	38	Avg 2.24	65	Avg 3.25	103	Avg 2.78
No Relevant Comment***	8	Tot% 89%	3	Tot% 38%	11	Tot% 65%	5	Tot% 25%	1	Tot% 6%	6	Tot% 16%	2	Tot% 11%	0	Tot% 0%	2	Tot% 5%

(Continued)

TABLE XXXVI. Continued

* Described here are the types of needs of families mentioned by those respondents who indicated the family, not just the patient should be the unit of care. The number of respondents whose responses are summarized here, then, equals Line 2 under VOLUNTEERED RESPONSES, "Family As Unit Of Care." The numbers do not sum to the number in Line 2, however, due to multiple responses by respondents.

**"Adj %" refers to the adjusted percentage; that is, the ratio of the number of people who mentioned this need to the total number of persons who indicated the family was the desirable unit of care. For example, three out of the six patients (50%) who indicated the family is the desirable unit of care described emotional support needs of families.

***Included here are the persons who volunteered no relevant comments as well as those who indicated the patient is the desirable unit of care.

four did not appear to understand it, and one responded, "I don't know." The one patient who both responded to the question and who seemed to understand it said, "They need help for themselves and friendship." In the second level of analysis, this response was classified in categories 8, "emotional support" and 1, "general help".

Five of the eight patients in hospice programs either indicated in the course of their interviews that they felt some attention should be paid by health professionals to the needs of family members or listed one or more ways in which the staff had helped their family, which they appreciated. A sixth patient discussed financial concerns he had for himself and his wife (a response not classified here, as it did not relate to the role of the health professional), and a seventh patient did not understand the question. The eighth patient noted that his kids were "grown up and married," and that he felt there was not much that could be done for the family by the health professionals. This patient's response was classified as indicating the patient only as the unit of care.

Five hospice patients, then, perceived the family as the desirable unit of care, while one patient felt health professionals could be of little assistance to families. Of the five who noted types of family needs, two described families' needs for emotional support (category 1: the staff should "make sure they make themselves available to

take and communicate with the family"; health professionals should "go to visit or call the family and talk to them"). Three made comments that indicated the family's need for interest and concern for them to be shown (category 5: "...showing you have sympathy for the family," "place yourself there;" "the service they have here where they take my wife back to her apartment after she visits me is a wonderful thing...and they get her coffee while she's here"). One patient suggested that staff "give family help for the care of ones that are sick" (category 6: respite), and two made comments about general needs for help (category 8: "I'm very concerned that my wife has proper care because she has many needs;" and "Ask what you can do to help the family").

Comparison Of Conventional And Hospice Patients.

Given the large quantity of missing data for patients in conventional settings, it is not reasonable to compare the responses relevant to this indicator of patients in conventional programs with those of patients in hospice programs.

Family Members' Responses. Of the 20 family members of patients who were or had been in conventional settings, 15 (75%) indicated ways in which they as family members had been helped or could have been helped by the staff (coded as "family as unit of care").

Among these 15 family members, the type of family need mentioned most frequently was that for emotional support and encouragement (53%), illustrated by the following response:

When they came, they not only visited with him and tended to his medical needs and requirements, but they visited me on a friendly basis. It was just wonderful to have them to talk to.

This need was closely followed by that for information and instruction regarding patient care (47%): "Explain to them what is happening to their loved one...explain what kind of a night he's had...explain frightening events so they are no more frightening than necessary;" "Give suggestions to family as to how they can help." The need for interest in and concern for the family, and for understanding was mentioned by 27% of the family members in conventional settings: "Be understanding of the family; know it's a terribly hard thing;" "Be interested in the family, recognize them; include them and treat them like they would want to be treated if the positions were reversed." Five family members (33%) mentioned the need for information on resources or for assistance with practical matters, and four family members (27%) mentioned families' need for a break or respite, or help in caring for the patient, such as this family member:

The last day, or the day before, he went to the hospital, I looked so exhausted that the home nursing girls suggested that someone come out and get him ready to go...it was a big help because I was getting pretty down, physically and mentally.

The average number of categories of need mentioned among the 15 families was 2.07.

Seventeen of the 18 family members of patients in hospice programs indicated some type of need of the family that was or could have been met by the health professionals (classified as "family as unit of care"). The remaining respondent made no relevant comment.

The most common categories of need mentioned by these 17 family members included those for emotional support (71%), information on resources and practical assistance (47%), for understanding of and interest in the family (47%) ("The family really needs help; it's hard for some of the people there (staff) working with (the patient) to understand what the family is going through; a lot has happened to us"), for "help" in general (41%) ("They always assured me that if there was any way they could help me, they would"), and for information on the patient (29%). While mentioned by only two family members of patients in hospice programs, one person had a particularly wrenching comment about the need for respite for the caregiving family member: "I feel because of my father's illness, my mother died, at age 46. She had not been a sickly person; she was a victim as much as my father. Somebody should have stepped in." The average number of categories mentioned was 2.65.

Comparison Of Family Members In Conventional Versus Hospice Programs. More hospice family members made comments

relevant to this issue of the appropriate unit of care than did conventional family members (94% compared to 75%). Among the family members mentioning particular types of needs, hospice family members mentioned a slightly greater number of categories of need per person (average 2.65) than did conventional family members (average 2.07).

Health Professionals. Seventeen of the 19 health professionals interviewed who were working in conventional programs volunteered comments with respect to the desirability of treating the family as well as the patient, and meeting the needs of families. All 17 felt families were the unit of care.

Among these 17, only two categories of need were mentioned with great frequency: the need for emotional support (mentioned by 94% of those describing particular family needs) and the need for "help" or "treatment" in general (65%). An example of the latter category is: "We sometimes spend more time nursing the families than we do the patients". The former category is illustrated by this health professional's response:

The family needs support. I say this because I've reached out for them and they seem to sigh in relief; their whole body relaxes. It's hard for them to initiate. I can be more objective; I'm an outsider. They have a fear of being a burden to their family member (the patient) or they don't really want to acknowledge death.

An example of the third most prevalently-mentioned type of need, that for information on resources and for

practical assistance (21%), came from a physician, who noted that families need information about what to do with the body and how to make funeral preparations:

It's very easy to avoid the problem, because they're not going to ask for that information, and if you don't volunteer it, everybody will go away...It's not that it won't work out; it will, ultimately. But it could work out better, and be a better experience if someone would volunteer this information...The level of information is so poor that they don't even know what questions to ask, and unless you tell them about this, they won't ask...

The average number of categories of need mentioned was 2.24.

All (n=20) of the health professionals working in hospice programs volunteered comments that indicated the importance for quality terminal care of treating the family as the unit of care, that is, of addressing families' as well as patients' needs. Among the most frequently mentioned categories of need by hospice professionals, as was true for professionals in conventional programs, were those for emotional support (85%) and for "help" in general (55%). Several other categories of need, too, however, received a number of mentions, including those needs of families for bereavement services and followup after the death of their relative (55%); the need for information about available resources and assistance with practical matters (40%); the need for information about the patient's condition (30%), and the need for respite (30%). The

average number of categories of need mentioned by hospice staff was 3.25.

Comparison Of Staff In Conventional Versus Hospice Programs. All of the professionals in both types of programs, conventional and hospice, seemed to feel that the family was the appropriate unit of care when the patient is terminally ill. Professionals in hospice programs, however, seemed to have a greater depth of understanding of families of terminally ill patients and their needs, or at least to attribute more needs to families; these professionals mentioned a larger number of categories of family need on average (3.25 compared to 2.12).

Indicator 2C: Availability Of Care

This indicator identifies respondents' ideal expectations concerning the availability and accessibility of health professionals to the patient or the family.¹ Table XXXVII summarizes the findings of the interviews with patients, family members and health professionals. The top portion of this table identifies the number of persons in each group who made any relevant comment, advocating in the ideal sense either limited availability or unlimited availability. The bottom portion looks at those comments which indicated immediate availability was the respondent's ideal and classifies them as to type of response.

Some clarification is required with respect to the pole called "Care Not So Available" in the Table. This pole refers to expectations that availability of care by health professionals be limited. As might be expected, very few respondents actually advocated limited availability of health professionals. In fact, as shown in Table XXXVII, the comments of only two respondents were classified as indicating such a preference. Both of these respondents were, somewhat surprisingly, family members. One woman

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Several respondents commented on availability of care in conjunction with the cost of care or the patient's and/or family's ability to pay for the care. Since this issue is more a system issue than a role socialization issue, however, these comments were not included in this analysis. Mention is made of the finding, however, in Chapter VIII, Summary, Discussion, and Implications.

TABLE XXXVII
INDICATOR 2C: AVAILABILITY OF CARE
SUMMARY OF RESPONSES
BY RESPONDENT GROUP

AVAILABILITY OF CARE	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Care Not So Available	0	0%	0	0%	0	0%	0	0%	2	11%	2	5%	0	0%	0	0%	0	0%
Immediate Availability	4	44%	6	75%	10	59%	17	85%	14	78%	31	82%	18	95%	16	80%	34	87%
No Relevant Comment	5	56%	2	25%	7	41%	3	15%	2	11%	5	13%	1	5%	4	20%	5	13%
TYPES OF RESPONSES * GIVEN	n	Adj %	** n	Adj %	n	Adj %	n	Adj %	n	Adj %	n	Adj %	n	Adj %	n	Adj %	n	Adj %
Things done promptly; Checking as requested or necessary (nurses)	4	100%	6	100%	10	100%	13	76%	9	64%	22	71%	17	94%	13	81%	30	88%
MD available, visiting or checking as necess.	1	25%	1	17%	2	20%	10	59%	7	50%	17	55%	1	6%	3	19%	4	12%
24 hour availability of professionals	0	0%	2	33%	2	20%	3	18%	5	36%	8	26%	2	11%	4	25%	6	18%
- - - - -																		
# Of Categories Mentioned	5	Avg 1.25	9	Avg 1.50	14	Avg 1.40	26	Avg 1.53	21	Avg 1.50	47	Avg 1.52	20	Avg 1.11	20	Avg 1.25	40	Avg 1.18
No Relevant Comment***	5	56%	2	25%	7	41%	3	15%	4	22%	7	18%	1	5%	4	20%	5	13%

* Described here are the types of responses given by respondents who expected prompt availability of care. The numbers do not sum properly, however, due to multiple responses.

**"Adj %" refers to the adjusted percentage; that is, the ratio of the number of people who gave this response to the total number of persons who expected, ideally, prompt availability of care.

***Included here are the persons who volunteered NO relevant comments as well as those who DID NOT expect prompt care availability.

stated that she felt the home health nurses had come too often. The other woman reported that her husband had wanted to hold theoretical scientific discussions with his home health nurse, and that the nurse simply did not have time for this, nor did this woman seem to feel that the nurse should have time for this, even ideally. As will be seen in the following paragraphs, other respondents, too, made comments acknowledging and even sympathesizing with nurses' or physicians' actual lack of time, but their ideal appeared to be that the health professional be more available to them.

About 60% of all patients interviewed commented about health professionals' availability to them. All but 13% of the family members and health professionals made relevant comments. This aspect of care, then, appears to be a particularly salient one.

To obtain a better picture of what types of comments were made that indicated a preference for health professionals who were immediately available, a subclassification scheme was developed based on an empirical analysis of the data. Those comments made by respondents who felt that, ideally, health professionals should be immediately available were of three types: those indicated that (1) health professionals (nurses and aides) should check regularly and often on patients, and they should respond and/or do tasks promptly when called or requested;

(2) the patient should be visited and checked on regularly and often specifically by his or her (or any) physician; and (3) health professionals should be available and accessible, in person or by telephone, 24 hours a day.

The category mentioned most frequently by all three respondent groups was the first; each of the four patients who made relevant comments gave a response of this type, as did nearly all of the health professionals and about three quarters of the family members. One patient commented, for example: "There's nothing worse than to be in pain waiting; I have to go up there (to the nurses' station) to get anything...This buzzer doesn't help. I get better service at night;" "They're right there--anything I need, I get;" "They should wait on you when you want the bedpan;" and "A lot of things you can't get done right now." This last patient was reluctant to complain, though: "Why should I be the big cheese? They've got a lot of other patients around here."

Family members' comments included: "They should come as soon as they can when he rings the bell;" "It's neglect--she sits on the bedpan for 45 minutes; this is ridiculous. She can leave the light on: no response;" "(Quality care is) availability of prompt help; somebody to answer that light;" and "If she wanted a drink of water, she'd have to wait an hour." Additional, longer and more revealing comments are the following:

When patients ring the buzzer, it should not remain unanswered for 10 to 15 minutes...I recognize the poor hospitals and nursing homes have their hands full trying to staff their places, but nonetheless, somehow there must be a solution to that;

There were times when I'd go, and I don't think anyone had been in to check on her. Her eyes were secreting, her face hadn't been washed. That could have been better. They could have checked her more... Sometimes they were very short-staffed, but you can't expect a great deal. There are not much better circumstances. Turnover is high, and they're underpaid; competent help is hard to find.

At (hospital) she wasn't looked after close...It's just that everyday care that she got wasn't up to par, I don't think...they didn't look after her quite as close as they did here (hospice).

They were all so rushed; she was not the only patient...The nurses don't have time to take care of their patients more because they have to make these awful reports...they have to sit down sometimes for half an hour, an hour, an hour and a half just to write out some type of report.

This same man also commented:

They used to drop in at times. Well, they wouldn't if we were there...they didn't particularly worry because they knew if anything was going wrong, we would call them. But I'm assuming that if we wouldn't have been there, how often would they go?...Sometimes when you have a case like that, if someone is there, fine, but if no one is there, how long would that person be in that predicament before someone came in to look and see if there was anything wrong?

Another family member was similarly concerned: "Mother may be neglected at times because of the family's being here--when they're short-handed, not coming in to check her as often."

What is striking about the comments of the family members is their reflection of the negative experiences the

respondents have encountered. In fact, most of the comments were negative, albeit some were also sympathetic to the plight of the nursing staff. There also were some positive comments, such as these: "Every time we would go there (hospital), they were just coming in or going out of the room; we just felt they were really taking good care of him;" and "The nurses would never say they were too busy."

The comments of health professionals that were classified in this category focused on the amount of time that health professionals had to adequately perform patient care tasks and, in some cases, to talk to their patients. (These latter types of comments were also classified in Indicator 2A, Scope of Care--physical only, or psychosocial also.) Health professionals' comments, as did patients' and families', frequently indicated a great amount of disparity between the ideal and the real, or actual situation. Frequent mention was made of the lack of an adequate number of staff. Another factor contributing to the often less-than-desirable amount of time health professionals had to spend with patients was, as noted by the family member above, paperwork and documentation. A third factor was discomfort with terminally ill and/or elderly patients.

Examples of health professionals' comments with respect to this subcategory are:

Terminally ill patients need more time, more care...Certain things have to be done in a day, and

you can't foresee everything...It makes a person feel unimportant if you have to look at your watch...And families get annoyed with nursing staff for being so busy and conveying this to the patient.

The terminally ill have such a fear of isolation, abandonment; it is critical that we be there, caring, holding their hands, whatever. Unfortunately, time is a problem. Getting through treatment comes first; then you can talk if you have time.

Being so shorthanded; you try to give a bath to 12 people in a day...Yesterday I had six patients, and we did so much. I felt so good; I went home with the neatest feeling. A lot of times I go home and cry because I can't get the work done.

Forever the staffing office will tell you that "Hey, you have 20 patients, you get this many nurses." And forever, I will say, "Hey, we have cancer patients; we need more nurses, you know. We don't have patients that are up and out of bed walking down the hallways, you know. These patients are much sicker, and they require emotional time, and it's difficult to convince people that, you know, we actually spend time sitting down talking to people. And it's difficult (for the staffing office) to see that that is relevant or feasible.

Before we started the hospice team, we'd do some psychological and emotional support, but we didn't have much time. Our hospice nurses make about three visits per day; the regular nurses make about five a day.

I finally feel for the first time since I got out of nursing school that I'm giving the type of care that I was trained to, because in nursing school you have to do such a small patient load that you're almost there constantly with them...On the other units I've been spread so thin that you just give what you are able to give--and that's just the basics.

Sometimes you don't have enough nurses, like if two patients are dying at once...and you haven't been able to be as supportive as you would have liked to have been.

Additional relevant remarks made were: "Barriers to good care are time and money; we don't have enough staff now; if we had more money we could hire more people;" I wish we could decrease the amount of paperwork for staff, but this is not realistic because we have to document it if we're going to be paid for it;" "I do wish our visits (home health) could be longer--they average one hour...I wish there was some way we could legitimately do it;" and "When you're understaffed, you cannot give a patient proper care...Quality is caring for what the needs are right when they need it--that time element."

Finally, the following comments addressing avoidance behaviors of health professionals toward the dying and the old were made: "Sometimes we feel discomfort (with terminally ill patients) and will go in quickly and not take extra time;" "In a hospital, I have worked with people who couldn't face dying patients, who avoided going in the room;" and the following two responses:

In some settings, old people are ignored. I know a doctor who will make an order for vital signs every two hours so the patient will get seen every two hours; otherwise they won't.

The dying patient tends to be shunned away a little bit, because either the staff or the family is not able to cope with that. And I think here we tend to be more attuned to that and hopefully are there more often with the patient.

Turning to the second subcategory of availability, physician availability and checking, as shown in Table XXXVII, two patients, both in nursing homes, gave this type of response. One noted, "No doctor has seen me here; the nurse was supposed to contact him; nothing's come of that." The other said, "The doctor comes very seldom; there's nothing he can do."

Among family members, the availability and accessibility of the patient's physician was a large area of concern. Some of their comments include: "The physician was very attentive while he was in the hospital; when he came here (nursing home), the doctor hardly came to see him at all, and that frustrated him a bit;" "Our own doctor has attended to her needs when called upon;" "Both his physician and his surgeons called on him often;" "Dr. ____ was very accommodating; he came by the house several times; he lived close by;" "Dr. ____ said he would visit at the nursing home, but later he said no, he doesn't visit nursing homes;" "Our doctor comes once every few weeks; there should be a medical staff here to keep a weekly check on (patient);" "I don't think she would have got pneumonia if she'd been watched over by her doctor;" "(Patient) had a reaction in the middle of the night, and Dr. ____ came right away;" and

Since the discharge from the hospital, we haven't seen him (doctor)...I feel like we've been left dangling. I feel resentful that he hasn't been more

helpful...His office is right across the parking lot.

The (home health) nurse and I took turns calling this hematologist. She was the first to call, and the receptionist said he'd come out. Then he called and said there was no way he could come out to the east side, and that when he agreed to come out he didn't realize where she lived...He dropped it completely...Our original internist came out on his lunch hour, and he took care of (patient), and he was very comforting.

I had to call him (doctor) for two and a half days, and he finally got back to me. I respect that his practice probably is sizeable, but I wish there could be one person who could sit down and answer our questions for us--a doctor; that's the doctor's type duty.

Only four health professionals, three in hospice programs and one in a conventional program, gave a response within this subcategory. The health professional from the conventional program noted a case in which care had gone badly because "the patient didn't have a doctor who had followed his care." The comments of professionals representing hospice programs were: "Many staff and physicians feel nothing more can be done, and so they spend less time; we don't do this;" "Unfortunately, we have no staff physicians here;" "We may have trouble getting physicians to remain involved."

Around-the-clock availability of care, the third subcategory of availability, was important to two patients, both in hospice programs. As one patient said, "The nurses there stood by me day and night."

The family members commented: "There's constant staff--in the hospital, she can get the best help as soon as she needs it;" "Here <hospital>, if he has any problem at all, he knows he's got professional help immediately;" "The <home health> nurse told us we could call her anytime, day or night, Saturdays or Sundays, or anytime during the week...We finally did call her on New Year's Eve...;" "No matter what time, day or night, they're on call--that's pretty wonderful;" "Mom was insecure after being at the hospital for four weeks and then to go home without a nurse right there at your finger." This family member ultimately took her mother back to the hospital, where her mother relaxed immediately.

Six health professionals (two conventional, four hospice) mentioned 24-hour availability of care as an ideal expectation. Examples of their comments include: "We're not operating 24-hour call--we haven't found it necessary; but we do have an answering service around the clock;" "What gives patients the most security is knowing they can call 24 hours a day;" "Twenty-four hour call is one of the best things available, because when something happens at home, there's always someone the family can call who knows the person; they know the nurse will come, night or day."

In sum, it appears that patients, families, and health professionals alike hold the ideal expectation that health professionals respond to patients promptly when called,

check patients frequently, and otherwise spend time with patients. The actual situation, however, appears to be one where health professionals often are rushed and unable to spend adequate time taking care of their patients. Some families feel their presence means health professionals do not check on the patient as much as they might otherwise. Terminally ill patients are reported to take more of the health professional's time, due to their increased physical care needs and to their emotional care needs. Visits by the physician, especially when the patient is at home or in a nursing home, but sometimes when in a hospital, remain important, despite the patient's terminal status, especially as reported by family members. And twenty-four hour availability is regarded highly by family members and patients, particularly where the patient is being cared for at home.

Indicator 3A: Care Approach

As described in Chapter VI, Analytical Model, this indicator examines whether the ideal expectation is for care to be generally or individually oriented. That is, under scrutiny is whether the ideal role expectation is that the treatment given to a patient by a health professional should be (1) essentially the same as that given to all patients (generalized care) or (2) tailored to meet the particular needs of each patient (individualized care)? Table XXXVIII summarizes the responses of respondents as they relate to this indicator.

As shown in Table XXXVIII, only one respondent indicated an expectation for generalized care, for basically the same care or treatment to be received by all terminally ill patients. This person, herself a patient, stated, "They've got a lot of other patients around here; why should I be the big cheese?" All other respondents, regardless of program, either expressed an expectation for individualized care or made no relevant response. Respondents in hospice programs were just as likely as those in conventional programs to make no relevant comment.

That only one respondent expected generalized care is not surprising; it would have been much more so had a number of respondents volunteered such a comment. Interesting, however, is the result that the majority of patients in both conventional and hospice settings (67% and 63%,

TABLE XXXVIII

INDICATOR 3A: CARE APPROACH
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

CARE APPROACH	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional		Hospice		TOTAL		Conventional		Hospice		TOTAL		Conventional		Hospice		TOTAL	
	(n=9)		(n=8)		(N=17)		(n=20)		(n=18)		(N=38)		(n=19)		(n=20)		(N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Generalization	1	11%	0	0%	1	6%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Individualization	2	22%	3	38%	5	29%	15	75%	12	67%	27	71%	15	79%	16	80%	31	79%
No Relevant Comment	6	67%	5	63%	11	65%	5	25%	6	33%	11	29%	4	21%	4	20%	8	21%

* Percentages may not sum to 100% due to rounding error.

respectively) volunteered no relevant comment. In contrast, less than a third each of the family members and the health professionals made no relevant comment. Perhaps other patients feel as the patient above: that they cannot, or should not, expect any treatment other than what is given to patients such as they in general. Alternatively, perhaps their expectation, whatever it is, is being met, and as a result, they neglected to mention it. This possibility seems unlikely, however, given patients' responses pertaining to other of the indicators, in which they mentioned both attributes of health professionals they particularly liked and disliked.

It should be noted that some of the responses classified as indicating an expectation or preference for individualization of care also were classified as one of the categories in Indicator 1A, Interpersonal Relationship, or Affective Involvement. The following comments by patients, for example, were considered as descriptive of both indicators: "Personal attention is the most important" (individualization of care and category C of Indicator 1A) and "They all seem to take a personal interest in you" (individualization of care and category C of Indicator 1A).

Examples of responses of family members in conventional programs that were classified here as representing an expectation or preference for individualization of care are: the health professional should "get to know the person;"

"they seem to have given her care a great deal of thought";
 "the ones who take her blindness into account;" "just having
 someone to call you by your first name, make you feel like a
 desired person;" "deal with a person's handicap or
 disability;" "adapting to that individual's particular
 needs;" "being noticed and spoken to is important;" and
 finally:

Sizing up the patient as to know what he really
 needs and wants. Some people are gruff. You have
 to decide, "Does he want me to bark back or wait on
 him hand and foot?" Many people like to push
 buttons and be waited on hand and foot. It's
 important to pay attention to those coming out of
 surgery. If not, they think they're getting
 snubbed. Say "hi" even if they don't need it.
 Tweek their toes. Tell them they're handsome, and
 they know good and well they're not. It makes them
 feel good for someone to pay attention...

Comments from family members in hospice programs
 included: "We all have different needs, so if you get
 approximately a little bit like it, you should feel
 satisfied, and that's what we do;" "Each one being made to
 feel that they are special;" "They didn't learn his name
 after three months;" "Anticipating their needs--that's
 it!;" "Talk more to the patient as an individual, as a one-
 on-one person, not as a number on the door."

Examples of relevant responses of health professionals
 in conventional settings are: "Be able to see the dignity,
 the individuality of the person, see the person inside, not
 be put off by their physical state;" "Be able to read
 people; treat the patient as a person, not just as a

diagnosis;" "We're not as quick to recognize needs as we should be;" "We try to make every one pretty individual...every individual situation is different;" "Good care is so individualized...I know the terminally ill are lumped together all the time, but it just doesn't work that way at all...the staff is innovative as well as flexible--one thing doesn't work for everybody;" "The care is ultimately tailored very specifically to the individual's needs."

Examples of relevant responses of health professionals in hospice programs are: "Our goals center around what's important in that person's care--that might include pain control, dealing with their anxiety or fears, dealing with the family;" "Really good staff are in tune with unspoken needs...(they) recognize changes, see something needs to be done and do it;" "They should have an ear that's been tuned to pick up little cues that the patient or family can give them;" "Make them a human being, an individual;" "The staff is willing to put together an individualized package;" "Get to know people, their strengths; mobilize those strengths;" "Quality care is tuning into, assessing the situation, meeting patients where they are;" "We did our best to make her feel special;" "(Quality care is) real examining of individuals as individuals...In acute care, you treat the disease rather than the person."

Indicator_4A: __Treatment_Goal

Examined in this indicator are the expectations concerning the goal of the treatment received by the terminally ill patient: whether the patient is to be treated with (1) a goal of life prolongation in mind or (2) the patient's quality and comfort of remaining life in mind. Should the focus of treatment be to make all attempts to treat (cure) the patient right up to the very end, or should the aim of treatment shift to comfort and quality of life for the patient? The medical model approach has as its goal life prolongation; the hospice approach adheres to a goal of comfort and quality of remaining life.

A review of the responses of the patients, family members, and health professionals who were interviewed, revealed that a decision would have to be made with respect what to do with responses indicating that once it was clear that a patient "was terminal," there was "nothing more that could be done." That is, some respondents acknowledged that cure was not possible, but did not switch the treatment goal to one of provision of comfort and life quality. Instead, they stated simply that "nothing more could be done." Upon reflection, this option of "doing nothing" seemed to the researcher to be a direct result of the treatment goal of life prolongation: when it becomes clear that the goal will not be accomplished, no new goal is adopted, there is no change of orientation; the goal (and often, the patient) is

simply abandoned. Such responses, then, were categorized as indicating a treatment goal of life prolongation.

Table XXXIX depicts the findings from the responses of the patients, family members, and health professionals who were interviewed. Over three-quarters of the patients indicated how they felt with regard to this issue, which is fairly high in comparison with the rate of response to other of the variables (indicators) under study. Eighty-four percent of the families and all but three (about 92%) of the health professionals made some comment relevant to this issue of the appropriate treatment goal.

As shown on Table XXXIX, five patients in conventional programs felt the treatment goal should be life prolongation; they continued to hope for a cure, or at least for improvement. One patient noted, for example, that she wanted to "get her feet walking" and "get better." Another felt that a good doctor is "one who gets a cure," and although he recognized that he had not been cured, he seemed to continue to hope. Another patient said, "They've been doing all kinds of things for me, all kinds of treatment." One patient stated, "I guess all I can say is it's a roof over my head and a place to exist in...I guess there's nothing more they can do for me." Only one patient in a conventional program acknowledged and seemed to support a treatment goal of comfort: "They try to keep me comfortable."

TABLE XXXIX
INDICATOR 4A: TREATMENT GOAL
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

TREATMENT GOAL	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Life Prolongation	5	56%	3	38%	8	47%	8	40%	5	28%	13	34%	2	11%	0	0%	2	5%
Life Quality and Comfort	1	11%	3	38%	4	24%	10	50%	9	50%	19	50%	14	74%	20	100%	34	87%
No Relevant Comment	3	33%	2	25%	5	29%	2	10%	4	22%	6	16%	3	16%	0	0%	3	8%

* Percentages do not always sum to 100% due to rounding error.

Of the six patients in hospice programs who made a relevant comment, three advocated a goal of aggressive treatment and life prolongation: "They're doing everything they can; my wife keeps saying she has a feeling that I'm going to get over all of this;" "It's very easy to give up, and most people do, but they shouldn't;" "I still hope for a cure; they have kept me alive for five years...If they can go to the moon, they ought to be able to cure cancer...My main goal in life now is to walk." This last series of statements was made by a patient who told the interviewer that the doctor was considering severing the nerve to the patient's leg, but since this might make walking impossible, the patient couldn't decide if it was worth it. For this patient, then, pain control might endanger, not aid, quality of life.

The other three patients in hospice programs felt that a goal of life quality and comfort was most appropriate. One of these patients reported that the doctors "talked nice" after his operation and convinced him to have radiation therapy. He tried one treatment, found it too painful, and said, "No, I want to die..." He continued, "I don't like very much the way they tried to get me into that...It looked to me like I was a guinea pig, an experiment for them--I was 82 years old." The second patient knew and accepted that she had cancer; she had been told she had "more than one or two months" to live, however.

She continued to receive therapy on her arm so that she could stay as independent as possible. The third patient, who already had lived much longer than the health professionals had believed she would live, noted that the social worker at the hospice "talked to me about what was necessary for me to be comfortable...You have to accept it, and just wait for the day to come when you are at the end. I think I'm prepared; I hope I am."

As shown on Table XXXIX , proportionately more families of patients in conventional programs than families of patients in hospice programs held life prolongation and continued active treatment as their expectation for the treatment goal. Responses classified here included those who noted their preference for health professionals who "didn't give up," who encouraged the patient to keep trying various types of therapies, and/or who were trying to make the patient better, which sometimes included forcing him or her to eat or drink. Examples of comments made include: "No one's given up on here...I think they're out to help as much as the patient wants help;" "They should give the patient encouragement to go ahead and try something else;" "The medical profession says they have gone as far with her as they can, that she's terminal, it's a matter of time; it's a question of making her comfortable...I keep telling her not to take anybody's word for it, that she should fight it through;" "They should keep trying, not to say it's no

use...Maybe tomorrow they'll discover something that will help them...Look what chemotherapy did for him--it gave him a whole year when the doctor didn't think he could take it more than four months." This same woman went on to say, "They should try to keep the pain down, stop the tumor from growing." In sum, comfort needs were recognized, as well; the emphasis seemed to be on continuing to treat and hoping for a cure, however. Another family member noted that one doctor did not treat the patient, saying, "You know you're not going to live," and that "from then on he got worse." A different family member also felt that "if encouraged, <the patient> might not have given up so much."

Many of those families who advocated the alternative treatment goal of enhancing quality of life and comfort for those who are terminally ill similarly did not want health professionals to "give up." At the same time, they did not want the health professional to give the patient or the family undue hope; their primary concern at that point was the patient's comfort. Several families also commented on the transfer of the patient out of the hospital after a determination is made that the patient is terminal. The general feeling was that this either should be done with much increased sensitivity or not at all. Exemplary comments included: "We want <the patient> to be comfortable; that's why we have her here; we can't do that at home...But you should give them all the encouragement,

hope you can, because sometimes there are miracles;" "Her quality of life is not good; (still) they should give you the idea that she's not crossed off;" "They should keep them comfortable, stable, but as far as prolonging their lives, that's foolish...On the other hand, we haven't just given up, either;" "They did everything they could to keep him comfortable; they made it easy for him to slip away...they didn't prolong it."

One family member felt her father's physician had been "seriously remiss" in not telling her father the impact the surgery would have, that it would mean that he would be in a nursing home for the rest of his life. She felt that her father "was talked into the surgery with no regard for quality of life...He had been ready to die." Another family member also described a situation in which she felt continued treatment had been inappropriate:

The nursing home continued to give (chemotherapy) to him, and they would not stop on our instructions; so we called Dr. ____ and asked him to order it stopped, and he wouldn't do it...They would force him to get up and tie him into a wheelchair, then they would leave him sit for an hour and a half at a time...Dr. ____ kept ordering that he be up twice a day, one hour each. And we felt that at that time it was ridiculous. Also, they wanted to take him into physical therapy then.

One woman, reported that upon learning that her husband's death was imminent:

I asked Dr. ____ that if death was imminent why was he still giving transfusions. He said that in order to stop them he would need permission from (the

patient). I said, "How can he tell you?" He was in no condition to do that. So I told him about (the patient's) uncle. The uncle who had raised (the patient) had been sick. We all prayed for him to live. (The patient) flew up to see him. He had changed so much, suffered so much that (patient) said at that time, "Don't pray for me to live." So they stopped the transfusions. They said they would make him as comfortable as they could.

Yet another family member said succinctly:

To me, the paramount issue is the comfort of the patient; therapy should not be forced...My wife and I were agreed that the only thing we could do was to make her life as pleasant and comfortable as was humanly possible, and that was our entire aim. PT became absolutely useless, and it was given up.

This same man was one of those who complained about the utilization review process, whereby patients who no longer require skilled nursing care are discharged from care:

Then finally came the big deal which is traumatic for the patient and the family. I can see the necessity of it, but there ought to be a better way to handle it. It gets to the point where the so-called utilization review board at the hospital makes an assessment that this is as far as the hospital can go, so you've got to get her out. Then the family must find a place to provide adequate care.

As shown on Table XXXIX, all but two of the health professionals who made a relevant comment subscribed to the ideal treatment goal of comfort and quality of life for the terminally ill patient. Furthermore, all but three health professionals (and these three were in conventional programs) did address this issue in their interviews. This apparent uniformity of response is misleading, however. While the goal of comfort was widely espoused, there seemed

to be wide variation among professionals with respect to the timing of the switch from active treatment to comfort and palliation (control of symptoms). Generally, professionals in conventional programs talked of making comfort the goal when the patient was actively dying, that is, dying within the next few to several days. Professionals in hospice programs more often talked in terms of months rather than days.

Of the two professionals whose expectations were classified as indicating a treatment goal of life prolongation, one (a physician) said:

That is a point we're adamant about--terminal illness does not imply any kind of change in care for a patient...other than perhaps to improve it, such as taking pains to make death and dying as comfortable as possible.

He went on to say that treatment continued, however. The other professional, a nurse, said approvingly, "The doctors usually don't give up 'til very late."

Responses relevant to this indicator that were made by health professionals whose ideal expectations were for a treatment goal of comfort and quality of life pointed once again to differences between ideal expectations and actual situations and experiences. Particularly important for this study is the finding that several professionals themselves admitted to having difficulty accepting the death of a patient, or asserted that other professionals with whom they worked had such a difficulty:

I get angry and frustrated, particularly with one patient, knowing that he was terminal and really liking that patient and not being able to help him too much other than to make him comfortable, and that was real hard for me...You know, it's hard for a nurse to, not exactly give up on a patient, but to actually accept it with a patient that they're terminal and that you can't just do everything for them.

Two nurses noted:

Physicians, once they know you care, they admit to problems dealing with death...Nursing is finally coming around, doesn't see so much as defeat--we feel our goal is death with dignity.

As long as cure is anticipated, everyone is willing to work very hard. As soon as the patient is not salvageable, it becomes very difficult. It's unconscious--attention is less, the staff finds it difficult to go spend time.

A nurse in an administrative position pointed out that in her program,

The non-written code is do not resuscitate. Some doctors will write, "Do Not Resuscitate" (on the patient's chart). Our doctors will not because they believe that people (nurses, aides, etc.) will say, "All right, they're gonna die so let's quit taking care of them" I as a nurse, and the nurses on this floor believe, "Hey, let's don't write them off; let's provide comfort, and let's provide palliation..."

Another nurse noted that "physicians" are a barrier to quality care; "They feel very threatened by the fact they don't feel in control...Many set unrealistic goals, estimates about time left to live."

Furthermore, several professionals argued that patients and/or families, as well, often are reluctant to give up active treatment: "Some doctors never quit

treating, and some patients never give up." Another health professional stated:

That's one of the differences in American medicine versus the British. We're not always able to distinguish...It isn't just the fault of the medical people; it's the American system. Americans want to be treated until the very end... I don't see any patients refusing another round of treatment. If they aren't offered it, they ask for it. So that's just one of the problems.

The responses of many of the patients and families interviewed, as reported above, bear this out. In addition, one health professional noted that patients hate to disappoint their doctor: "The patient feels bad for letting the doctor down and not getting well."

Also lamented was the difficulty in knowing the appropriate time to change the treatment goal from one of active therapy to one of palliation, illustrated by this comment: "With this man, we never knew when we were being realistic, such as whether PT (physical therapy) was helping or pushing him beyond his capabilities." The fact that methods for ensuring "comfort" may be at variance with one another was noted as well.

One professional made several of the above points herself in describing three of her cases, one in which a patient and her husband "fully expected a miracle from God." This nurse wondered, "What will this do to his religion?" Another case was one in which "comfort would have had more priority if we'd realized she was so close to death." In

the third case, the patient had had three bouts of pneumonia, and "could have been let slip away; but you can't assume that's what they want--in this case, her husband has to feel everything humanly possible was done, otherwise he must carry a tremendous burden of guilt." This same professional felt that "You have to feed patients; I do not feel you can keep patients comfortable who are starving to death. Give them an IV, minimal flow, to keep them hydrated and comfortable, not to keep them alive."

Two persons not in hospice programs commented specifically on the nature of hospice care. One said, "The hospice word is a new word we're using, but it's a very old form of care." The other asserted, "Everyone's saying they're giving hospice care right now; they're giving portions of hospice care, but not complete, overall care."

The following additional comments are illustrative of those made by professionals whose responses were classified as indicating an ideal expectation for the treatment goal of comfort and quality of life:

With the seriously ill, treatment remains aggressive, emotional support secondary; even the experience of pain comes secondary to treatment in serious illness. With the terminally ill, pain control is our primary consideration.

Our goal is to keep people as independent and comfortable as possible, at home...There have been many medical advances to keep them more comfortable...The quality of life left should be as good as you can possibly make it; sometimes that's bringing a puppy to the door.

We ought not to press too hard, try too hard, in my mind, to continue on and on in terms of treatment in somebody who has late stage disease, compared to someone who has a much better type of prognosis.

"For people who are dying, basically, you bend the rules;"

"Therapy is used as necessary for comfort;" "We felt the patient was terminal and the doctor didn't agree...The recommendation that we send the patient to the hospital (from the nursing home) didn't seem appropriate;" "With the terminally ill, the focus of care is to keep them comfortable, free of pain and discomfort, and deal with them with the expectation that they will continue to get worse;"

"The goal is to facilitate the patient and the family coping with living until the patient dies, to promote comfort measures and adequate medical supervision;" "With the terminally ill, we don't push them...But in this one case, I think it was medical mismanagement; the physician's attitude was that she's old, she's dying;" "Our goal is to assist the person to maintain the things that make their life worth living and to realize and minimize things that make their life miserable;" "If you don't address comfort needs, it's almost silly to address anything else." "One barrier is physicians' not accepting their patient's treatment is not working, the patient's cancer is not going to respond, that plans for symptom control rather than tumor control must pervade." At the same time as describing his goal and that of the program as to provide comfort, a physician described

the case of "a lady who looked like she was dying, but on a quick exam, I found simple treatments, like cleaning up a mouth infection, treating her confusion, depression, that I though would improve her life by days; now it's six months, and she was able to go home." He seemed to be saying that hope should not be given up.

Indicator 4B: Pain Control Practices

Role expectations with respect to pain control practices to be followed by health professionals in the care of terminally ill people are examined in this section. Expectations concerning pain control practices that are indicative of the medical model are those for pain medication to be given on an "as needed" basis, that is, as is felt necessary by the health professional or as requested by the patient. Those holding expectations of this type are those likely to be concerned about narcotic addiction. Expectations consistent with the hospice model are for pain to be controlled, generally through the administration of pain medication at regular time intervals. Persons holding this latter type of expectation are primarily concerned with the comfort and quality of life of the patient, and feel that given the limited life expectancy of the patient, addiction is not an appropriate concern.

Among the comments classified here were those that were volunteered by respondents when responding to a checklist item (item h) that asked them to rate how much it mattered that "pain medication is given on a regular basis without patients asking for it." As noted in Chapter V, the rating scale on this checklist of several items often did not seem to differentiate respondents very well. Also, several respondents appeared to have difficulty understanding the scale. Certain items, too, posed

problems; this one on pain control is among those items that proved problematic. The major difficulty, easy to spot in retrospect, is that most respondents were careful to note that medications should be given only when pain was a problem, only when such medications were truly necessary. As noted by some health professionals, pain is a problem in only 50-60% of terminal cancer patients. Furthermore, all respondents may not have given similar meaning to the phrase "regular basis."

In light of these difficulties, only the comments of respondents who volunteered additional remarks either in response to another question or in explanation of their rating on the checklist item were analyzed here, thereby providing a context for their response. Nonetheless, the reader should use caution in interpreting the results.

Table XL contains a summary of the responses of the persons interviewed. Over two-thirds of the patients made a comment regarding their preferences concerning pain control practices. Ninety percent of the health professionals and 84% of the family members addressed this issue in the course of their interviews.

Looking just at those patients who made a relevant comment, we see that the expectations of patients in conventional and hospice programs alike were fairly evenly divided between the two approaches to pain control. About 55% of the patients had expectations for pain to be

TABLE XL
INDICATOR 4B: PAIN CONTROL PRACTICES
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

PAIN CONTROL PRACTICES	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Pain Medication Given On As Needed Basis Only (Intermittent)	3	33%	3	38%	6	35%	8	40%	8	44%	16	42%	7	37%	1	5%	8	21%
Pain Medication Given On Regular Basis (e.g., Every Four Hours)	2	22%	3	38%	5	29%	9	45%	7	39%	16	42%	10	53%	17	85%	27	69%
No Relevant Comment	4	44%	2	25%	6	35%	3	15%	3	17%	6	16%	2	11%	2	10%	4	10%

* Percentages may not sum to 100% due to rounding error.

controlled through "as needed," intermittent administration of drugs; 45% preferred regular administration of drugs when this was deemed necessary.

The family members who made relevant comments were evenly split between the two pain control practices. Whether respondents represented a conventional program or a hospice program made no difference.

Health professionals in conventional programs were more likely to prefer the pain control practice of providing medication only on an intermittent, as needed (PRN) basis than were the hospice professionals, although the majority held ideal expectations for regular administration. Of those in conventional programs who responded, 41% preferred that pain medications be administered PRN, compared to 6% of the hospice professionals who responded. Combining both groups, 77% of all health professionals who responded indicated a preference that pain medications be administered regularly.

Perhaps of more interest than the preferred approach to pain control are the various additional related themes addressed by respondents in their comments. Among these themes were:

1. the potential for patients or their family members to be reluctant for the patient to take pain medication, often due either to a fear of addiction or to a fear that if

too much medication is taken it will become ineffective later on (a fear of the patient's becoming "immune");

2. the belief that the patient should not be overmedicated or "snowed" (except in the case of one nurse, who felt that "snowing" was acceptable; she just wanted patients to be free of pain) and that medications should be very carefully monitored;

3. the belief by some patients and families that whatever practice was recommended by the doctor was that which should be followed;

4. the assertion that the patient's preferences with regard to pain control practices should be considered;

5. the existence of different types of pain; and

6. the resistance encountered by many patients, family members, and health professionals on the part of (other) health professionals in giving appropriate pain medication, whether "appropriate" was considered to be regular administration or PRN administration.

The following responses are illustrative of the various themes.

1. Patient Or Family Reluctance To Take Pain Medications. Three patients made comments relevant here. One, in a conventional program stated: "I'm not afraid to take medication... (but) I'm trying to keep away from it." Another, also in a conventional program, advised others: "Stay away from the needle as long as you can; you don't

want to build up tolerance; you may want that needle later on." The third, in a hospice program, said, "They wanted to give me pain medicine regularly, but if I have no pain, I don't take any medicine." (As discussed earlier, hospice proponents argue that in cases where there is pain, and pain medication is administered regularly, the patient often comes to believe that he or she no longer has pain.)

Family members who made comments of this nature included seven in conventional programs and five in hospice programs. While several family members were concerned about addiction, others were not. Some of the remarks made by those in conventional programs, which represent these opposite points of view, were: "In (patient's) case, he's asking for it too often, and sooner or later they have to limit or or he'll be living on it completely;" (an interesting twist, this person advocated regular administration to alleviate this problem); "I don't understand the thinking that says you can have morphine shots as they need them, or something like that, and who cares whether they're going to be addicted; that seems so wrong I can't fathom their thinking;" "My mother would never ask for pain shots;" "He didn't ask for his medication; I had to keep track;" "I don't care if the patient is to the point where they use medication as a crutch; if it makes them feel better, they should have the privilege of using that crutch."

Family members in hospice programs commented: "You shouldn't take anything unless you have to;" "They get so that they look forward to it;" "I don't, and she didn't, want to take it unless needed;" "I heard the nurses say !Let's try to hold off,! so patients wouldn't become immune;" "I don't like the idea of becoming addicted."

Only five health professionals (one conventional, four hospice) made comments relevant to this issue of addiction: "Try to alleviate pain not with medication, if nursing procedures can alleviate it...Too much medication leads to addiction;" "Sometimes a patient abuses some of her medicine, but if you have patients that have previously done this, they don't change just because they are terminally ill;" "A lot of people are willing to live with a lot of pain, and they're not willing to look at an alternative to that; it's real hard to convince them."

And finally, this comment by a physician:

One of the real problems is that very often people with severe pain who are going to live over a year, people don't want to treat their pain for fear of addiction, in other words, dependence...People with diseases like cancer are essentially not taking the drug for any high; they're not like street addicts, and there's no reason to withhold drugs. They all worry about anyone going over a year, but still, in all, they have a right to pain control. And therein lies one of our biggest problems with some physicians we've had, and even patients themselves: they really were so hung up on this they refused to give good pain control...

2. Not Overmedicating, Or "Snowing" Patients:

Monitoring Them. Three patients (two in conventional

programs, and one in a hospice program) discussed this issue, two of whom said their medications sometimes caused them to hallucinate, and the third who simply noted the importance of monitoring pain medication.

Only one family member in a conventional program mentioned this theme. She noted that even though the patient's medication was "very strong, huge doses," it never affected his mind. Four family members in hospice programs commented: "The medications should be given correctly; patients should not be overmedicated;" "In the hospital, they're inclined to over- or under-medicate...Here they're used to giving medication;" "I was very happy with how the doctor, he didn't push drugs, yet I felt he had a real balance in how he approached it;" and

Good care is to see that whoever it is, the patient is made comfortable; not to say just inject a shot of stuff and knock 'em out completely--that's taking care of them, but then there is no communication with the family, so it doesn't help the family to try to relate to the patient, or the patient to the family.

Five health professionals in conventional programs (one of whom was the nurse described above who did not oppose "snowing" patients) mentioned this area of concern, compared to two hospice professionals. Those in conventional settings commented: "Patients should be medicated, free from pain, so they can finish unfinished business, yet not obtunded so they can't think; it's a

delicate balance;" "You should carefully avoid over-medication;" "We couldn't manage this patient's pain; we "snowed" the patient; I don't know why it couldn't be controlled;" "Alertness must be maintained for optimal time." The hospice professionals said: "We push a lot of medication--not so people are "snowed;" it's just...so pain is just, can be, pretty much non-existent;" "Good care is having patients who are comfortable and alert."

3. Adherence To Whatever The Doctor Recommends. One patient (conventional) and three family members (two conventional, one hospice) made a point of stating that the patient's doctor should determine what pain control practice is to be implemented. The opinions of these individuals were at variance with those who noted instances in which they felt health professionals had acted inappropriately with regard to pain control (theme 5).

4. The Patient Should Be Asked His Or Her Preferences. Two patients (one conventional, one hospice), six family members (three conventional, three hospice), and five health professionals (one conventional, four conventional) made a statement indicating the patient's preferences with respect to pain control should be ascertained and taken into account.

5. The Existence Of Different Kinds Of Pain. Mentioned by only one health professional (from a hospice program), this theme seems worthy of noting due to its

unusual nature. This respondent talked of the existence of not just physical pain, but also spiritual pain. He said:

Some patients, due to some spiritual or other dimension, may feel they deserve to experience some of that pain. Sometimes that's so strong that to render pain control is inappropriate.

He went on to describe a situation in which a woman's body position had indicated severe pain, so a nurse, of her own volition, gave her medication. The next morning, the woman was very angry and wanted to know, "Who denied to me making peace with my God?" He gave other examples, as well, of patients who appeared to be in physical pain, but for whom the treatment was ineffective because their pain was not physical.

6. Resistance By Health Professionals In Giving Appropriate Pain Medication. One patient (in a conventional program) reported:

They're pretty callous about pain here...At night, I get medications every four hours. During the day, I have to fight for it...The ideal would be if I could get medication within five minutes of ringing the bell. Right now, they neglect me so much I'd like to get it every four hours on the hour--I could depend on that.

Six family members (three conventional, three hospice) described instances in which health professionals had been resistant to giving pain medication in the way in which the patient, family, and/or doctor wanted: "<Patient> had to beg for pain pills; they didn't seem to think it was

necessary, I guess;" "Dr. ____ wouldn't authorize the injections for pain." One family member reported:

(Patient) was supposed to get Valium at 10:00 every night, but she hadn't got it. I asked why, and they said she hadn't asked for it. The nurses didn't like giving it regularly, maybe because it made the patients harder to care for, or it was hard to remember.

Another family member said the doctor didn't want to give the patient pain medication because "he didn't want her to become addicted." Even after the respondent made a trip to the doctor's office, he still would not give her strong enough pain medication.

Seven health professionals in conventional programs (33% of those who responded relative to this indicator) and six (38%) in hospice programs related various situations in which they felt other health professionals differed in their philosophy regarding appropriate pain control practices from the respondent's own philosophy. Often, these other professionals were seen as resistant, unenlightened, and as constituting barriers to the provision of quality terminal care. Some of their comments follow:

Philosophies regarding terminal care differ--for example, concerning pain medication, and what you're giving pain medication for. Some nurses give a lot, other don't, based on their own feelings about pain and medication.

Some people want to keep the patient completely pain-free, including some families. Others try to monitor pain with as little medication as possible so that patient can function.

Some nurses withhold medication simply because they don't understand the dying process...There is a need for retraining of nurses; usually you can do this on a one-to-one basis.

These shorter comments also were pertinent: "Sometimes we have trouble getting physicians to give pain orders;" "When we wanted to get stronger pain meds for her because she was having quite a bit of pain, the doctor wouldn't order things for her;" "This patient wanted to die pain-free, and morally some nurses felt that wasn't right."

Comments made by hospice professionals included that of a respondent who related how a patient's doctor had refused to believe she had pain, and had diagnosed her as having a lot of psychosomatic illnesses. Another person said, "There's a lot of ignorance about pain control in other professionals." Finally, the following two quotes from different respondents are illustrative:

We have such a problem getting doctors to agree to give adequate pain medication in some cases...If we extend the definition of "terminal" or "late stage cancer" to nine to twelve months, people will be happier with that; we'll do a better job treating our patients and controlling their symptoms.

There are a lot of nurses that aren't comfortable giving large doses of medicine. This causes problems sometimes because the nurse won't give it, and the family says, "But you promised you'd keep her comfortable!"

Indicator_4C:___Patient_Involvement

Examined here are expectations for the health professional role with respect to involvement of patients in care-related decisions. An achievement orientation is implied by the expectation of no involvement of patients in care-related decisions; this orientation sees the professionals as "knowing best," due to their specialized training. Involvement of patients implies an ascription orientation, since patients are involved not as a result of their competence or performance as providers of health care, but instead, because of their ascribed status as patients, and as those directly affected by the care they receive.

As noted in Chapter VI, Analytical Model, certain conditions serve as enabling factors for involvement, or participation, in care-related decisions. Particularly, patients likely will need to be informed of their diagnosis and prognosis and also will require information concerning treatment options and available resources. Another condition for involvement concerns the health professionals' openness to such involvement, that is, to allowing patients some say, or input, into these decisions and/or respecting their wishes. The link between these conditions is best illustrated by the comment of one of the health professionals interviewed: "The dying patient must have the say over his own dying; he must have as much information as needed to deal with this."

Respondents' feelings concerning each of these three conditions (information about diagnosis and prognosis, information concerning treatment options and resources, and willingness to allow patients some say or input into care-related decisions) are examined here. Included as data for this analysis are all volunteered comments that pertain to these three conditions, or sub-indicators. Two items on the checklist that was part of the original instrument used to interview respondents (see Appendix B) address these issues. As discussed earlier, respondents were asked to rate the importance of each item. The two items were: item b ("Patients are kept informed of their condition and what's being done") and item m ("Patients decide how much and what kind of care they get"). Also discussed earlier were the difficulties encountered overall with this checklist (see Chapter V, Research Design and Methods, Phase III). In light of these problems, checklist data were utilized only for those respondents whose answers included explanatory remarks accompanying their importance rating on these two items. The data for this indicator (or rather, its three sub-indicators), then, consisted of these checklist data and those comments which were volunteered elsewhere in the course of the interview.

Two additional notes concerning the data for checklist items are necessary. First, item b was ambiguously worded and, therefore, was interpreted by some individuals to mean

"tell them their diagnosis/prognosis," by others to mean "give them information about their treatment," and still others to mean both things. Where meaning was unclear, responses were placed in both sub-indicators. Second, a number of people qualified affirmative responses to item b or item m with comments such as "if they're not senile," or "if they're not in a coma." For the purposes of this analysis, adequate mental capacity and alertness of patients were assumed; therefore, these persons' responses were tabulated as "yes;" the category "maybe/depends" was reserved for other qualifiers or situations, as described below.

This section examines each of the three sub-indicators, or conditions, for patient involvement separately. Table XLI summarizes the data obtained from study participants.

Provision Of Information To Patients Regarding Diagnosis And Prognosis. Only about a third of the patients interviewed provided comments that were tabulated. Families were much more vocal on this issue, with three-quarters responding. About half of the health professionals made a relevant comment. While the rate of response did not differ greatly by sub-group (conventional versus hospice), the pattern of response did appear to differ somewhat. Furthermore, the three groups' (patients', families', and health professionals') opinions, seemed to differ from one

TABLE XI
INDICATOR 4C: PATIENT INVOLVEMENT
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

PATIENT INVOLVEMENT (THREE SUBINDICATORS)	PATIENTS							FAMILIES							HEALTH PROFESSIONALS						
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)			Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)			Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)		
	n	%	n	%	n	%		n	%	n	%	n	%		n	%	n	%	n	%	
PROVIDE INFO. TO PATIENTS: RE: DIAGNOSIS, PROGNOSIS:																					
No	0	0%	1	13%	1	6%		1	5%	1	6%	2	5%		0	0%	0	0%	0	0%	
Yes	3	33%	1	13%	4	24%		5	25%	9	50%	14	37%		8	42%	8	40%	16	41%	
Maybe, Depends	0	0%	1	13%	1	6%		10	50%	4	22%	14	37%		2	11%	2	10%	4	10%	
No Relevant Comment	6	67%	5	63%	11	65%		4	20%	4	22%	8	21%		9	47%	10	50%	19	49%	
PROVIDE INFO. TO PATIENTS: RE: TREATMENT, RESOURCES:																					
No	0	0%	0	0%	0	0%		0	0%	0	0%	0	0%		1	5%	0	0%	1	3%	
Yes	0	0%	1	13%	1	6%		6	30%	9	50%	15	39%		1	5%	7	35%	8	21%	
Maybe, Depends	0	0%	0	0%	0	0%		4	20%	1	6%	5	13%		0	0%	0	0%	0	0%	
No Relevant Comment	9	100%	7	88%	16	94%		10	50%	8	44%	18	47%		17	89%	13	65%	30	77%	
ALLOW PATIENTS INPUT/ CONTROL IN THEIR CARE																					
No	1	11%	0	0%	1	6%		5	25%	1	6%	6	16%		0	0%	0	0%	0	0%	
Yes	6	67%	3	38%	9	53%		11	55%	11	61%	22	58%		12	63%	16	80%	28	72%	
Maybe, Depends	0	0%	0	0%	0	0%		2	10%	3	17%	5	13%		3	16%	1	5%	4	10%	
No Relevant Comment	2	22%	5	63%	7	41%		2	10%	3	17%	5	13%		4	21%	3	15%	7	18%	
NO RELEVANT COMMENT IN ANY OF THE ABOVE	2	22%	3	38%	5	29%		1	5%	2	11%	3	8%		3	16%	2	10%	5	13%	

* Percentages do not always sum to 100% due to rounding error.

another. To facilitate comparison between these groups, the percentages reported in the text that follows are adjusted to include only those respondents who volunteered a relevant comment (i.e., those whose comments were classified as "no," "yes," or "depends/maybe").

Among the patients who were interviewed, three patients in each type of program (conventional and hospice) responded. The patients being cared for in conventional programs all felt that patients should be told their diagnosis and prognosis. The three patients in hospice programs were divided among the response categories, with one indicating "yes," one "no," and one, "depends."

Of the respondents of both patient groups (hospice and conventional) combined, 67% felt that patients should be informed of their diagnosis and prognosis. As one of these patients noted, "It's a lot better knowing; if you don't know the truth, how are you going to cope?" One patient (17%) preferred not to know: "Don't tell a patient how long he has to live...We'll go when our time comes...When the doctor told me I had two months to live, it upset me and my whole family." The last patient (17%) felt that generally it was a good idea to tell patients, but not all patients. He gave an example of a neighbor of his who had "quit" upon finding out he had cancer.

The pattern of response for responding family members differed for those in conventional programs compared to

those in hospice programs. While one person in each subgroup felt that patients should not be made aware of their prognosis, 31% of the family members in conventional programs indicated the patient should be told, compared to 62% of those in hospice programs; 63% of those in conventional programs qualified their responses, compared to 31% of the hospice family members. These respondents felt that patients' desire to know or not know, and/or their probable response to the news, given their emotional makeup, should be taken into account. Some respondents specified that the doctor should tell the family and let the family decide if the patient should be told.

The combined percentages for family member respondents (conventional and hospice) are: 7% indicating that patients should not be told, 47% that they should be told, and 47% that it depends on the individual.

Of the two respondents who argued patients should not be made aware of their diagnosis and prognosis, the one in the conventional program stated, "I don't believe in that too much... I think it puts a worry on their minds, and it slows down their process of getting better, if there is any chance of getting better." The family member in the hospice program noted that, at the same time, false hope should not be given, either.

Examples of comments made by those who felt that patients should be told, both about their diagnosis and

prognosis and about treatments (the second sub-indicator) follow. The response quoted first also indicates that patients should have some input and control (the third sub-indicator) in their care.

Everybody has a right to know that they are going to die so that they can do those things that they must do before they die...If I'm dying and I don't know it, I could curse everybody to hell and back again. Why? Because you're not giving me the privilege of making that decision about what my life or death should be, what I must do or mustn't do. It should be my choice...I believe everybody should have the right to choose what they want prior to their death.

At (hospital), we didn't know too much what was going on. I was surprised how much the doctor told us at (another hospital). He told me and her both; that's the way it should be.

Patients absolutely should be told, but doctor's don't. Doctors are not only smart medical men, but they are masters of the English language; they can give you more gobbledygook to cover up a situation than you can absorb, without saying anything.

People will come in and talk with her in generalities, not really telling her what's ahead, how she's doing...She's not gotten one doctor to sit down with her at (hospital) and say, "This is what's going on," "This is what we may or may not be able to predict," or "Do you have any questions?"

The pattern of response did not differ much between health professionals in conventional programs and those in hospice programs. None of the health professionals who responded felt definitely that patients should not be told their prognosis, and only four (two conventional, two hospice) indicated that there were situations (other than mental incapacity) in which patients should not be told

(e.g., if they did not wish to know). This left 80% of those in conventional programs and of those in hospice programs saying patients should be made aware of their prognosis. The combined percentages for both sub-groups were: 0% "no," 80% "yes," and 20% "maybe/depends."

Examples of professionals' comments include: "You must tell people if they are terminally ill; people have a right to know;" "If a patient isn't aware of his prognosis, the staff can't talk with them, help them deal with their huge fear;" "The patient kept asking, but no one wanted to say that her death was fairly imminent;" "Sometimes doctors aren't totally honest with patients;" and the comment by a nurse:

People often are not very well-informed by their physician. The physician should be the one who's informing them, keeping them up to date, telling them what their status is medically. Often it's hard for us if they aren't well-informed.

Two physicians responded: "One barrier (to the provision of quality terminal care) is that patients must accept that they're dying, and if the doctor isn't going to admit it, the patient won't be told;" and

It's very rare that we don't tell a diagnosis...We usually always let people know their prognosis. People ask the question, they get an answer. And we don't believe in holding back. I think that being able to do that is very satisfying.

In sum, the ideal expectation of all three groups generally appears to be that patients should be made aware of their disease and their prognosis, at least for patients

who wish to know and/or are judged to be emotionally stable enough to handle such information.

Provision Of Information To Patients Concerning Their Treatment Options And Available Resources. Only one patient (6%) gave a response that was categorized here; over half of the family members interviewed made a relevant comment, however. Only about one quarter of the health professionals commented on this issue. Substantially more health professionals in hospice programs (35%) than in conventional programs (10%) gave a relevant response.

Among those persons who did comment, only one, a health professional, felt that this type of information should not be provided. This person gave an example of a case in which the provision of information about the treatment the patient was receiving would not have been "fair." The patient "didn't have the background to understand."

The majority of the remaining respondents who commented felt that information about resources and/or treatment options generally should be provided (again, as long as the patient was not mentally incapacitated). A few family members, especially those in conventional programs, remarked that it depended on the patient and what they wanted to know.

The patient stipulated that information should be given that was "understandable." The responses quoted in

the above sub-section ("Provision of information regarding diagnosis and prognosis") are exemplary of those given by family members. Health professionals noted: "Let patients know what resources are available;" "The ideal is a compassionate physician who will give them information--just basic information about everything is so helpful to them: side effects of medicine--just basic things."

Interesting to note in some of the responses concerning the provision of information both about treatment options and the disease and about the patient's diagnosis, medical status, and prognosis is the clear designation of the physician as the preferred purveyor of this information. Nurses generally either do not seem to feel comfortable providing this information, or do not feel it is appropriate for them to do so. Patients and families usually focused on the physician, also, as the individual who should provide information to the patient.

Also of importance is the apparent discrepancy between the ideal and the real; many situations were related in which desired information was not provided to the patient.

In general, there was little difference between the expectations of those in hospice programs and those in conventional programs, except (1) in the frequency with which the "it depends" category was used, (2) family members in conventional programs were more likely to feel that patients definitely should not be allowed say in their care,

and (3) hospice professionals were more likely to mention expectations that the health professional should provide information about treatment options and resource availability. Of the three groups (patients, families, and health professionals), more families responded than any other group.

Openness To Patient Input/Control In The Care. Prior to examining the responses relevant to this indicator, note should be made of the categories of response for this sub-indicator. Specifically, the "maybe" category was developed for classifying the comments of those respondents who gave conflicting information in the course of their interviews regarding their views. Examples are given below.

More individuals in all three groups volunteered comments pertaining to this sub-indicator than to either of the other two. About 60% of the patients, 87% of the families, and 82% of the health professionals made a relevant comment. Fewer patients in hospice programs remarked on this issue than did patients in conventional programs.

All but one of the patients who responded indicated that they felt patients should be allowed at least some say in their care. The patient who felt otherwise said "The nurses and nurses aides know what they're doing." The other patients' comments included those of a man who liked the

fact that he was allowed to "sleep practically as long as I want and stay up as long as I want to," but he did not appreciate being told when to take his bath. This man also related an incident where he asked his doctor to alternate his medications so that he "wouldn't build up a tolerance." The doctor agreed to do this, and the patient was pleased. The remaining patients in conventional programs expressed their dissatisfaction with "nurses" who were "too bossy," "overbearing and sassy," or who "wouldn't give water enemas" despite the patient's wishes, and with health professionals in general who "force things on you all the time; I don't like to be forced to do anything" (e.g., eat, drink).

The comments of the patients in hospice programs centered around the administration of medication. One patient noted that "doctors don't believe you" if you tell them about ill effects of particular medications. Another said, "Well, if you're in pain, it's important to get help-- usually I ask for pain killer for my arm." The third asserted:

The patient should have the say. You know your illness; you know when it's hurting you worse than other times. Now, sometimes it's hard to convince a nurse or doctor that maybe you are hurting a whole lot worse than they think you are.

All but five family members in the sample (two in conventional programs and three in hospice programs, or 13%), made a comment relevant to this issue of patient input and control. Five family members in conventional programs,

compared to only one in a hospice program indicated that the patient should not have such input and control. Typical comments included: "That would be impossible...some demand more than they need;" "I think the doctor and nurse know better than the patient;" "I don't think they're capable; that's what the doctor is for;" "No, that should be done by doctors." All of these comments were in response to checklist item m.

The majority of family members felt that patients should have at least some input into their care and care-related decisions. Among these respondents was a family member who noted that her relative did not want intravenous feeding and nasogastric tubes, and that the doctor finally agreed to stop this treatment; this was "hard for the family, but it's what (the patient) wanted." The experience of another respondent was the opposite, however; despite the patient's and the family's wishes to have chemotherapy stopped, the doctor refused. Another respondent felt her mother would have received more attention if she had taken a larger role in her care: "It's the squeaky wheel that gets the attention and Mother didn't squeak. She didn't ask for anything--she didn't want to bother." Two other respondents agreed: "Mother never complained, you had to ask her; even then, she seldom complained; it might have helped if she had;" "The problem is some patients are not real assertive to saying; I'd like to see a patient advocate."

Other people noted, however, that patients had to be careful not to complain too much so as to avoid alienating care providers: "If you don't cooperate with (program) they cut you off, and she was in no position to be cut off." This same family member reported that the doctor had promised the patient that he would not take her to a nursing home, yet the next morning an ambulance had come and taken her to one. One family member asserted that the patient should have therapy "only if the patient feels like it; if, not it should not be forced." Other comments included: "They respected his feelings;" "The decision process should be the patient's;" "Some, but not all, the say should be the patient's;" "Patients should have 100% say."

As noted above, the third response category, "Maybe," was developed for those respondents who gave conflicting information in their interview. Generally, the conflict in information came when respondents had related incidents or made statements that implied that they felt patients should have at least some say in their care, yet who responded to item m by saying, for example, "That should be determined by the physician, the hospital, the nursing home--as much as the patient needs." This statement was made by the man quoted above in sub-indicator 1, who asserted so vehemently patients' right to know if they are terminally ill, and to "choose what they want prior to their death." Such

conflicting information may have arisen from difficulties experienced in interpreting the checklist item m.

The health professionals' comments which were classified in this "maybe" category were were similar to those of the families. That is, they responded to item m saying that they felt it was not particularly important for patients to decide how much and what kind of care they get, yet they made statements earlier in their interviews that indicated that they felt patients should have at least some say in care-related comments. The responses of four health professionals (three in conventional programs, and one in a hospice program) were of this nature. One professional in a hospital (conventional), for example, made the following statements:

As a nurse, it's hard for me to say, "Let them do what they want!" It's hard to switch gears from the acute to the terminally ill. With an acute patient, what you do or don't do can drastically affect the outcome of the person's illness.

A lot of terminally ill patients don't want you to do supportive care, but I think it's necessary.

Sometimes you need to give them their own way--it doesn't matter.

Examples of the responses of health professionals who indicated patients should definitely have some say in their care are: "With the terminally ill, we're more concerned about what they want to do, what they feel they need;" "Caregivers have a tendency to take control, yet patients need to be maintaining control and need to be involved in

decision-making concerning their care;" "Sometimes the patient won't say, or will be afraid to say (what they want);" "The most important thing is care that incorporates the patient into his own care, that isn't totally determined by the family, doctor, or nurse;" "A lot of times we get people at home we feel in a professional way they shouldn't be there, but they want to be at home, so we try to support them the best way that we can;" "Have the person tell you what their needs are rather than you telling them; sometimes you perceive their needs differently than they do...give them some control, some say-so;" "It's hard when we can't be open to patients, when they aren't asking questions, aren't involved, when they don't want to take responsibility to do anything--they suffer more;" "It's difficult when patients make inappropriate choices, though."

One professional noted the reticence of elderly patients, in particular, in making their wants known:

Older patients are so...they take such pride in doing for themselves, and to even ask for anything is an indication of weakness. They will endure; they've done it before. And they're not going to spend their money on themselves because they want to have some for their kids. And they're just not going to!

This same person went on to say, "Involvement of the client is important so the person getting the services has the ability to choose, to make their wants known...Patients need to decide, but they need help." Another professional gave

an example of the way in which she tries to incorporate patients in their own care:

When the doctor's written something, I usually immediately try to go over with the patient what was done that day, what has changed, and I think that's real important for them to be involved, because that way they feel that they haven't lost control, they still have some handle on what's going on. So many times in a hospital that control is taken away from them. They're always told "You'll have your bath and your whatever at this time."

Finally, one professional noted that "Patients take control, anyway," whether the professional wants them to or not.

Certain themes emerged in these comments of patients, family members, and health professionals. One theme is that most patients do not appreciate being "bossed" or "forced." Another is that some patients, and particularly elderly patients, are reluctant to speak up about their needs because of their fiercely independent nature, their fear of reprisal by health professionals, simply because they are not assertive. A third is that inpatient environments must work harder at facilitating and preserving for patients some degree of control over their care. Finally, a fourth theme is that of the difficulty experienced by health professionals when patients make decisions that are at variance with what the health professionals feel is best and most appropriate for the patient.

Indicator 4D: Family Involvement

This section examines respondents' expectations of the health professional with respect to involvement of families. Just as involvement of patients in their own care and in care-related decisions implies an ascription orientation on the part of the health professional, so does involvement of the patients' families. Expectations that health professionals not involve patients' families, that the professionals "know best," are achievement-oriented.

As was the case in Indicator 4D, Patient Involvement, relevant comments made by respondents in the course of their interviews, as well as data from two checklist items ("e" and "i") were included in the analysis, if respondents made a remark explaining their response to the item (see previous section, "Indicator 4D" and Chapter V, Research Design and Methods, Phase III for an explanation of this decision). The two checklist items asked respondents how important it was that: "Patients' families have a say in the patients' care;" and "Patients' families help care for the patient." "Help," in this latter item, was interpreted variously by respondents to mean help with the physical care of the patient, help through serving as an advocate for the patient, or help with care just by being with the patient, visiting him or her, and providing emotional support.

As was "involvement" of patients, "involvement" of families has been operationalized to include three sub-indicators. These sub-indicators differ somewhat, however, from those of patient involvement.

The first sub-indicator, "providing information to families," includes not only information concerning diagnosis and prognosis, but also information concerning treatment options and available resources, as well as training in actual care techniques. These types of information, separated into two sub-indicators in Indicator 4C, Patient Involvement, were combined here because respondents tended either not to differentiate between them or to desire all such information, with the exception of training in specific care techniques, which was mentioned only by those respondents representing home care programs, both conventional and hospice.

The second sub-indicator, "letting families have some say in the patient's care," is the corollary to the third sub-indicator in Indicator 4D, Patient Involvement, "openness to patient input and control in the care." Included are responses that dealt with expectations of health professionals with regard to their respecting the wishes of the family.

The third sub-indicator, "encouraging participation by the family," was developed to reflect expectations of respondents concerning the desirability of active

solicitation, encouragement, or facilitation by health professionals of family participation in the patient's care. Such expectations included those that addressed respondents' preferences with respect to health professionals' encouragement of families to provide physical care (especially in patients' own or families' homes) or their facilitation of the family's presence (in an inpatient facility) through the making of provisions for them to visit the patient at other than posted visiting hours, to sleep in or near the patient's room, to eat with the patient in the patient's room, to bring food in, and other such instances of "bending the rules."

Table XLII summarizes the findings with regard to these three sub-indicators of family involvement. The text that follows addresses each area separately.

Providing Information To Families. None of the patients interviewed mentioned this as an expectation, yet over half of the family members did, and about 40% of the health professionals. All of the family members who commented felt that health professionals definitely should provide information to patients' families. One said, for example:

Be understanding of the family; don't criticize or belittle them...Explain to them what is happening to their loved one...Give suggestions to them about things they might not have thought of; pass on information they might need.

TABLE XL11

**INDICATOR 4D: FAMILY INVOLVEMENT
SUMMARY OF RESPONSES
BY RESPONDENT GROUP ***

FAMILY INVOLVEMENT (THREE SUBINDICATORS)	PATIENTS							FAMILIES							HEALTH PROFESSIONALS						
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)			Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)			Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)		
	n	%	n	%	n	%		n	%	n	%	n	%		n	%	n	%	n	%	
PROVIDING INFORMATION TO FAMILY																					
No	0	0%	0	0%	0	0%		0	0%	0	0%	0	0%		2	11%	0	0%	2	5%	
Yes	0	0%	0	0%	0	0%		10	50%	11	61%	21	55%		7	37%	7	35%	14	36%	
Maybe, Depends	0	0%	0	0%	0	0%		0	0%	0	0%	0	0%		0	0%	0	0%	0	0%	
No Relevant Comment	9	100%	8	100%	17	100%		10	50%	7	39%	17	45%		10	53%	13	65%	23	59%	
LETTING FAMILY HAVE SAY IN PATIENT'S CARE																					
No	0	0%	0	0%	0	0%		2	10%	2	11%	4	11%		2	11%	0	0%	2	5%	
Yes	2	22%	1	13%	3	18%		6	30%	10	56%	16	42%		6	32%	10	50%	16	41%	
Maybe, Depends	0	0%	2	25%	2	12%		3	15%	1	6%	4	11%		1	5%	0	0%	1	3%	
No Relevant Comment	7	78%	5	63%	12	71%		9	45%	5	28%	14	37%		10	53%	10	50%	20	51%	
ENCOURAGING FAMILY SUPPORT OF PATIENT																					
No	0	0%	0	0%	0	0%		3	15%	0	0%	3	8%		2	11%	0	0%	2	5%	
Yes	1	11%	2	25%	3	18%		6	30%	7	39%	13	34%		12	63%	9	45%	21	54%	
Maybe, Depends	0	0%	0	0%	0	0%		1	5%	1	6%	2	5%		1	5%	1	5%	2	5%	
No Relevant Comment	8	89%	6	75%	14	82%		10	50%	10	56%	20	53%		4	21%	10	50%	14	36%	
NO RELEVANT COMMENT IN ANY OF THE ABOVE	7	78%	4	50%	11	65%		3	15%	2	11%	5	13%		1	5%	3	15%	4	10%	

* Percentages do not always sum to 100% due to rounding error.

Another family member noted, "They sometimes talk in language you don't understand; they get put out when you ask for something to be repeated." This same person, as did a few other family members, felt that "Some things should be told to family first." Also illustrative of several persons' comments were those by this family member:

More than one person needs to hear what might be done to help a person...I remember my mother commented, "I am so glad you were there because I can't remember what he told me was ahead for me"...I don't want to take advantage of their time or unnecessarily tie them up. I feel we really have the right to answers, and I won't push and take advantage, but I'm going to hang around until an answer comes...I wish there were one person, a doctor, who could sit down and answer our questions for us.

Additional comments by family members included:

I'd call a couple of nice nurses who would give me information on platelets, white count, and hemoglobin--really give me information. Then I ran across some who wouldn't give me the time of day. I'd wait until they were off shift.

They're <nurses> willing to talk to me, not embarrassed if I ask them questions. The family should be told exactly what the situation is so that they know how to deal with it. Of course, some people can't handle something like that, but I think anybody who's training to go into it can tell when they can be told and when they shouldn't be.

This person also described a situation in which she had not been given valuable information:

At <hospital>, nobody could tell me where I could get...equipment that I'd need at home. And the nurses didn't mention 'til I brought it up what was available in the way of home help.

The majority of the health professionals interviewed also viewed the health professional as having a responsibility to provide information to families. Some of their comments were: "The family needs honesty from the doctor and the staff;" "Let families know what resources are available;" "Make them aware of agencies that can help."

Two health professionals, however, felt that the provision of information to families was not particularly important, or at least they did not like having to do this, and saw it as interfering with their ability to do their work. These two professionals, both in the same inpatient facility, resented having to explain what they were doing with the patient, and why they were doing it (e.g., when they put the patient on the commode, or when they did particular medical treatments). As one said, "One of the biggest barriers is when families come; it's hard when families are standing there and watching you--you have to explain."

Letting Families Have Some Say In The Patient's Care.
Families themselves, again, were much more likely to comment with respect to this issue of "say," or input into the patient's care, and especially families in hospice programs, than either health professionals or patients. Of those patients who did respond, all favored at least some family say, although a few issued cautionary notes, such as that by a man who stated that only one family member should have

such input because of the potential for conflict, and the plea by another male patient that families not treat the patient like a child; this had happened in his case, and he felt it was "demoralizing."

Among the families who responded, the majority (67%) felt that families should have input into the patient's care. One woman believed this, yet reported:

The nurses would get so snappish--just irritable at me for butting in. I've gotten so weary--it's like dealing with children who you tell to clean up their room; you get irritable that they're not doing what they should do.

Another had had a very positive experience:

People were very open and honest with me--all the doctors, all the nurses. The suggestions I had were listened to and acted on...At no time did anybody tell me what to do. They gave me choices and eventually I made the decisions, and I appreciate that...My mom had some problems with her pain medication. Dr. ____ gave her a drug, and she had a very bad response which the doctor didn't see. And so I went to the nurses, and I told them. Somebody could have said to me, you know, "Lady, let us do the job." And they didn't do that. They changed the medication...They were just more than cooperative.

A number of these family members, however, did qualify their statements, being careful to note that the patient's wishes should have priority, or that only the immediate family (e.g, spouse) should be involved in order to avoid confusion.

A few of the family members who made relevant comments expressed ambivalence ("maybe/depends"), generally seeming to feel that the family should have at least some input but

deferring to the judgment of the professionals. For example, one person commented that the family should "be aware, keep their eyes open," but that "they should leave the major part of nursing to professional people." Another said:

I think it should be more or less up to the doctor; of course, the family knows the patient's needs, and I think should talk about it. If they feel the patient needs something extra, I feel they should tell the doctors and nurses.

Four family members, (two in conventional programs, two in hospice programs) felt much more strongly that families should not have say, as illustrated by these comments:

It should be between the patient and the doctor. The family shouldn't have anything to say if the patient is mentally alert; this gets the patient mixed up. People tell other people what to do too much."

I was invited to one of those meetings (of the health professional team), and I just was turned off. I didn't want to be responsible for some of the things that were going on at the time.

About half of the health professionals made comments that were relevant to this issue of family input in the patient's care. All of those in hospice programs who mentioned this issue favored family input. Most of those in conventional programs did, as well, although a few qualified their remarks, stating the patient's wishes should be considered first, or that the family should have say "except when it's bad for the patient." One person, whose response

was tabulated as a "maybe," stated, "Families need to be consulted, dealt with, even before they enter the facility." She felt this was an important strategy for keeping them from being too demanding:

Families have a tendency to want a terminally ill patient to have more care. Sometimes we get accused of not caring for them enough. They forget that they have placed their family member here...The family is the biggest barrier; they are overly protective, expect a lot more, want everything to be done to just perfection."

The two health professionals who felt it better that families not have say in the patient's care stated: "Families don't understand some of the physical care that's done--they think we're trying to kill them;" and "Many times they don't understand what is necessary." The first of these health professionals continued, "If the family comes in and picks all the time, then you don't want that patient."

Those who felt that the family should have some say, that their wishes should be respected, commented: "We provide services at a level the family can accept;" "We try to maximize the choices for the patient and the family; they have all the say;" "In this case, we had family conferences; the whole family got together, rallied around her...As problems came up we were able to find solutions as a team;" and finally:

Families need to feel involved, have a say in what's happening. They don't necessarily have to help with daily care. They must feel that the nursing staff

is receptive to their suggestions, won't override their wishes.

Despite the general consensus that the health professional should listen to the families' suggestions and respect their wishes, a majority of the health professionals who made relevant comments reported situations in which they felt this way was not in the patient's best interest, or made the job of the health professional especially difficult. Particularly problematic, as hinted at above, are those families who are "critical," "unrealistic," "overprotective," "picky," "fault-finding," and/or who "mistrust" or "undermine" the health professionals. Families who are cooperative and with whom "good communication" or a "good relationship" has been established, who are "involved with the staff as a team," and/or who are satisfied with the care their relative had received were much appreciated.

A few family members themselves noted that families could sometimes be overly demanding, critical, or interfering. Some advocated "developing rapport" with the health professionals, ("The family needs to get to know the aides and nurses, too, so there's rapport between them").

One family member stated:

Sometimes, the question should be, "What can the family do to be a better team member?" It has to be approached as a two-way situation. I was there long enough to develop tremendous respect; I was there a lot, all three shifts. The family must be cognizant of the working relationship; it's not a servitude-type situation.

Approaching this problem from the negative side, one family member noted: "I dread the thought of pressuring--she'll <patient> really suffer for it. They'll <health professionals> leave her up way too long, and it's going to cause her pain."

Encouraging Participation. A few patients, just under half of the family members, and about two-thirds of the health professionals made comments regarding health professionals' active encouragement or facilitation of family participation in the patient's care. Fewer hospice professionals than professionals in conventional programs made relevant comments.

All of the patients who commented were in favor of health professionals encouraging family participation, although one asserted, "I don't think they <health professionals> like it too much, but my wife helps a lot--it saves them." One of the other two patients was grateful that "the oncology department at the hospital allowed my husband <to be here> all the time; this was very important." The other patient noted with appreciation that "the aides...bring your family into it, too, so there's a coordination."

Nearly all family members in hospice programs who made a relevant comment felt that health professionals should facilitate and encourage family members to help in caring

for the patient, either in the physical care or in providing emotional support. The majority of the family members in conventional programs who addressed this issue felt similarly. Examples of comments made include: "The administrator and the head nurse are very good about making us feel welcome as a family--they always smile when we come in;" "They let the whole family go in, grandchildren go in--best medicine that he had;" and the following longer comments:

When she (patient) was first wheeled in there, one of the head nurses said, "We just love to have families take an interest in these patients. There's nothing that pleases us more." Well, I discovered this was purely lip service. I soon found out they resented my being there as much as I was. They insisted on calling a big conference between the head nurse and our preacher and myself to reach an understanding. I had to bend on some things and they compromised on some other things.

I slept on the sofa in the lounge because I would not leave him; they didn't mind. They were most cooperative...One nurse even found an empty suite...we had all our family coming down to give blood, and we needed that extra room. My husband liked having his children there.

In the hospital they're so professional, in the sense that they'd say, "Well, you gotta get out of here now." Well, here we could stay, except in extreme cases, like they'd say "Well, we have to change her and..." But it wasn't the brush off. For instance, if you die in the hospital, well, that's the first thing they tell you: "Get out." That's not how it was here...This is a way for a family to renew whatever they had as a family.

The last respondent also commented on the idea of being able to help in the patient's physical care: "There's a strange morality today--suing; so the institution is reluctant to

let you help." A few family members told of how they had been allowed to bring in food for their ill relative.

A somewhat surprising finding was that some family members were either ambivalent about health professionals' encouraging them to participate in their relative's care or were not in favor of this. Respondents who made remarks of this nature generally were those who felt unable to care for their relative at home. In a few cases, such respondents had been made by health professionals to feel guilty for not caring for their ill relative in their or the patient's home, such as the following two persons:

One person at <program> said I didn't want him home. I said that had hurt me. Of course I wanted him home; my doctor said I couldn't take care of him.

I felt like I ought to do all this care, but felt at the same time that I couldn't, and to hear the professionals say I should really made me feel bad.

Also contributing to some ambivalence about being encouraged to participate in the patient's care by the health professionals was the feeling on the part of a few family members that the presence of the family might actually be detracting from the quality of care received by the patient, because nurses were less likely to check on the patient. This theme was noted in Indicator 2A, Availability of Care, as well.

The majority of the health professionals who responded held ideal expectations that families should be encouraged by health professionals to participate in the patient's

care. Two professionals did not feel this way, though. One was the same person who was reluctant to allow families to have say in the patient's care, and who clearly felt that families more often than not contributed negatively to health professionals' ability to provide quality care. The other person felt that a family's continual presence "kept the patient from adjusting to us."

A few other health professionals were ambivalent due to their awareness of just how difficult, physically and emotionally, the provision of care was on family caregivers, especially older caregivers. Family members themselves noted this fact as well. Nearly without exception, the family members who were providing care at home for their ill relative, or who had done this at one time in the relative's illness, stressed the physical and emotional strain this caused them, and, in many cases, their own immediate families, such as their children and husband.

One health professional who did support the idea of encouraging family members to participate in the care of the patient felt a simultaneous responsibility to help families, especially wives, not to feel guilty if this care got to be too much for them, and not to feel that they had to do it all themselves. She tried to reassure them that "no one works 24 hours a day."

Other health professionals' comments focused on efforts that should be made: to provide accommodations for

family members who came from out-of-town; to institute flexible visiting hours and policies (except for one physician who continued to feel that children should not visit in the hospital); and to facilitate privacy for families and patients. One person stated:

I think that's been the most exciting thing--I've seen such family involvement...Some are here 24 hours, sleeping here with them all the time. And if it isn't, you know, the spouse, it's other family members.

At the same time, many professionals reported that often these were ideals, that there was room for much improvement, especially in the area of institutional support for opening up facilities to families, and in terms of difficulties imposed due to fire, sanitary, and other regulations (e.g., no families in the halls).

Indicator_4E:___Volunteer_Involvement

Examined here are respondents' expectations concerning health professionals' involvement of volunteers in the care of patients. As was argued in Chapter VI, Analytical Model, willingness to use volunteers represents an ascription orientation (pole 2). This is because such volunteers generally are lay people with no formal training in medicine or nursing; they are involved as a result of some personal attribute, such as desire to help. An achievement orientation is implied through an unwillingness to use volunteers; health professionals with this orientation see no one but the health professional as capable or qualified to provide care (pole 1).

The data for patients, families, and most health professionals that pertain to this indicator consist completely of comments volunteered in the course of respondents' interviews; no direct question about volunteers was asked. The health professionals who were interviewed as the administrators of their respective programs are the exception. They were asked: "Are volunteers used here? If so, what are their functions? What are the training, experience, or other requirements for volunteers?" It should be clarified that expectations concerning the use only of volunteers directly affiliated with a program, or a desire to have volunteers affiliated with a program, were examined.

Table XLIII summarizes the responses of respondents with respect to whether or not their ideal expectation is that health professionals include volunteers in the care of the patient. Only one patient and four family members mentioned the use of volunteers; all of these respondents were from hospice programs. The patient remarked simply that she liked the volunteers, that they were "very, very nice." Three of the family members reported types of assistance they or their ill relative had received from program volunteers, including a volunteer who stayed with the patient on two occasions while the family member conducted personal business, a volunteer who stayed with the patient one night per week so that the family member could go to church (both of these family members were caring for their ill relative at home), and a volunteer from the hospital who gave the patient "a lot of pleasure." This last volunteer "was there quite a bit; she even made visits out here when she (patient) was at home." The fourth family member did not describe specific tasks that were performed by the volunteers in the program where his wife had been cared for; he simply stated that the volunteers had been appreciated and that "they need more volunteers."

In addition to the health professionals (administrators) who were asked specifically about their use of volunteers, four health professionals, all in conventional programs, made a comment in the course of their interviews

TABLE XLIII
INDICATOR 4E: VOLUNTEER INVOLVEMENT
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

VOLUNTEER INVOLVEMENT	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
No	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	1	5%	0	0%	1	3%
Yes	0	0%	1	13%	1	6%	0	0%	4	22%	4	11%	9	47%	5	25%	14	36%
No Relevant Comment	9	100%	7	88%	16	94%	20	100%	14	78%	34	89%	9	47%	15	75%	24	62%

* Percentages do not always total 100% due to rounding error.

that indicated their feelings with respect to the use of volunteers. Two of these respondents noted with favor that their programs used volunteers; both of the others could see a role for volunteers and wished that their program would use them.

Of the ten administrators, all five of the hospice administrators said volunteers were used in their programs (although one said the program was not well coordinated), compared to only two of the five conventional programs. Of the remaining three administrators, one was considering beginning to use volunteers, a second used an existing volunteer service through another agency, and the third said her agency did not use volunteers, and would not use them. Apparently this was due to resistance on the part of others in the program.

While hospice programs clearly appeared to use volunteers more consistently in the care of their patients, it should be noted that these volunteers cannot be considered to be entirely "lay" volunteers. Four of the five hospice programs specified various types and hours of training undergone by volunteers, as well as careful screening procedures that were in place. This training was seen as essential not only for the volunteers to provide quality care, but for the volunteers' own peace of mind and their comfort in being with terminally ill people.

Indicator_4F:--Criteria_For_Evaluating_The_Health
Professional

As noted in Chapter VI, Analytical Model, this last indicator of the achievement--ascription-orientation pattern variable differs in perspective from the previous six.

Instead of ascertaining the role expectation with respect to how the health professional is expected to treat or evaluate the patient or other members of the role set, this indicator examines the expectation concerning how the patient and other members of the role set evaluate or assess the health professional. Specifically at issue is how the health professional is to be assessed: (1) on the basis of his or her effectiveness, competence, skills and capacities (performance capacity), or (2) on the basis of his or her sex, age, intelligence, physical characteristics, or group membership (e.g., M.D., R.N.) (ascriptive qualities).

In Chapter VI, Analytical Model, it was stated that in the medical model, since the patient is expected to comply unquestioningly with the health professional, evaluation of the professional under this model likely would be ascribed, based primarily on the health professional's position as a doctor or a nurse, or on other personal ascriptive characteristics. Alternatively, in the hospice model, since the patient is expected to take a more active role in his or her care, it was posited that the health professional would likely be evaluated on the basis of performance capacity,

not simply position or qualifications as a doctor or nurse or other ascriptive characteristics such as sex or age.

Table XLIV summarizes the pertinent responses of the patients, family members, and health professionals interviewed. It must be noted that the distinction between ascriptive-oriented and performance-oriented role expectations was not always an easy one to make. Particularly troublesome were comments made by health professionals themselves that related to the health professional's "qualifications." Such comments could be interpreted to mean that the health professional simply was expected to be licensed or certified (she is a nurse; he is a doctor), in which case an ascriptive orientation was inferred. Alternatively, these comments could be interpreted as meaning special skills and talents possessed by the health professional that would contribute to his or her performance capacity (performance orientation). When these difficulties arose, the full interview was returned to and the comment was reviewed in the context in which it was made. Also difficult to classify were comments that concerned personal characteristics of health professionals. The guideline used here was that if the primary focus was those characteristics as they directly affected the professional's perceived effectiveness or competence in the provision of quality terminal care, they were classified as performance oriented characteristics.

TABLE XLIV
INDICATOR 4F: CRITERIA FOR EVALUATION
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

CRITERIA FOR EVALUATION	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Performance, Competence	4	44%	6	75%	10	59%	16	80%	16	89%	32	84%	16	84%	20	100%	36	92%
Ascriptive Qualities	2	22%	2	25%	4	24%	10	50%	2	11%	12	32%	1	5%	7	35%	8	21%
No Relevant Comment	4	44%	1	13%	5	29%	2	10%	2	11%	4	11%	3	16%	0	0%	3	8%

* N's do not sum properly and percentages do not total 100% due to multiple responses.

Most apparent on first glance at Table XLIV is the finding that some patients, family members, and health professionals evaluated health professionals in both ways-- in terms of their performance (competence, skills, training, and experience) and their ascriptive qualities. It is for this reason that the n's and percentages do not sum to 100% within the three respondent groups. While the Analytical Model called for a choice between the two poles, such a choice was not possible; these respondents included both types of evaluative comments in their responses.

A second finding is that, with the exception once again of patients in conventional programs, relatively fewer respondents made no comment relevant to this indicator than was the case with other indicators. To facilitate further comparison of the three groups, however, respondents who made no relevant comment are excluded from the discussion that follows, and the percentages reported are adjusted accordingly.

Among the patients who made relevant comments, 80% of those in conventional programs evaluated health professionals in terms of their performance and/or perceived competence and skills, compared to 86% of those in hospice programs. Forty percent of the patients in conventional programs used ascribed criteria, compared to 29% of the patients in hospice programs. When both groups of patients who made relevant comments are combined, 83% evaluated

health professionals in terms of performance criteria, and 33% evaluated them using ascribed criteria.

Performance-oriented comments by patients included: "She knows what she's doing;" "My doctors are good, all but one;" "The nurses are good;" "They take wonderful care of you here;" "Some people have a knack for being a nurse, and some don't." Two patients described doctors who had misdiagnosed their disease, and two others commented on having received either "good" or "poor" surgical operations.

Two patients who made ascriptive-oriented remarks focused on the gender of the health professional. One stated he didn't know his doctors well because "It's hard for me to get to know men, myself." The other said, "I don't think a man makes a very good nurse." The ascriptive quality of physical strength on the part of a nurse was valued positively by a patient, and another patient felt it was a boost to have "young people interested--it gives you courage."

Among family members in conventional programs who made relevant comments, 89% mentioned achievement (performance)-oriented criteria, and 56% mentioned ascriptive-oriented criteria. Interestingly, among the hospice families, all who made relevant comments had performance-oriented role expectations; only 13% had ascriptive oriented role expectations. Combining the family groups yielded 94% of

those who made relevant comments mentioning performance criteria, compared to 36% mentioning ascriptive criteria.

Performance oriented expectations by family members concerned nurses and doctors who were (or were not) "well-trained," "skilled in handling emotional needs," "knowledgeable," "experienced," "specially trained in family reactions," who made (or did not make) a correct diagnosis, and who did (or did not) refer the patient to a specialist soon enough. Also included were comments about professionals who were "patient, easy-going type people," who had a "talent for caring for old people," who had a "tolerance for ill people," who had "personality," who were "able to work for death," who had a "compassionate capacity," who were "special people," and who had "something within...an inner warmth for it." These comments, then, focused both on medical/nursing skills and on interpersonal and personal skills and capacities.

Ascriptive-oriented expectations concerned health professionals who were "young" (too young), "immature," "older," (valued positively for their maturity), "males," (who this respondent felt should not provide personal care), who "had their degree," and who were (or were not) intelligent.

All of the health professionals who made relevant comments, whether they represented a conventional or a hospice program, listed performance criteria. Ascriptive

criteria were mentioned by only 5% of the health professionals in conventional programs who responded, yet by 35% of those in hospice programs. A total of 21% of the conventional and hospice professionals, combined, used ascriptive criteria.

Performance-oriented expectations centered around general technical and interpersonal skills, training and experience as well as specific training and understanding with respect to death and dying, pain control, and the possible needs of terminally ill patients and their families. Having the "right personality," or the "right attitude" or being the "right type of person" was also mentioned by several health professionals, as was the need for having a "good, integrated personal philosophy of life and death" and not being afraid of death or aging, being emotionally strong and stable, being self aware, and being capable of making independent decisions. Having "spirituality" or "faith," or "being a Christian," also was mentioned by a few professionals.

Ascriptive qualities included being "intelligent," and being "credentialed" or having a degree, license, certification, or "qualifications" (e.g., R.N., or B.A.).

Indicator SA: Motivation Of Health Professional

This indicator, the first of three related to Parsons' Self-Collectivity Orientation pattern variable, concerns the health professional's relationship with the patient. Specifically, it addresses the issue of whether the health professional's welfare (self, pole 1) or the patient's welfare (collectivity or service orientation, pole 2) is paramount.

As noted in the description of the analytical model for this research (see Chapter VI), both the medical model and the hospice model appear to prescribe that professionals have a collective orientation; both models fall on the collective-oriented pole. It was earlier posited, however, that health providers in conventional (medical model) programs may be less collectivity-oriented than those in hospice programs. This was not borne out in the data, as will be discussed below. Table XLV depicts the responses of the patients, family members, and health professionals interviewed with respect to this indicator.

A look at Table XLV reveals, not surprisingly, that none of the patients or family members held an ideal expectation for health professionals to be self-oriented, that is, to consider their own self interests before those of their patients. In fact, many of these respondents specifically stated that health professionals who were doing this kind of work "simply because it's a job" or for profit

TABLE XLV
INDICATOR 5A: MOTIVATION OF HEALTH PROFESSIONAL
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

MOTIVATION OF HEALTH PROFESSIONAL	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Self (Health Professional First)	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	7	37%	14	70%	21	54%
Collectivity (Patient First)	4	44%	4	50%	8	47%	15	75%	14	78%	29	76%	13	68%	15	75%	28	72%
No Relevant Response	5	56%	4	50%	9	53%	5	25%	4	22%	9	24%	4	21%	1	5%	5	13%

* N's and percentages do not sum to 100% for the health professional group due to the mention of the need for both a self and a collectivity orientation by a total of 12 health professionals (4 conventional, 8 hospice).

motives were undesirable. Notable, once again, is the high rate of "no relevant comment" among patients (about half of the sample), and the fairly high rate among family members (about one-fourth). There appears to be little difference among patients or family members in conventional, as opposed to hospice, programs.

Among the patients and family members who did make relevant comments, there was a strong expectation for health professionals who are "helpful," who are "sincere," who are "interested in their jobs," and who give priority to patients' and families' needs and schedules, not their own. Examples of comments made by patients include: "Anything that she can do, she'll be glad to do it, willing to do it; you won't have to tell her a second time;" "Everything is for the patient;" "Some staff want a strict routine to keep order, but I find that there are people who are...willing to give their time just to be with the patient; the patient can tell if this is artificial or genuine." One man said that when he needs pain medication, "If I get a hold of one and there's a whole flock of 'em, nobody listens; if they were busy, I could understand it." These health professionals apparently are more interested in talking among themselves than serving patients, from this man's perspective. Another man reported that he had been admitted into the hospital for tests and kept over the weekend, yet no tests were done on the weekend. This was valuable time for him that he felt

was wasted in order to meet his doctor's or the hospital's scheduling needs. Another patient, too, noted with disfavor the regimentation of the hospital staff, which was suited to their needs, not his.

Family members' comments included: "They gave any help they could;" "Here they seem to take more pains to find out what to do to help you and things; a lot of it is the attitude;" "They were absolutely devoted and really went beyond the call of duty;" "They have to want to take care, to give tender loving care;" "Those people were hand-picked; they were not working for the money they were making, and that's unique;" "They gave support every way that they could; the attention they give is genuine;" "They should be interested in the person not just because of the bill;" "Too many people are in it just for a job--a way of earning a living; some would go to that extra effort to help, but for some, it was just a job;" "Nurses should do everything they can for the patient;" "Doctors shouldn't think about the money they can make;" "They'd call up Sunday and say get your wife in this afternoon, which we did several times; they'd schedule without notice to us--bone scans and liver scans;" "The doctors there have a fraternity where if somebody makes a mistake, nobody will criticize." Finally, one woman noted, "The only thing my husband complained about--he understood, but it was hard for him--the students have to learn and observe, and it was hard for him to answer

the same questions over and over again...At <hospital> there were five students in there all at one time." The priority there was teaching students, not caring for the patient, she felt.

Returning to Table XLV to examine the responses of the health professionals, it is important to note first that the sample sizes do not sum to their proper totals, nor the percentages to 100%. This is due to responses by some health professionals (four from conventional programs and eight from hospice programs) indicating that both a self orientation and a collectivity, or service, orientation are essential for the provision of quality terminal care. This was an unexpected finding, as was the finding that nearly twice as many hospice professionals indicated the need for a self-orientation, either solely or in conjunction with a collectivity-orientation. These findings are discussed momentarily.

Another difference between conventional and hospice professionals was that in response rate: one-fifth of the professionals from conventional programs compared to one-twentieth of the professionals from hospice programs made no response relevant to this indicator. In addition, hospice professionals making relevant comments tended to make a greater number of such comments than did professionals in conventional programs.

The finding that several health professionals asserted the need for a self orientation on the part of the health professional in order to assure the provision of high quality care was surprising. Responses of professionals from conventional programs who asserted the need for a self-orientation (only or in addition to a collectivity-orientation) included: "They must be able to recognize what their own needs are so it isn't just a one-sided effort;" "We pay our nurses two dollars an hour less than in the acute hospital setting; people don't live on commitment alone;" "You must take care of yourself and your own feelings; only then can you deal with patients and accept them where they are and what their feelings are;" "They'll never keep me at the salary they're paying; it's valuable experience, but I don't feel I have to sacrifice myself for the profession;" "They tell us to punch out before finishing our work for the day (due to financial constraints); no way anyone will do that;" "You feel best when you've taken care of the patient, the family, and yourself."

Hospice professionals made the following types of comments related to the need for a self orientation (only or in addition to a collectivity-orientation): "We haven't really talked about the needs of staff--the staff needs time off, support, chances for continuing education;" "Staff need to be able to ventilate;" "They have to have some kinds of outside activities other than work... (at the same time) they

must be interested not in meeting only their own needs...they need a willingness to give;" "Dealing with the terminally ill and the chronically ill is different--burnout is tremendous; it's important to keep things balanced;" "The potential for stress is very high, for burnout is very high; it's important that we help each other;" "You get so much from these people...you get more than you give."

These comments of health professionals that relate to an expectation for a self-orientation seem to point to a need for such an orientation for one of two primary reasons: for an adequate standard of living and an adequate salary, and to forestall "burnout" among staff, to enable them to give quality care to patients.

Responses of health professionals in conventional programs that were classified as indicating an ideal expectation for a collectivity orientation include: "They must be interested in the front line and want to work with terminally ill patients;" "They should have the philosophy that the patient comes first;" "With the terminally ill, staff seem to be more willing to go out of their way;" "Staff should have flexibility and helpfulness;" "The goal is to give the patient the best treatment possible; the patient is first and foremost; however, they don't always get it;" "The patient is most important;" "Meet the patient's and the family's needs, not your own;" "They should have high motivation; it's hard physical labor."

Responses of health professionals in hospice programs that reflected an ideal expectation for a collectivity orientation include: "Beware the profit motive;" "They need to want to give;" "I see people not just going the extra mile, but the extra five miles;" "They should have personal dedication and should have done some real soul-searching on why they're interested in working with these patients;" "There are an awful lot of self interests in the hospice movement; this is the single biggest problem;" "Nurses should have unselfish motives, should be able to offer people something--in listening or in physical assessment."

In summary, all three groups--patients, families, and health professionals--appear to hold an expectation that the health professional should be service-, or collectivity-, oriented. Several health professionals, however, and particularly those associated with hospice programs, note the need for a self-orientation as well; many of these professionals argue that such an orientation is necessary as a means to prevent burnout, thereby enabling the professional to be helpful to the patient, to "go above and beyond the call of duty." In other words, while there is agreement that the health professional should be oriented to serving the patient, it may be that in order to do this, the professional must meet his or her own needs as well, either first, or simultaneously. Furthermore, it could be argued that even a self-orientation for an increased salary could

ultimately contribute to the health professional's ability to provide quality terminal care in the sense that his or her morale and/or self esteem would be improved.

It should be noted that while it appears in Table XLV that none of the patients and families interviewed were cognizant of health professionals' needs and their needs to have these needs met, this is slightly misleading. Although it is true that none advocated a primarily self-orientation on the part of the health professional, a few respondents did note, albeit indirectly, that health professionals had needs, too. Such comments sometimes were made in conjunction with statements relating to Indicator 1a, Interpersonal Relationship (affective involvement) concerning the need for health professionals not to get too emotionally involved with patients for the sake of their own mental and physical wellbeing. Similarly, comments were made in relation to Indicator 2C, Availability of Care by some patients and families who noted health professionals often were not as immediately available as the patients and families would like due to understaffing and underpayment.

Indicator 5B: Interprofessional Communication

Examined in this indicator is the role expectation with respect to the need for health professionals to (1) function separately, individually, or (2) coordinate their efforts, to communicate, to work together, and/or to be a "team." Health professionals who function separately and independently are seen as self oriented (pole 1). Health professionals who coordinate their efforts and are supportive of one another are viewed as being collectivity oriented (pole 2). Table XLVI summarizes the findings with regard to this indicator.

As shown in this Table, not one of the respondents advocated a separate approach, or a self orientation; all of the persons who made relevant comments advocated communication, coordination, and consistency among the health professionals involved in a given patient's care. The number of patients who made any relevant comment, however, is very low: only two (one conventional and one hospice) responded. Over half of the family members interviewed commented on this issue, although nearly twice as many hospice as conventional family members noted the desirability of coordinated health professional efforts. This issue appeared to be most salient for health professionals themselves: 92% of them made a relevant comment (all of the hospice professionals, and 84% of the conventional professionals). As has been the case with

TABLE XLVI
INDICATOR 5B: INTERPROFESSIONAL COMMUNICATION
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

INTERPROFESSIONAL COMMUNICATION	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Separate, Not Communicating	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Communicating, Cooperating, Working Together	1	11%	1	13%	2	12%	5	25%	10	56%	15	39%	16	84%	20	100%	36	92%
No Relevant Comment	8	89%	7	88%	15	88%	15	75%	8	44%	23	61%	3	16%	0	0%	3	8%

* Percentages do not total 100% due to rounding error.

other of the role expectation indicators, hospice professionals tended to make a greater number of classifiable comments (here, to mention more types of desirable collaborative efforts) than did conventional professionals.

Of the two patients who made relevant comments, one referred positively to the "team approach" to care. The other felt frustrated because "there's so much conflict between doctors."

The responses of the five family members representing conventional programs who made relevant comments all concerned the lack of communication among health professionals. This communication gap was reported to occur between outgoing and incoming shifts of nurses within a program or between professionals from different disciplines or departments, either within or external to the given program.

Most of the comments of the family members representing hospice programs also focused on communication (or the lack thereof) among the various health professionals, often among the numerous doctors who happened to be involved in the patient's care. One man said that he had had "three of the finest doctors in the city working on" his wife, and none knew what the other was doing; one would order a bone scan, and the others would not know this and order another. He said that he finally had to go to the surgeon and say, "I

want the three of you to get together and coordinate this thing." In another case, "Altogether there were nine physicians...they did bone scans, liver scans, chemotherapy...(but) Dr. ___ was...in charge. He made recommendations and the rest followed through on it." A daughter commented on the need for communication between doctors and nurses:

Dr. ___ was willing to listen to the nurses. Sometimes there can be a communication gap. The doctor sees the patient for 10 or 15 minutes, fills out an order, and then the nurses come. Nurses care for the patients. Sometimes the nurses would see things, sometimes I would see things, and the nurses really needed to get back to the doctor in order to change something. And Dr. ___ listened to what was going on...Some doctors are unresponsive to the nurses. Hopefully doctors and nurses communicate; it should be a two-way communication...The nurse needs to take more initiative in communicating with the doctor.

This same woman also reported on communication between the home health nurses and the hospital nurses:

The other thing that amazed me was the communication system that I was able to detect and become aware of: the fact that the (home health) nurses would come in and talk to the nurses on the (hospital) floor. There were a lot of gaps filled; it was really a team effort.

Another family member, too, talked positively of the "team." One person described professionals who were open to collaboration: "If they didn't know, they got somebody who did." Finally, a family member was pleased that the doctor had arranged for home health nurses to become involved.

Health professionals in conventional and hospice programs alike talked of the desirability of positive and supportive working relationships between physicians and nurses, nurses and aides, nurses on the same shift and on different shifts, aides on the same shift, administration and staff (including physicians, nurses, and aides), the "staff" or the "team" in general, and finally, between their agency and other agencies or organizations. Most common were comments that concerned the need for: (1) all "staff" or the "team" to work together; (2) physicians who were "interested," "supportive," "involved," and "not resistive;" and (3) support for the health professionals from the administration.

Examples of the comments made by professionals in conventional programs were: "The most important thing is to have a consistent, coordinated team approach, with no disagreements;" "The doctor was real resistive...he'd come back with "She really shouldn't be at home;" "If there had been more communication between the nurse and the doctor, it would have saved a lot of bad feelings between everybody;" "There should be a consistency between everybody; there's nothing more confusing to the patients and family than if everybody has a different goal, and it's not their goal;" "Teamwork--all aides working together;" "A positive attitude of superiors toward staff;" "When other departments accommodate what I ask for and do their job;" "There was

a lot of disagreement between doctors and nurses concerning what the treatment should be for this patient."

Examples of comments made by hospice professionals include: "You have to be a team worker, very open to others; it can become a problem for burnout if you feel you are the person;" "Staff should be philosophically together;" "They should work well with others and feel comfortable with other nurses taking calls on their patient;" "We have a good working relationship with the doctors;" "Getting the general duty nursing person involved, understanding what hospice care is;" "We try to keep in good contact with the patient's physician so they know what's going on;" "Communication between doctors, the community, the hospice nurses...Doctors are finally beginning to understand it's not a personal affront for one of their patients to die; some are beginning now to work as a team with the nurses;" "Getting the doctor involved, the authority figure (to the patient) who says things are going well;" "Good care is a very fluid and cooperative team effort, where each relevant discipline is aware or made aware of how they may help;" "The staff supports each other; there's no bickering; personal problems are solved right away;" "One problem is with other agencies: there seems to be a lot of territoriality, holding onto space;" "The administration is supportive, open;" "The hospital has provided lots of care that's not paid for--if I ask for it, I'll get it, if it's needed for patient care:"

and "We have an administration who knows the program and its philosophy, who backs up the staff by giving extra staff, who trusts staff judgments, and who provides a caring atmosphere."

Indicator 5C: Interprofessional Decision-Making

Closely interrelated with Indicator 5B (Interprofessional Communication) is this indicator which concerns the role expectations with respect to the status relationship between health professionals. As discussed in the previous section, within the responses relevant to Indicator 5B that were made by a few families and several health professionals is evidenced a strong conviction with respect to the need for health professionals to relate well with one another. Several comments pertained to the ideal expectation that doctors should listen to and work cooperatively with nurses. Included among many of these comments were statements about the roles and authority of physicians and nurses in actuality as compared to the ideal. It may be recalled that no respondents seemed to feel that health professionals should not communicate and coordinate their efforts. At the same time, there is the question of who should make the final decision, who should be in charge. Should the decision be made as a group or team, or by an individual, usually a physician? This indicator looks at

those comments that dealt specifically with this question of decision-making and authority.

In the medical model, the physician clearly is the authority figure in both the ideal and the real sense. In the holistic model of care, ideally all disciplines involved have equal input to decisions, and the decision is made as a group. In pattern variable terms, the team approach could be seen as a collectivity orientation; the hierarchical, single professional as decision-maker approach could be viewed as self-orientation.

In most instances, the comments made by respondents focused on authority and decision making in the nurse-physician relationship, although a few related to the administration-staff relationship or the nurse-aide relationship. Table XLVII displays the findings that concern this indicator.

A note is in order with regard to the classification of comments as representing an ideal expectation for either group/team decision making or hierarchical, single professional decision making. The distinction between the two categories is one of degree and emphasis. Among respondents whose comments were classified as advocating group decision-making, there still was clear, usually stated, acknowledgement of the continued primacy of the role of the physician. That is, while these respondents' ideal was one of physicians cooperating with nurses, following

TABLE XLVII
INDICATOR 5C: INTERPROFESSIONAL DECISION-MAKING
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

INTERPROFESSIONAL DECISION-MAKING	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Single, Independent, Hierarchical	0	0%	0	0%	0	0%	4	20%	2	11%	6	16%	7	37%	0	0%	7	18%
Group, Team, Egalitarian	0	0%	0	0%	0	0%	0	0%	3	17%	3	8%	7	37%	14	70%	21	54%
No Relevant Response	9	100%	8	100%	17	100%	16	80%	13	72%	29	76%	5	26%	6	30%	11	28%

* Percentages do not always total 100% due to rounding error.

through with nurses' recommendations, there continued to be acknowledgement that physicians "write the orders;" the ideal, therefore, was to get the physician or administrator to write orders based on and following the assessment and recommendations of the nurse. Similarly, respondents' whose remarks were classified as indicating a preference for a single decision-maker or authority figure did not advocate that this decision-maker make treatment decisions in a vacuum; they simply felt that responsibility and control should rest with this one person.

As shown in Table XLVII, none of the 17 patients interviewed, and only about one-fifth of the families, made specific comments with respect to who should make decisions in their care. This was surprising, in that the sense obtained when reading the interviews was that a majority of both patients and families clearly placed their doctor(s) in the role of decision-maker and considered their doctor as the most important health professional. This sense may be due in part to the number of patients and families who expressed a desire for the doctor to visit the patient frequently, as discussed in the section describing the findings with respect to Indicator 2C: Availability, where these comments were classified.

Among the families who did make comments classified here, all four family members from conventional programs seemed to express an ideal, or at least accept that the

physician be the decision-maker, be in charge. These respondents noted that "The nurse should follow the doctor's orders," "The nurse was authorized by the doctor to do that," and that "Nurses can't do some things, like write a prescription for catheter."

The families representing hospice programs and who made relevant comments were divided in their ideals. Two expressed a preference for primacy on the part of the physician (e.g., "Nurses should follow doctors' orders"), while three family members seemed to prefer a more egalitarian approach either between physicians and nurses or among the nurses involved in a case. One of these three was quoted in the previous section describing the findings with respect to Indicator 5B, where it was noted that she said, "Some doctors are unresponsive to the nurses. Hopefully doctors and nurses communicate; it should be a two-way communication." The second family member commented with admiration that "The nurses communicated with the doctor; they weren't afraid or anything!" The third family member whose response was classified here commented on the fact that the private duty nurses she had hired had felt that the home health nurses of the agency that was involved had "looked down on" them, and that she felt this status differential was inappropriate.

Nearly three-fourths of the health professionals interviewed made comments that were classified here, and

those who did not were divided fairly equally between those representing conventional programs and those from hospice programs. The expectations of the health professionals did appear, however, to be associated with the type of program they represented--conventional or hospice. While all of those from hospice programs who made relevant comments expressed group or egalitarian decision-making as their ideal, those from conventional programs were split equally in their ideals for egalitarian vs. hierarchical authority and decision-making.

Ten of the professionals in conventional programs commented specifically on the physician-nurse relationship, with four indicating that one person (and implying this person should be the physician) should be the decision-maker and six expressing a preference for a more egalitarian relationship between the physician and the nurse. Examples of the comments classified as indicating a single person decision-making approach included: "There should be a primary caregiver who coordinates care;" and that of a physician, who stated:

There should be a core of nurses who will see to it that the guidelines established by the physician are handled properly...If a committee makes decision rather than a person, it is my opinion that the end result will suffer. The best system is where a single, senior, mature person is in charge and authority is delegated in that manner.

Examples of comments indicating egalitarian relationships as the ideal include: "We have to have signed

doctor's orders for all services at all times; we can't even give a bath without doctor's orders;" "This doctor finally did come around, after good documentation and constantly bringing the problem to his attention;" "Doctors usually are very good, accepting our assessment and recommendation... Good care is having adequate doctor's orders to handle the situation." Also included were the following statements by two nurses:

In the hospital, I never felt as free to suggest a lot of things as I do here because you have to check with doctors frequently about orders before you do anything. Here, many times...again, they have to rely on me--physicians aren't seeing them;, and they really have to rely on your assessment of things and what you think ought to be done...The independence that comes with home nursing makes it easier.

The nurses' input is really very important and well-synthesized in making a decision, but it is the ultimate decision of the physician...Here, it's not at all a dictatorship, it's not at all the kind of hospital where the physician comes in, writes his orders, and doesn't talk to the nurses. I don't stand up when a doctor walks into the room. I call them by their first names, they call me by my first name, unless it's a staff physician, which I call by their last name, Dr. ___, out of respect, and they call me Mrs. ___.

Four professionals in conventional programs commented on the relationship between the administration and the staff, one of whom noted that an egalitarian relationship is preferable: "I try not to ruffle staff by overriding them...we have good relations here, and I don't want to hurt them." The other three seemed to accept and feel comfortable with the administration-staff hierarchy.

Following are some of the comments made by hospice professionals, all of whom espoused the merits of egalitarian relationships between (1) physicians and nurses, (n=11), (2) between nurses and aides (n=3) and (3) between the administration and staff (n=1).

When a patient is uncomfortable, it is very frustrating. There is not much you can do without a physician's order...Whether he will accept our (nurses') suggestions depends on how secure he is.

It's been real exciting because we see things that need to be done here and we can get an order for them...Letting doctors know that the medication isn't adequate, and their being real good with their assessments and following through with our recommendations.

As Medical Director, I don't look at myself as "top dog" as they do in England. In meetings, I rely on other members. By law, I ultimately make decisions, I have to write the order. Usually the team tells me enough.

Our team meetings are headed by the (nurse's) aide because they're in direct contact with that person and can be very influential in what happens to the person. Also, they are one of the best resources in terms of information about the person.

Additional comments included: "There's no hierarchy in our team; I don't see it at all;" "The administration treats the staff as equals;" "The physician is always the final decision-maker in the hospital...the idea is to get him or her to write an order;" "Nurses get burned out and frustrated by the demands of doctors."

What is clear from the statements made, particularly those of health professionals themselves, is the continued primacy, in reality, of the role of the physician. As one

respondent said, "The doctor in our society still has the golden word." This was the case regardless of the ideal expressed, and appears to be a result of the physician's sole legal authority to perform certain tasks, such as the writing of prescriptions and orders.

Furthermore, it appears to be precisely because of their legal authority, specifically in the arena of the writing of prescriptions and orders, that many respondents feel the doctors' working as a team with the nurses is critical. If, for example, prescriptions for appropriate and adequate pain medication cannot be obtained, from the point of view of many health professionals and family members, the quality of care that can be given to the patient is seriously jeopardized. Recall the statement made by the daughter (quoted in the previous section, Indicator 5B) concerning how much and why she appreciated the doctor who would listen to the nurses' recommendations concerning her mother's care. The rationale for minimizing hierarchy between RNs and aides and between administration and staff is similar.

Indicator 5D: Professional-Patient Continuity

This indicator was created after the Analytical Model had been developed because a satisfactory category for comments that addressed respondents' ideals and preferences with respect to the continuity of the professional-patient relationship could not be found. As expressed in the comments of respondents, the ideal could be either: (1) for different professionals to be involved in a given patient's care, or (2) for the same professionals to be involved throughout a patient's care. It is posited that the latter option represents a collectivity orientation, and the former, a self-orientation, in that the principal reason for having different professionals involved, at least as described by these respondents, is protection (decreased stress) of the health professional.

Table XLVIII summarizes the responses of those interviewed. The response rate was not high for any of the three respondent groups: only 6% of the patients, 26% of the families, and 54% of the health professionals made relevant comments. Nonetheless, the issue of continuity seemed very important to those who did raise it, and it was decided that the issue should be examined separately.

Only one patient, who happened to be in a conventional program, made a comment relevant to the notion of professional-patient continuity. This man noted, "At

TABLE XLVIII

INDICATOR 5D: PROFESSIONAL-PATIENT CONTINUITY
SUMMARY OF RESPONSES
BY RESPONDENT GROUP *

PROFESSIONAL-PATIENT CONTINUITY	PATIENTS						FAMILIES						HEALTH PROFESSIONALS					
	Conventional (n=9)		Hospice (n=8)		TOTAL (N=17)		Conventional (n=20)		Hospice (n=18)		TOTAL (N=38)		Conventional (n=19)		Hospice (n=20)		TOTAL (N=39)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Same Professionals	1	11%	0	0%	1	6%	5	25%	5	28%	10	26%	10	53%	9	45%	19	49%
Different Professionals	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	1	5%	1	5%	2	5%
No Relevant Comment	8	89%	8	100%	16	94%	15	75%	13	72%	28	74%	8	42%	10	50%	18	46%

* Percentages do not always total 100% due to rounding error.

(hospital), they assign me one doctor, and he graduates, and I get another with a radically different opinion."

Five family members in conventional programs made similar comments, one of whom was a relative of the patient above. This man stated:

At (hospital), they have too much of a personnel change. I've never spoken to the same doctor twice in a row. They come and go...I must have discussed his case with six or seven doctors when he was there.

The other family member was not particularly pleased with the fact that "There were different home nursing girls every time, except one who came twice; they said they like for them all to be familiar with the cases."

Of the five family members in hospice programs, one stated: "They rotate the teams quite a bit in the hospital, and I wonder about that; about the time they get familiar, they get moved." Another family member who was from an isolated rural area but had moved to Portland when her husband became critically ill stated:

The government sends doctors down there; they don't seem to stay too long; they stay a year or so and then they're gone...We lived there 34 years. I can remember the names of 22 doctors. So that's the big problem down there: having dependable doctors.

The remaining family members in hospice programs who made relevant comments noted with favor that "the same nurses were there the whole time" that their family member had been ill.

A somewhat greater number of health professionals in conventional programs (58%) than in hospice programs (50%) made comments relevant to this issue of professional-patient continuity. Most interesting, however, is the fact that two of these professionals (one in a conventional program and one in a hospice program) advocated the use of various different professionals (but of the same discipline--specifically, nurses) in the care of a given patient. As described above, this ideal was conceived as representing a self-orientation. In one of these two cases, this conception seems correct, at least in part. The hospice nurse explained:

We rotate every two weeks to avoid burnout; some patients require heavy physical care. Plus we get better insight into how to help patients if more than one nurse sees them. At first, this caused a lot of controversy, but we found that by changing every two weeks, giving good report (we take report on all patients every day), keeping up constantly with all, it works better..."

The other nurse (in a conventional program) commented similarly: "More than one R.N. sees the patient so all staff know all the patients." It should be pointed that this latter program is the one referred to by one of the family members quoted above.

Among the health professionals whose ideals were for the same staff to see a given patient, staff turnover and its contribution to lack of continuity was mentioned by a total of five health respondents (four in conventional

programs, and one in a hospice program). As one of these health professionals noted, a barrier to quality care is "not being able to find enough staff; it's difficult to maintain continuity of patient care without staff." Perhaps not surprisingly, all of the respondents who made comments of this nature were in administrative positions.

Eleven professionals (four in conventional programs and seven in hospice programs) noted that having the same professionals involved throughout a patient's care was valuable for (1) establishment and maintenance of patient trust and/or (2) giving professionals enough time to perform their jobs adequately. Some of the comments made by professionals in conventional settings were: "The ideal would be to be able to follow them during all of their care, no matter what the setting;" "Being able to follow a patient for weeks and weeks leads to a lot of trust;" "The patient should have the same nurse when he comes back to the hospital...One woman we have now is very angry, won't say anything; if someone had known her from the beginning, she might trust them with her emotions;" "It's best when we (home nursing team) get called in when we should be called, when we get involved before a crisis occurs."

Similar comments by hospice professionals included:

Patients have to see so many different staff; continuity is difficult here. The ideal would be to have one primary nurse and one other, on an emergency basis; the second nurse could be a floater.

The problem is continuity; it's more appropriate to be followed up by the same staff. Ideally, we should structure care to make continuity possible, maybe through a ten-hour day.

One negative case was where we were not able to help the patient or his wife because the timing of the referral was inappropriate. The man died in 24 hours, and the wife was hysterical--"We failed to do anything to cure his cancer." She didn't understand the program; evidently their physician hadn't explained it or had done so poorly...We can't do much of anything for anybody that comes in actively dying, except medical. If we see pain we can maybe remove it before the person actually dies, but that's it. We have no time to build up a relationship with the survivors, the family, no time to build rapport, trust, so that we can practice our skills."

The remainder of the comments made were similar to the following: "Staff having days off blows continuity; the patient and the family don't understand when someone else is caring for the patient."

Summary

Indicator 1A: Affective Involvement. Because the typical bipolar designation for respondents' comments used in the other indicators seemed inadequate in this case due to the loss of too much detail, four categories forming a continuum of affective involvement were developed. Also, it should be remembered that respondents gave multiple responses; that is, some respondents held expectations relevant to two or more of the categories.

Responses relevant to this indicator were given by 88% of the patients, quite a high rate of response compared with that of the other indicators. Patients' expectations centered around professionals being pleasant and cheerful (category B) and being warm and caring (category C). Family members' expectations, too, were concentrated in these two categories, but the pattern of response was different: the expectation that the health professional be warm and caring (category C) was mentioned more often than was the expectation that the health professional be pleasant and cheerful (category B). In addition, a greater percentage of families mentioned the desirability of professionals who would treat patients as though they were family members, who would give them love, and who would get emotionally involved (category D). Families' expectations, especially those of family members whose relative was being cared for in a conventional program, then, were for somewhat more affect

and emotional involvement than were patients'. Health professionals' expectations for professionals in the role of provider of terminal care were for even greater emotional involvement than expected, or hoped for, by family members. It seems that health professionals may put more pressure on themselves to establish a more personal relationship with the patient than is expected by either families or patients.

Family members mentioned the greatest number of categories of affective involvement, followed by patients and then by health professionals. This issue, then, appeared to be of particular salience to family members.

Each of the levels of affective involvement has its drawbacks or risks as well as its benefits, according to respondents. Specifically, category A of affective involvement, or polite distance, generally was felt by each of the three groups to be inadequate for the provision of quality terminal care. At the same time, health professionals who are too bubbly and cheerful (category B), who share too much information about themselves, thereby burdening the patient or family (category C), or who are too emotionally involved with their patients (category D) are viewed unfavorably, at least by some respondents.

Expectations by subgroup (conventional compared to hospice) did not differ substantially for patients or health professionals, although health professionals in hospice

programs were slightly more likely to mention the highest category of affective involvement (D). Family members in conventional programs made more mention of each of the four categories of affective involvement than did family members in hospice programs.

Indicator 2A: Scope Of Care. The ideal expectation held by the majority of all three groups was for psychosocial care needs of patients to be met as well as their physical needs. All of the health professionals and nearly all (97%) of the family members interviewed made comments relevant to this issue, compared with 65% of the patients. Talking, and especially encouragement from the health professional was desired by patients and families, although not all seemed to feel they can expect busy doctors and nurses to sit down, talk with, and encourage the patient. A few patients and family members but none of the health professionals focused exclusively on the physical aspects of care. Not all patients and families, then, expect and/or are aware of the possibility that doctors or nurses could meet patients' psychosocial needs as well as their physical needs. Indeed, disparity between the ideal and the real was particularly evident in the remarks of several health professionals and some family members who lamented professionals' lack of time to adequately address patients' psychosocial needs.

Interestingly, patients in conventional programs were somewhat more likely to expect or wish for certain psychosocial needs to be met by health professionals than were patients in hospice programs. There were no sub-group (hospice-conventional) differences among the family members or the health professionals interviewed.

Indicator 2B: Unit Of Care. Of the patients, family members, and health professionals who made comments relevant to this issue, all but one (a patient) felt that families as well as patients had needs that should be addressed by the health professional. The types of needs of families mentioned by patients (in order of frequency of mention) included needs for interest and concern, for emotional support, and for help in general. The types of needs mentioned by families included those for emotional support, information on resources, information on the patient's condition, and for interest and concern for the family's well-being. Health professionals most frequently mentioned families' needs for emotional support, help in general, and bereavement support. Patients as a whole had a particularly low rate of response with respect to this indicator (41%) compared with 84% of the family members and 95% of the health professionals.

When respondents in conventional programs were compared with those in hospice programs, a number of differences were evident. First, patients, family members,

and health professionals in conventional programs were considerably less likely to make any comment with respect to this indicator than were those in hospice programs. This was true especially among patients and families. Because of the low rate of response for patients in conventional programs, further comparison of the subgroups (conventional-hospice) of patients cannot be made.

Second, the types of needs of families mentioned by family members and health professionals in conventional programs differed in breadth, or quantity. Third, the types of needs mentioned differed substantively. That is, family members and health professionals in hospice programs mentioned more and different types of family needs than did those in conventional programs. In sum, it appears that respondents in hospice programs have greater expectations with respect to health professionals' meeting families' as well as patients' needs and that these respondents are more attuned to the needs of families than are those in conventional programs.

Indicator 2C: Availability Of Care. The majority of the patients, family members, and health professionals held the ideal role expectation that the health professional providing terminal care should be available to patients, responding promptly to patients' calls, checking frequently on patients, and otherwise spending time with patients or being available to them. Again, many patients (41%) did not

make a comment relevant to this issue. Family members, in particular, commented with respect to the physician's availability. The comments of two family members were classified as indicating an expectation for limited availability on the part of the health professional: one person felt the home health nurses came too often, and the other did not feel it was appropriate nor did she expect the nurse to spend a lot of time in intellectual discussions with her husband (the patient).

Patients in conventional programs were somewhat less likely to make a relevant comment than those in hospice programs, and slightly fewer health professionals in hospice programs commented on this issue than did those in conventional programs. Among those respondents who did make a relevant comment, patients, family members, and health professionals in hospice programs were somewhat more likely to mention an expectation for 24-hour availability of health professionals.

With respect to this indicator, as with others, the actual or real situation seemed to differ from the ideal expectations. Reports especially by families and health professionals indicate that health professionals often are rushed and unable to spend the amount of time they would like taking care of their patients, due primarily to inadequate staffing and, to some degree, paperwork and documentation requirements. A few families who visited

often with their ill relative expressed concern that the presence of the family might lead to less checking on that patient by the health professional.

Indicator_3A:___Care_Approach. Only 35% of the patients made comments relevant to this issue, 71% of the families, and 79% of the health professionals commented. These rates are low for each of these groups compared with their rates of response to other of the indicators. All but one of those who did have a response, however, expressed an ideal expectation for individualized as opposed to generalized care. The remaining respondent was a patient who seemed to accept the fact that she was "not the only patient" and could/should not expect to receive special treatment. The rate of response did not differ between subgroups (conventional and hospice).

Indicator_4A:___Treatment_Goal. This indicator yielded greater disparity between the respondent groups than did the others. The response rate also was higher, especially for patients: 71% of the patients, 84% of the family members, and 92% of the health professionals made a relevant comment. The majority (66%) of the patients who responded expected cure or life prolongation (pole 1) from the health professional; they hoped to get better. Almost 41% of the family members indicated that they expected that treatment should be aimed at life prolongation or maintenance or cure; many continued to hope for "a miracle." Only two health

professionals (both in conventional programs) held an expectation for treatment to continue to be aimed at cure or at least life prolongation.

Not surprisingly, patients, families, and health professionals in conventional programs were more likely than those in hospice programs to expect a treatment goal of life prolongation or cure. More interesting is the finding that some patients and family members in hospice programs still hoped for cure or life extension. Even most of those who felt that a treatment goal of comfort and quality of life was most appropriate in their situation held onto a bit of hope for cure and continued to expect the health professionals to "encourage" the patient, "because sometimes there are miracles."

There was no difference in response rate between patients in conventional programs compared with patients in hospice programs. Family members in hospice programs were slightly less likely to respond than family members in conventional programs. Each of the three health professionals who made no comment relevant to this issue of expectations concerning the goal of treatment were working in a conventional program.

Indicator 4B: Pain Control Practices. The three groups of respondents were divided between the medical model and the hospice model approaches with respect to their expectations concerning appropriate pain control practices.

Of the patients who addressed this issue, 55% felt medication should be given on an "as needed," intermittent basis, and 45% felt it should be given at regular intervals, if such medication were necessary. Family members were evenly split between the two approaches. The majority of the health professionals expressed an expectation for administration of pain medication at regular intervals. About 65% of the patients, 84% of the family members, and 90% of the health professionals made comments relative to this indicator.

The expectations of patients in conventional programs did not appear to differ from those in hospice programs, although patients in conventional programs were somewhat less likely to comment with respect to this issue of pain control practices. Family members did not differ by subgroup (conventional compared with hospice) either. Health professionals, however, did differ, with professionals in conventional programs being more likely than those in hospice programs to hold an ideal expectation for pain medication to be administered on an "as needed" basis only.

Certain themes which emerged in respondents' comments with respect to this area of appropriate pain control practices were: (1) patient or family reluctance to take pain medications due to fears of drug dependency or reduced effectiveness; (2) the importance of not overmedicating or

"snowing" patients; (3) the belief by some patients and families that "the doctor knows best" and whatever practice is recommended by the doctor is that which should be followed; (4) the belief that the patient's preferences with regard to pain control practices should be ascertained and respected; (5) the need to recognize the existence of different kinds of pain, such as psychological or spiritual pain, and to understand that physical pain control practices will be ineffective in controlling these types of pain; and (6) the fact that some health professionals resist giving adequate (effective) amounts of pain medication due to their fears of the patient's becoming dependent on the drugs.

Indicator 4C: Patient Involvement. To enable a more complete description of the data with respect to this indicator, three subindicators were developed: the provision of information to patients regarding diagnosis and prognosis; the provision of information to patients regarding treatment options and resources; and willingness to allow patients some input into care-related decisions. Just over 70% of the patients interviewed commented with respect to one or more of these three subindicators. Over 90% of the family members and 87% of the health professionals made a relevant comment.

Patients' comments were concentrated in the areas of health professionals' willingness to allow patients some input in care-related decisions and the provision of

information about their disease and prognosis. Family members and health professionals commented most often with respect to the professionals' willingness to allow the patient some say in his or her care, then the provision of information about diagnosis and prognosis, then the provision of information about treatment options and available resources. Family members commented more about this latter type of information than did health professionals or patients.

Very few respondents had an expectation that the health professional should definitely not involve patients in their own care through the provision of either of the types of information or through the professional's being willing to allow patients some say in care-related decisions. The exception was that 25% of the family members in conventional programs expected that the health professional (usually the doctor), not the patient, should make care-related decisions. Also, if the "no" and "maybe, depends" categories are combined, family members, especially those in conventional programs, expressed ambivalence with respect to patients being given information concerning their diagnosis and prognosis. Family members and health professionals in hospice programs were more likely than those in conventional programs to discuss involvement of patients in their care through the provision of information on treatment options and resources and through health

professionals being willing to allow them some input. The three respondent groups differed somewhat, then, in the ways in which they expected patient involvement in the care, but generally did expect that patients should be involved.

A substantial number of respondents in each of the three groups designated the physician as the preferred purveyor of information to patients. Some family members and health professionals noted that elderly patients, in particular, tend to be reluctant to make their wants known, to take an active role in their care. Several respondents within each of the three groups reported instances in which desired information had not been provided to the patient; the actual situation had differed from their ideal expectations. A few respondents from inpatient programs, conventional or hospice, indicated that patient involvement in the care is more difficult in inpatient environments. Finally, it was clear that health professionals, regardless of the type of program they were in, experienced personal difficulty when patients made decisions that were at variance with what the health professional felt to be in the patients' best interests.

Patients in conventional programs did not appear to hold expectations different from patients in hospice programs except that fewer patients in hospice programs commented regarding their expectations concerning health professionals' willingness to allow patients some say in

their own care. Most patients did not appreciate being "bossed" or "forced" to do things. Family members in conventional programs were somewhat less likely than those in hospice programs to hold an ideal expectation that patients should definitely be involved through the provision of information to them concerning their diagnosis and prognosis and were more likely to feel that care-related decisions should be left to the health professional. Health professionals in hospice programs were somewhat more likely to hold expectations that patients should be given information about their treatment options and available resources and that health professionals should be willing to allow patients say in their own care than were health professionals in conventional programs.

Indicator 4D: Family Involvement. "Involvement" of the family was operationalized to include three subindicators: provision of information (diagnosis, prognosis, treatment options and techniques, and available resources); letting the family have some say in the patient's care; and actively encouraging family participation. Only 35% of the patients interviewed commented with respect to any of these three subindicators, compared with 87% of the family members, and 90% of the health professionals. The issue did not appear to be a salient one for patients.

The patients, family members, and health professionals who responded generally favored family involvement in each of the three ways (provision of information, family say in the care, and active encouragement to participate). More family members commented with respect to their expectations for information from the health professional and their expectations to have some say in the care than did either health professionals or patients. More health professionals than family members discussed their expectations concerning active encouragement of family involvement.

Family members and health professionals alike noted the difficulties posed by families who were overly critical. Also, members of each of these two groups noted situations in which active encouragement of family participation in the patient's care was not desirable, such as when family members are unable to provide care due to their own poor health or because of conflicting demands imposed by their own immediate families. These respondents stipulated that families should not be made to feel guilty if they are unable to be extremely involved in the patient's care. A few family members offered another reason for less family involvement: they felt that their presence detracted from the amount of care and attention received by the patient from the health professionals.

Patients in hospice programs were somewhat more likely than those in conventional programs to comment with respect

to two of the subindicators of family involvement. Family members in conventional programs were somewhat more likely to discuss expectations in the areas of provision of information to the family and family say in the patient's care than were family members in hospice programs. Family members in hospice programs, however, were more likely to expect that the health professional allow the family some say than were family members in conventional programs. Hospice professionals were somewhat less likely than those in conventional programs to discuss the provision of information to family members and the active encouragement of family participation in the patient's care. All hospice professionals who commented on the issue of family say in the care favored letting families have some input; while most of the professionals in conventional programs favored this also, not all did.

Indicator 4E: Volunteer Involvement. This indicator received the least amount of attention of all the indicators. Only one patient and four family members, all from hospice programs, commented on the use of volunteers. Four health professionals in addition to the ten program administrators (who were asked directly about their use of volunteers) discussed the use of program-affiliated volunteers. Each of these four was from a conventional program, and each favored volunteer involvement. Each of the five hospice program administrators favored the use of

volunteers and had volunteer components in their programs. Two of the five conventional program administrators favored and used volunteers in their programs, two others favored the use of volunteers (although one of these programs made use of volunteers provided by another agency), and the fifth noted that her agency was opposed to the use of volunteers. Because of the amount of training typically undergone by the volunteers who were involved in patient care, consideration of these individuals as purely "lay" workers is somewhat inaccurate.

Indicator 4F: Criteria For Evaluating The Health Professional. With the exception once again of patients in conventional programs, the rate of response with respect to this indicator of role expectations was fairly high: 71% of all patients, 89% of the family members, and 92% of the health professionals made some relevant comment. In fact, several respondents used both performance-oriented and ascriptive criteria. The majority of all three groups used performance-oriented criteria.

Family members in conventional programs were much more likely to use ascribed criteria than were those in hospice programs. Among the health professionals, while all of the hospice professionals expected that the health professional should be evaluated on the basis of performance-oriented criteria, seven (35%) also used ascriptive qualities, compared to only one (5%) health professional in a

conventional program. Among the patients who gave a relevant response, the expectations of those in conventional programs did not appear to differ from those in hospice programs. Considerably fewer patients in conventional programs than in hospice programs, however, made a comment relevant to this issue.

Indicator 5A: Motivation. Only 47% of the patients, 76% of the family members, and 87% of the health professionals interviewed gave responses that addressed their expectations concerning the appropriate motivation (self or collectivity) of the health professional providing terminal care. Not surprisingly, all three groups held an expectation that the health professional should be motivated to serve the patient. None of the patients or family members who responded felt that the health professional should be motivated to meet his or her needs first, and then those of the patient.

Several of the health professionals, however, indicated that both a self orientation or motivation and a collectivity orientation were essential for the provision of quality terminal care. Over half of the health professionals interviewed described ways in which they felt the needs of the health professional had to be met first, or at least simultaneously with those of the patient. This was an unexpected finding and was related to a belief that if the health professional was to be able to meet the needs of

terminally ill patients, his or her own needs (including those for emotional support and stress reduction in order to forestall "burnout," as well as those for an adequate standard of living and an adequate salary) had to be met. In fact, twice as many health professionals in hospice programs compared with those in conventional programs advocated a self-orientation. Another difference between health professionals in hospice programs and those in conventional programs was the slightly lower response rate on the part of health professionals in conventional programs.

Indicator 5B: Interprofessional Communication. All of the respondents who made a comment relevant to this issue expected that health professionals should communicate, coordinate, and collaborate with each other. The number of patients who commented, however, was very low (two, or 12%). The issue was only somewhat more salient for family members, 39% of whom made a relevant comment. Nearly all of the health professionals (92%) commented with respect to this issue.

The only within group differences appeared among families. Twice as many family members in hospice programs compared with those in conventional programs made a relevant comment.

Indicator 5C: Interprofessional Decision-Making. This issue was addressed by none of the patients and by only

24% of the family members interviewed. Just over 70% of the health professionals made a relevant comment.

Of those respondents who made a comment relevant to this issue of expectations concerning decision-making and authority, the majority of the family members felt that the hierarchical approach, with the physician as decision-maker, in charge, was appropriate. The majority of the health professionals who responded held an ideal expectation for an egalitarian approach.

Family members in hospice programs differed from those in conventional programs; a majority of those in hospice programs expressed a preference for an egalitarian approach, while all of those in conventional programs favored, or at least accepted, the hierarchical approach. There were differences among the two subgroups of health professionals as well. Respondents from conventional programs were evenly split in their preferences, while all of those from hospice programs voiced expectations for the egalitarian approach.

Indicator 5D: Professional-Patient Continuity. Only 6% of the patients, 26% of the family members, and 54% of the health professionals commented with respect to this issue of whether they held expectations for (1) the same professionals to be involved in the patient's care or (2) different professionals to be involved. All but two of those who made a relevant comment (both health professionals, one from a conventional program and one from

a hospice program) favored involvement of the same professionals in the patient's care.

There appeared to be little difference within groups with respect to their rate of response, or comment, on this issue.

RESEARCH QUESTION 3: HOW DO THE ROLE EXPECTATIONS OF
PATIENTS, FAMILIES, AND HEALTH PROFESSIONALS FOR THE
PHYSICIAN AND NURSE PROVIDER OF TERMINAL CARE
COMPARE WITH THE ROLE EXPECTATIONS TO WHICH
PHYSICIANS AND NURSES ARE SOCIALIZED?

The following paragraphs compare the findings from Research Questions 1 and 2 for each indicator.

Indicator 1A: Affective Involvement

Four categories of affective involvement were developed to better describe the empirical data provided by the study participants concerning their expectations with respect to affective involvement of the health professional with the patient. Some respondents made comments that addressed more than one of these categories. In order to compare respondents' expectations with those expectations learned and held by professionals, as reported in the socialization literature, this four-category scheme must be collapsed into the bipolar scheme used in the majority of the indicators

If category A (being courteous, polite, with no involvement) is considered as pole 1 (neutral affect, medical model) and categories B (pleasant, nice, cheerful), C (warm, caring, compassionate), and D (loving, treating the patient as family, very personally involved) are considered as pole 2 (positive affective involvement, holistic model),

it is clear that, regardless of their multiple responses, patients, family members, and health professionals all expected some degree of affective involvement on the part of the health professional providing quality terminal care.

Both the socialization literature and some study participants, however, cautioned against health professionals' becoming overly involved with patients (Category D). At the same time, 41% of the health professionals, 34% of the families, and 29% of the patients still expected, or hoped for, this level of affective involvement. It is interesting that health professionals expected a greater degree of affective involvement than families, and families expected more affective involvement than did patients themselves.

The analysis of the literature on socialization of physicians and nurses yielded the findings that: (a) physicians reportedly are not socialized to be affectively involved with their patients; physicians receive little training in interpersonal skills (medical model); and (b) nurses sometimes receive training in interpersonal relations with patients, but simultaneously learn the value of "professional distance" (that is, absorb both models). Respondents' ideal expectations for the health professional providing terminal care appear, therefore, to conflict with the norms and values to which physicians, especially, but also nurses, to some degree, are socialized.

Indicator_2A: __Scope_Of_Care

The ideal expectation held by the majority of the respondents in each of the three groups (patients, family members, and health professionals) was for psychosocial care needs of patients to be met as well as their physical needs (holistic model). According to the literature reviewed, however, physicians are socialized to address primarily patients' physical needs (medical model). Nurses appear to receive conflicting socialization, learning on the one hand that patients have psychosocial needs, but not receiving, on the other hand, specific training with respect to how to meet these needs. Also, many nurses find upon entry in the workplace very little, if any, time to devote to meeting patients' psychosocial needs (both models).

The problem of professionals' lack of time to address these additional, non-physical needs was apparent in the remarks of several of the study participants, also. Health professionals, in particular, were careful to note the frequent disparity between their ideal expectations and the real constraints. Even patients and families differentiated between their ideals and what they viewed to be realistic, making comments indicating "appreciation" if the health professionals took time out to talk (and meet patients' psychosocial needs), but showing reluctance to stipulate that the "busy doctors and nurses" should do this.

It appears that respondents' ideals for patients' psychosocial needs to be met as well as their physical needs conflict to some degree with the role expectations to which physicians and nurses are socialized. At the same time, there was not a clear imperative from patients and families, at least, to actually have these ideal expectations met; first on most of their minds was the need for patients' physical needs to be adequately addressed. Expansion of the scope of care to include addressing patients' psychosocial needs, while desirable, may be of less importance to patients and families than certain other issues.

Indicator 2B: Unit Of Care

All but one (a hospice patient) of the study respondents who addressed this issue felt that families as well as patients have various needs that should be attended to by the health professional (holistic model). The rate of response for the three groups, however (41% for patients, 84% for families, 95% for health professionals), may be significant here, especially considering that the majority of those who made no relevant comment were from conventional programs and, therefore, might be less likely to include the family in the unit of care.

The review of the physician socialization literature revealed a relative lack of attention to this issue. Those sources that did address it generally reported that

physicians hold role expectations consistent with the medical model: the patient is the unit of care. The nurse socialization literature that was reviewed indicated a similar lack of attention to this issue of the appropriate unit of care. Those sources addressing the issue indicated conflicts in the socialization received (both models).

Respondents' stated expectations, then, appear to conflict with those to which physicians and nurses are socialized. The lack of attention to this indicator by patients in conventional programs, however, raises the question of its salience to this group. A lack of comment may even indicate an expectation that only the patient should receive care. A similar conclusion may be drawn with respect to the role expectations learned by physicians and nurses, based on the lack of attention to the needs of families in the physician and nurse socialization literature.

Indicator 2C: Availability Of The Health Professional

All but two (both hospice family members) of the respondents who commented regarding this issue expressed an expectation for the health professional to be promptly available. This issue was salient to all three groups: 59% of the patients, 87% of the families, and 87% of the health professionals made relevant comments.

"Availability" included regular and frequent checking on patients and prompt response to their calls; regular visiting of the patient specifically by his or her physician; and 24-hour availability of the health professional. The comments of respondents often indicated a severe disparity between the ideals of respondents and the actual availability of health professionals. Several patients and families complained about (a) nurses' lack of prompt response to patients' calls and (b) physicians' apparent abandonment of patients. Some of the health professionals who were interviewed noted their and other professionals' tendency sometimes to avoid dying patients.

The literature on the socialization of physicians and nurses addressed this issue of availability primarily in terms of the tendency of both of these professional groups to avoid patients who are dying, to be unavailable to them. Such avoidance was implied to result from the discomfort with death on the part of the teaching faculty, the students themselves, and the professionals in the workplace. As such, availability appeared to be closely related to the expected goal of care (Indicator 4A).

The ideal expectations of respondents, then, appear to be at variance with those reported in the literature to be learned and held by physicians and nurses.

Indicator_3A:___Care_Approach

All but one of the respondents who made a relevant comment asserted their expectation that patients be given individualized (holistic model), not generalized (medical model) care. The response rate was low, though, among patients (35%), and somewhat lower than for other indicators among family members (71%) and health professionals (79%).

The consensus among the literature reviewed was that both physicians and nurses learn to be disease-centered and to depersonalize patients, particularly dying patients. To the extent, then, that respondents hold ideal expectations for individualized and personalized care, these expectations are not likely to be met, according to this literature.

Indicator_4A:___Treatment_Goal

Most of the respondents volunteered comments with respect to this issue: 71% of the patients, 84% of the family members, and 92% of the health professionals. If all respondents are considered, even those who made no relevant comments, the statement can be made that a majority expected the treatment goal of comfort and quality of life (hospice model). If only those respondents who made relevant comments are included in the analysis, however, respondents' ideal expectations can be seen to differ by their group membership: the majority of patients who made a relevant

comment adhered to a goal of cure or improvement (medical model), while only a slight majority of family members and nearly all of the health professionals held ideals for comfort and quality of life (hospice model). Respondents in conventional settings were more likely to expect a goal of cure or life prolongation. Even some patients and families who advocated a goal of comfort and quality of life, regardless of whether they were in a conventional or a hospice program, expected the health professional to continue to "encourage" the patient, to not give up hope completely.

The literature on physician socialization revealed that physicians generally are socialized to the medical model and are unprepared to switch from a treatment goal of cure and prolongation of life to one of comfort and quality of life. Nurses receive conflicting socialization; they are trained in comfort aspects, but simultaneously are strongly influenced by physicians' norms of cure (both models).

Interestingly, the ideal expectations of health professionals themselves are more at variance with the expectations which are learned by physicians and nurses through their socialization experiences than are those of patients and families. An unwillingness to give up hope of a cure is clear in the expectations of several patients and families; these respondents' expectations, therefore, are likely to be met.

Indicator 4B: Pain Control Practices

The three groups of respondents differed in their ideal expectations for pain control. About two-thirds of the patients interviewed addressed this issue, as did 84% of the family members and 90% of the health professionals. Of those who responded, a slight majority of patients preferred that medication be administered only on an "as needed," or "when requested," basis (medical model). Families were evenly split between the two poles, or models, and the majority of health professionals preferred administration of pain medication on a regular basis (hospice model). Health professionals in hospice programs were much more likely to advocate this approach than those in conventional programs, however.

Comparison of the findings from the interviews with respondents with those from the analysis of the literature cannot be made as only one source in the reviewed literature addressed this issue. This source argued that physicians learn and adhere to the medical model approach, while nurses are more skilled in pain control practices and have an approach more consistent with that of the hospice model. The lack of attention to this issue in the physician and nurse socialization literature may be an indication that current socialization practices continue to emphasize the

traditional, medical model, medication on an "as needed" basis only.

Indicator 4C: Patient Involvement

Overall, the majority of the respondents who made a comment relevant to one or more of the three subindicators developed (provision of information regarding diagnosis and prognosis; provision of information concerning treatment options and available resources; and willingness to allow patients some input in care-related decisions) felt that patients should be involved in their care. Family members in conventional programs, however, were inclined to expect that the professionals, not the patients, should make the care-related decisions. A total of 70% of the patients, 92% of the family members, and 87% of the health professionals who were interviewed volunteered comments with respect to this issue.

Most of the literature reviewed addressed this issue with respect either to the provision of information to patients (usually concerning their diagnosis and prognosis) or to the professional's willingness to allow the patient some say in his or her care. According to the literature reviewed, physicians generally learn (a) to withhold information and (b) to adhere to the norms of "medical responsibility" which dictate that doctors have responsibility for their patients, which results in

reluctance to involve patients in care-related decisions (medical model). At the same time, there was evidence of movement toward the norms associated with the holistic model of care in the more recent sources that were reviewed, due, possibly, to a "pro-truth cultural mood" and increasing sophistication on the part of patients, as argued by Haug (1979) and Veatch & Tai (1980).

The analysis of the literature on the socialization of nurses revealed little consensus on the part of the sources reviewed. Some asserted that cooperative (passive) patients are preferred, that nurses tend to avoid the subject of death, and that they do not share accurate information with patients. Others noted that nurses learn to be favorably disposed toward "involving the patient," but they receive little practical training in how to do this, or they feel obliged to leave the provision of information to the physician. This literature, too, pointed to the erosion of professional authority through the increasing sophistication of patients, signaling a trend toward the norms associated with the holistic model of care.

Respondents' expectations for the involvement of patients, therefore, appear increasingly likely to be met both by physicians and nurses, if only because of cultural and sociodemographic factors that appear to be forcing professionals toward a more egalitarian relationship with those whom they serve. At the same time, the possibility

exists of going too far toward the other extreme, providing information and otherwise involving patients who do not wish to be involved.

Indicator 4D: Family Involvement

As in Indicator 2B: Scope Of Care, few patients (35%) volunteered comments with respect to this issue of family involvement, compared with families (87%) and health professionals (90%). Of those respondents who did make relevant comments, the majority held an expectation that the family should be involved in the patient's care by the health professional, either through the provision of various types of information, through a willingness to allow the family some input into the patient's care, or through encouraging the family to participate in caring for the patient.

Only a few sources in the physician and the nurse socialization literatures (three in each literature) addressed this issue of family involvement. Among these sources, there were conflicting reports with respect to whether or not the physician or nurse learns to involve the family. While some sources reported that the family is excluded, especially when the patient is actively dying, others discussed means by which the family may be involved, such as through the provision of information (although this is traditionally the role of the physician) and the

relaxation of visiting rules. In this indicator, as in Indicator 28, the lack of attention in the literature to this issue may signal a general lack of socialization of physicians and nurses to the expectation that they involve families.

Because of the limited coverage of this issue in the physician and nurse socialization literatures, comparison of role expectations learned through socialization with those expected by the respondents is not possible. While most of the family members and health professionals interviewed appeared to expect that the health professional should involve the family in some way in the patient's care, these expectations may or may not be met because health professionals do not seem to receive specific training with respect to how to involve families and because nurses appear to learn to let the physician decide the extent of family involvement as it relates to the provision of information. Also, the involvement of families may be threatening to some health professionals.

Indicator 45: Volunteer Involvement

Of the very few respondents who mentioned this issue, the majority favored the involvement of agency-affiliated volunteers. None of the sources in the literature reviewed on the socialization of physicians and nurses addressed the issue. This lack of attention may indicate that those who

hold ideal expectations that volunteers be available may not have these expectations realized, since health professionals in training may not be exposed to the concept of volunteer involvement.

Indicator 4F: Criteria for Evaluating the Health Professional

The respondents who were interviewed included both ascriptive (medical model) and performance (holistic model) criteria in the evaluations that they volunteered of health professionals. The majority of all three groups used performance criteria. As expected, family members in conventional programs were more likely to use ascriptive criteria. Hospice professionals, however, were more likely to use ascriptive criteria than were professionals in conventional programs. Hospice professionals stipulated that health professionals, particularly nurses, who worked with the terminally ill should be credentialed or licensed.

There was no consensus in the literature reviewed concerning which criteria for evaluation physicians and nurses are socialized to expect. Most sources reported that physicians and nurses receive conflicting socialization, learning on the one hand that as physicians and nurses, they are infallible and that it is improper to criticize the performance of one another--the professional is good because he or she is a professional (ascriptive criteria, medical

model)--and on the other hand, that it is important to be self critical and to hold high performance standards (performance criteria, holistic model).

The conflicting socialization received by physicians and nurses is likely to translate into mixed success with respect to meeting respondents' expectations.

Indicator 5A: Motivation

Not surprisingly, the majority of the respondents held an ideal expectation that the motivation of the health professional should be to meet the patients' needs first (collectivity orientation--both medical and holistic models). An unexpected finding was that at the same time, a slight majority of the health professionals, especially hospice professionals, noted that the health professionals had needs that had to be met as well, either simultaneously with patients' needs or before meeting patients' needs (self orientation--hypothesized as congruent with neither model, but more with the medical than the holistic model). The meeting of these needs of health professionals was seen not as an end, but as a means to enable health professionals to address patients' needs adequately.

The literature reviewed generally reported that the role expectation learned through socialization both by physicians and nurses has been for a service (patient's needs first) orientation, although professional and

bureaucratic role demands also are sometimes experienced (professional's needs first). There was evidence of movement toward a self orientation in physician socialization for the same reason given by respondents: to enable the health professional to better serve the patient. One source in the nurse socialization literature noted that a self orientation on the part of nurses is becoming more acceptable, that responding to personal goals first is all right.

With respect to this issue of expectations concerning the proper motivation of the health professional, then, the expectations of the health professionals, especially those in hospice programs, appear to be congruent with recent trends in socialization practices. In addition, the expectations of patients and families are likely to be met as well, as long as the health professionals view the meeting of their own needs before those of patients as a means to the end of better serving patients.

Indicator 5B: Interprofessional Communication

Of those respondents who made a comment relevant to this issue, all expected that health professionals should communicate, coordinate, and collaborate with each other (holistic model). Very few patients and families (especially families in conventional programs), however,

responded; the issue was most salient to health professionals and to families in hospice programs.

Only three sources in the physician socialization literature addressed this issue. They noted conflicting socialization between the two models, with a tendency toward autonomy, competition, and poor communication between professionals. Five sources in the nurse socialization literature addressed this issue. They reported that nurses, too, receive conflicting socialization and that poor interprofessional communication is common.

It appears that the expectations of those respondents who made a relevant comment, then, may not be realized in practice, due to the conflicting socialization received by physicians and nurses and the predominance in the workplace of a tendency toward interprofessional rivalry and poor communication.

Indicator 5D: Interprofessional Decision-Making

No patients addressed this issue, and only one-fourth of the families, compared with three-fourths of the health professionals. The majority of the families who responded felt a hierarchical approach (medical model), with the physician as decision-maker, was appropriate, although those in hospice programs advocated the egalitarian approach (holistic model). The majority of the health professionals preferred the egalitarian approach, although half of those

in conventional programs expressed a preference for the hierarchical approach.

The four sources in the physician socialization literature who addressed this issue reported that traditionally there has been a hierarchy among professionals, with the doctor being higher than the nurse and being the leader. Sources also noted that physicians receive conflicting socialization and learn to be team members, as well as leaders, and that the doctor-nurse relationship is becoming a more egalitarian one. It even was suggested that in the area of terminal care, nurse leadership might actually be more appropriate.

The majority of the sources in the nurse socialization literature that were reviewed addressed this issue; it clearly was an important one. A summary of their reports yielded the finding that nurses are socialized to hierarchical decision-making (medical model). There was no agreement, however, as to which professional the nurse was socialized to view as being at the pinnacle: the physician or the nurse.

Those who hold expectations for health professionals to have an egalitarian approach to decision-making may find some physicians and nurses who hold similar ideals, but in general, a struggle appears to be underway with respect to which professional, the physician or the nurse, is to be dominant, particularly in the area of terminal care.

Indicator 5D: Professional-Patient Continuity

This indicator was not part of the original Analytical Model; it was developed after the review of the physician and nurse socialization literature had been completed in order to accommodate some otherwise unclassifiable comments of respondents. Comparision of the findings of Research Questions 1 and 2, therefore, is not possible.

CHAPTER VIII

SUMMARY, DISCUSSION, AND IMPLICATIONS

This chapter summarizes the major findings of this research and discusses their implications, highlights the contributions of the present study, and suggests directions for future research. First, however, several factors which limit the extent to which generalizations may be drawn from the findings of this research are recalled.

LIMITATIONS OF THE RESEARCH

The ability to make generalizations based on the findings of this study is constrained by several aspects of the research design. These limitations are described in detail in Chapter V, Research Design and Methods. Briefly, the limitations associated with the third phase of the research--the interviews with respondents--result from the use of interview data from an earlier study that had a focus slightly different from that of the present work, the small number of respondents interviewed, the non-random nature of the respondent selection process and the non-representativeness of the respondents interviewed, the qualitative, open-ended nature of the data, and the subjective nature of the content analysis performed.

Additional limitations are associated with the second phase of the research: the content analysis conducted of the physician and nurse socialization literatures. Among these limitations are the facts that the literature was not reviewed exhaustively and that the literature analyzed covered a period of several years. Furthermore, there appeared to be a relative lack of literature based on systematically-derived, empirical data on the actual socialization experiences of physician and nurses; much of the literature was impressionistic, consisting of essays, assertions, and anecdotes. Finally, as Bloom (1979:32) points out, the relevance of the findings of research into socialization for the professional role for behavior in this role "has been largely a matter of assumption." Indeed, as noted on several occasions, respondents' ideals frequently varied considerably from their performance and/or experiences. The following summary of the findings by research question is provided with these limitations in mind.

SUMMARY AND DISCUSSION OF MAJOR FINDINGS¹Research_Question_1

This question concerned the normative role expectations to which physicians and nurses are socialized in their professional (formal) socialization and their workplace (informal) socialization. It was hypothesized that the expectations to which these health professionals are socialized would parallel those characterizing the "professional" role as delineated by Parsons (1951), which, in turn, typify those prescribed by the medical model of care.

Finding_1: Physician Socialization. The analysis of the literature on socialization for the role of physician , revealed that the role expectations to which physicians are socialized professionally and in the workplace generally appear to be congruent with the norms of the medical model, as hypothesized. There appear, however, to be some issues with respect to which socialization for the role of physician is (a) conflicting and/or (b) seems to be moving toward the normative role expectations associated with the

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The numbers and letters in parentheses that appear throughout this final chapter, e.g., "(4A)," refer to specific indicators of role expectations that were developed as part of this study. See Chapter VI, Analytical Model, for details.

holistic model. These issues include patient and family involvement in the patient's care (Indicators 4C and 4D), evaluation of the health professional on the basis of performance or on the basis of ascribed characteristics (4F), interprofessional communication (5B), and interprofessional decision-making (5C).

Finding 2: Nurse Socialization. While certain of the role expectations to which nurses are socialized are congruent with those typifying the medical model of care (i.e., availability (2C), care approach (3A), interprofessional decision-making (5C)), there are many other role expectations on which nurses appear to receive conflicting messages. That is, elements of both the medical and the holistic models are learned. It is difficult, therefore, to characterize the role expectations to which nurses are socialized as belonging to either the medical or the holistic model.

Finding 3: Salience of Particular Issues. Role prescriptions with respect to the treatment goal (4A), the scope of care (2A), patient involvement (4C), and affective involvement (1A) received the greatest amount of attention in the physician socialization literature. In the nurse socialization literature, most prevalent were discussions of role prescriptions with respect to interprofessional decision-making (5C), treatment goal (4A), scope of care (2A), and affective involvement (1A). This analysis, then,

reveals considerable commonality of focus on particular issues in socialization for the roles of physician and nurse.

Also noteworthy, however, is the relative lack of mention, in both literatures, of role prescriptions with regard to the involvement of volunteers in the patient's care (4E), pain control practices (4B), family involvement in the patient's care (4D), and interprofessional communication (5B). This lack of attention leads to speculation about causes. Perhaps these issues are taken for granted and/or are deemed unimportant and noncontroversial, and the norms of one model or the other (medical or hospice) are followed. The information gleaned from the interviews with respondents with respect to their actual experiences and observations (see Chapter VII, Results, Research Question 2) points to a likelihood that these issues are not addressed in the socialization of health professionals, or if they are, the norms associated with the medical model of care are prescribed.

Implications

As a result of the conflicting messages received in socialization for the roles of nurse and physicians, role theorists would point to the strong potential for role strain on the part of nurses and physicians. An alternative way of viewing this phenomenon, however, is that exposure to

the norms of both models of care can provide the professional with greater perspective and ability to tailor the care provided to the needs of the individuals they serve.

Another implication is that of the potential for conflict between physicians and nurses as a result of nurses' socialization for increasing autonomy in decision-making. The literature reviewed indicated that physicians appear to learn both that they are the primary decision-makers and that they are members of a team of health professionals. While in the past, nurses appeared to learn that their role was secondary to that of the physician in terms of decision-making, recent socialization literature suggests that values of autonomy and independent decision-making are being imparted. Some sources suggest that these values go beyond egalitarianism to domination, particularly in the area of terminal care. Indeed, comments of a few of the family members and several of the health professionals interviewed indicated ways in which the quality of care received by terminally ill patients might be, or had been improved, especially with respect to pain and symptom control, as a result of nurses' recommendations to physicians and physicians' willingness to listen to the nurses. A new role with increased responsibility for nurses in the domain of terminal care, then, may be emergent.

At the same time, the finding with respect to the treatment goal to which nurses are socialized should be remembered. The common perception is that nurses are trained to "care" more than to "cure." The socialization literature, however, indicated that especially in the workplace, but to some degree in their formal education as well, nurses become oriented more to the goal of cure, feeling frustration and discomfort with dying patients similar to that of physicians. Not all nurses, then, may be prepared to assume a dominant role in the provision of terminal care.

A negative response by physicians to their "loss" of power, too, might be anticipated, except, perhaps, by those physicians whose discomfort with dying patients leads them to welcome increased role responsibilities for nurses. Yet another consideration is whether or not patients and families will accept the nurse as decision-maker. Some of the comments in the interviews with patients and families reveal that resistance might be encountered, particularly by those receiving care in conventional programs. For these respondents, as well as for some of those in hospice programs, visits and checking on the patient specifically by the doctor, the provision of information by the doctor to them and the following by nurses of the doctor's "orders" and recommended treatment are of considerable importance. Finally, only physicians have the legal authority to write

prescriptions, and only treatments authorized by them are eligible for reimbursement by third parties. These very real constraints cannot be ignored when considering the possibility of increased role responsibilities on the part of the nurse in the care of the terminally ill.

Another interesting finding from the analysis of the literature was the apparent trend in the socialization of both physicians and nurses away from a solely service or collectivity orientation (meeting the patient's needs first) toward a service orientation coupled with a self orientation (meeting the health professional's needs first), regardless of the medical vs. holistic model issue. The rationale for this change was that patients' needs can best be met if the health professionals' needs are addressed as well. A similar finding emerged in the interviews conducted with health professionals, especially those health professionals in hospice programs. This addition of a self orientation may have implications for the very definition of a "professional," at least as the professional is conceptualized by Parsons (1951), Goode (1960), and Freidson (1970a), who argue that it is this role expectation for a service orientation that distinguishes the professional role from the roles of other occupational groups.

Research_Question_2

This question concerned the role expectations held for the ideal provider of terminal care by a group of terminally ill patients, family members of terminally ill patients, and health professionals who themselves provide terminal care.

It was hypothesized that: (1) these ideal expectations would be consistent with the holistic (specifically, the hospice) model of health care; (2) respondents' expectations would differ based on their group membership (patient, family member, or health professional); and (3) respondents' expectations would differ based on their subgroup membership (i.e., whether they were receiving or providing care in a conventional, or medical model, program or in a hospice, or holistic model, program).

Finding_1:___Model_With_Which_Ideal_Expectations_Were_Consistent. In general, as predicted, the ideal expectations of respondents who made comments relevant to the indicators of role expectations (see Chapter VI, Analytical Model) were most consistent with the holistic (hospice) model of care. Hospice principles appear to be widely discussed and upheld, at least in the realm of the ideal.

There were, however, some notable exceptions to this finding. These exceptions are described in Finding 2, as they also are associated with differences between the respondent groups.

A caveat is warranted concerning the qualifying phrase "of respondents who made comments relevant to the indicators." The reasons for respondents' lack of attention to particular issues, or indicators, cannot be known. One can speculate, as above in Research Question 1, that failure to address a given issue might indicate its lack of salience to the respondent, or that the issue is a noncontroversial one for the respondent, or is taken for granted and not worthy of comment; respondents were asked to comment on aspects of health professionals' attitudes and behaviors that they particularly liked (or felt facilitated the provision of quality terminal care) or disliked (or felt constituted barriers to the provision of quality terminal care). Failure to address a given issue might also be an indication of adherence to the role expectations consistent with the conventional, or medical, model, in that this model has been the predominant one to date to which professionals and lay people (patients and families) alike have been socialized.

Finding 2: Respondents' Expectations By Group Membership. Contrary to what was hypothesized, respondents' expectations generally did not differ by group. Exceptions occurred with respect to four of the fifteen indicators of role expectations: treatment goal (4A), pain control practices (4B), motivation of the health professional (5A), and interprofessional decision-making (5C). The ways in

which the three groups differed in their expectations in these areas are summarized in subsequent paragraphs. A second way in which the three groups differed, their response rates and the apparent salience of the indicators, also is discussed.

The majority of the patients who commented regarding their expectations concerning the appropriate treatment goal (4A) felt that this goal should be to prolong life (the expectation consistent with the medical model), and almost half of the family members who responded felt similarly. The majority of the health professionals held ideal expectations for a goal of comfort and quality of life. At the same time, several health professionals expressed the difficulty they and other health professionals sometimes experienced in working with dying patients, in making the transition between the goals of "cure" and "care."

The respondent groups also differed in their expectations as to whether the health professional should administer pain medication on an "as needed" or "as requested" basis (medical model) or on a regular basis (hospice model) (4B). The rationale for this latter approach is that the administration of medications at regular intervals is more effective in keeping patients from experiencing pain, but also maintaining their alertness, thereby enhancing the patient's quality of remaining life. The patients and family members who made comments relevant

to this issue were evenly divided in their ideal expectations or preferences, while the majority (but not all) of the health professionals advocated regular administration. Fears of addiction and loss of effectiveness of the drugs were voiced as the primary concerns with regular administration. Fears of addiction would appear to be irrelevant in the case of terminal illness, and those of loss of effectiveness of the drugs only minimally realistic, as dosages can be increased if necessary for adequate pain control.

As noted above, a number of health professionals held ideal expectations that their own needs (for emotional support, stress reduction, an adequate standard of living, avoidance of "burnout") should be met first (self orientation), and then the patients' needs in order to enable them to better serve patients (5A). Patients and families expected that the patients' needs should come first. It should be noted, however, that several patients and family members did recognize the existence of various needs of health professionals.

Finally, while no patients commented specifically with regard to the issue of interprofessional decision-making (5C), and only about one-fourth of the family members, the majority of those family members who did make relevant comments indicated expectations for hierarchical decision-making (medical model), with the physician as the final

authority. The majority of the health professionals, including both physicians and nurses, held expectations for egalitarian decision-making (holistic model).

Implications

The finding that patients' and families' expectations differ from those of health professionals' on these four indicators, and the finding that patients' and families' expectations with respect to these four indicators are consistent with the role expectations typifying the medical model have serious implications. There are implications for (1) professional-lay relations, (2) the definition of a "professional," (3) urban health care systems, and (4) the viability of the hospice concept.

With regard to the first implication, in Chapter III numerous theorists were cited who argued that where differences exist in role expectations, conflict is likely between role occupants. Patients, families, and health professionals, then, are likely to experience some conflict surrounding their expectations in these four areas.

Concerning the second implication, as noted in the above discussion of the findings of Research Question 1, the addition of a self orientation to the service orientation may indicate a need to redefine just what a "professional" is, and how the professional role is distinguished from other occupational roles.

The third implication for urban health care systems is that due to the difficulty often experienced by health professionals in making the transition between the treatment goals of cure and life prolongation, on the one hand, and comfort and quality of life, on the other hand, separate programs for care of the dying are likely to be necessary. Further diversification and fragmentation of urban health care systems, therefore, is probable.

This finding also has implications for the viability of the hospice concept in the U. S. Specialized hospice programs for care of the terminally ill, as separate and alternative programs, are likely to be embraced as better suited to provision of care for these patients.

Also relevant for the viability of the hospice concept, however, is the finding that a substantial proportion of patients and family members adhere to expectations for the role of the health professional that are consistent with the medical, not the holistic or hospice, model. Moreover, two of the expectations on which patients and families are at variance with the hospice model embody the very essence of hospice care: that the treatment goal should switch to one of comfort and quality of life, and that pain, where present, should be controlled through regular administration of medications so that patients remain free from pain, yet alert. To the extent that patients and families do not "buy into" these values,

provision of "true" hospice care becomes difficult, if not impossible. If the hospice model of care is to be accepted fully, it appears that considerable education of patients and families, as well as socialization of health professionals, especially those working in conventional programs, will need to be done by hospice proponents.

At issue, however, is who is "right." In some instances, there is real, objective information that indicates which viewpoint is "correct" or "accurate," such as that related to pain control practices. In other situations, it is difficult to know which group, patients, families, or health professionals, should be targeted for change. Of particular importance in this issue are potential cohort effects: if "quality" care is defined, for example, on the basis of patient satisfaction, which is related to the values and beliefs to which the patient has been socialized, the definition of "good" or "quality" care may change with each cohort. The implication is that there is likely to be a continual lag between what is taught as being important in the provision of terminal care and what patients and families receiving the care believe to be important.

Turning to the finding that the groups did not differ on the remaining eleven indicators is significant in its failure to substantiate role theory. The most plausible explanation is that the hospice movement may indeed be a

social movement; many of the principles of hospice care appear to have broad appeal and hospice ideals, at least, apparently have filtered down to the lay public. The current consumer rights and self-help movements are related movements that are having an impact on health care provision (Haug, 1979, and Veatch & Tai, 1980).

With respect to the second way in which the groups did differ, this study found differences associated with group membership in the rates of response to the various indicators of role expectations. If salience can be assumed to be indicated by the degree to which particular indicators were addressed by respondents in their comments, it appears that the three groups attributed varying levels of importance to the various indicators. Indicators receiving the most comment by patients included affective involvement (1A), treatment goal (4A), patient involvement (4C), and criteria for evaluating the health professional (4F). The indicators commented on most by family members included affective involvement (1A), scope of care (2A), patient involvement (4C), and criteria for evaluating the health professional (4F). Those receiving the most response by health professionals were scope of care (2A), unit of care (2B), treatment goal (4A), criteria for evaluating the health professional (4F), and interprofessional communication (5B).

Very few patients and family members commented with respect to the interprofessional communication (5B) and the interprofessional decision-making (5C) indicators, although a substantial number of health professionals did comment. All three groups had fairly low rates of response for the volunteer involvement (4E) and patient-professional continuity (5D). Patients had lower response rates than either family members or health professionals on all of the indicators; they were simply less verbal. Patients commented substantially less often than did either family members or health professionals concerning the care approach (individualized or general) (3A), perhaps because they felt they could not expect to be treated specially, as they were among other patients who also were dying; family involvement (4D); and unit of care (patient or patient and family). Patients' lack of attention to the needs of the family and also to the role of the family in the care was especially interesting; apparently, many were not able to see these needs in light of the gravity of their own personal situations.

In sum, the ideal expectations of those respondents who made a relevant comment did not differ according to the group membership of the respondents on the majority of the indicators. Differences in response rate and presumed salience did exist, however. In addition, the differences between the three groups' expectations on the four

indicators described above are important.

The differences in response rate merit discussion, especially the considerably lower rate of comment by patients. Persons who are in the final stages of terminal illness, as most of the patients interviewed were, are not likely to be garrulous; they must conserve energy. Ethical considerations dictate that the researcher must be sensitive to terminally ill patients' frailty, prematurely ending the interview, if necessary. At the same time, most of the patients whose interviews are analyzed in this study seemed pleased to have the opportunity to discuss their experiences and to share their views with the researchers. The majority of the family members interviewed also appeared to be glad for the opportunity to talk; this was especially true for family members whose relative (the patient) had recently died. In fact, for many of these family members, the interview seemed to be a cathartic experience. Researchers should be aware of this possibility, allow additional time for these interviews, and respond with sensitivity.

Finding 3: Expectations By Subgroup. As hypothesized, differences by subgroup (being associated with a conventional program versus a hospice program) did emerge. These differences included those of response rate as well as differences in the ideal role expectations held.

Specifically, respondents in conventional programs, especially patients, but sometimes family members and health

professionals, had lower rates of response for nine of the fifteen indicators. Plausible explanations for the generally lower response rate of patients in conventional programs include the possibilities that patients in conventional programs were more sick than those in hospice programs, that patients in hospice programs were more comfortable, physically or mentally, and were better able to respond, or that patients in conventional programs simply did not feel these issues were important.

On two indicators, respondents from hospice programs, specifically, health professionals, had slightly lower response rates than those in conventional programs: availability of care (2C), and volunteer involvement (4E). The lower response rate for the latter indicator seemed to have resulted because a few health professionals in conventional programs perceived and expressed an unmet need for volunteers in their programs; the hospice programs all had volunteers affiliated with their programs. No readily apparent explanations exist for hospice professionals' somewhat lower response rate with respect to the availability indicator, other than the possibility that their expectations were met (their programs all had 24-hour availability of professionals, and their staffing ratios were slightly higher), making this issue less salient for them, or that some hospice professionals did not see this

issue as a particularly important one for the provision of quality terminal care.

Differences in the ideal expectations between those respondents in conventional programs and those in hospice programs who did make relevant comments emerged for nine of the fifteen specific indicators. These nine indicators were 1A, 2A, 4A, 4B, 4C, 4D, 4F, 5A, and 5C (see Chapter VII, Research Question 2, for details). Essentially no differences appeared between the responses of subgroups (conventional versus hospice) for indicators 2B, 2C, 3A, 4E, 5B, and 5D.

Socialization theory would predict that the expectations of the respondents in these subgroups would vary due to the differences in the contexts in which their members are receiving or giving care. That is, patients and families in hospice programs would be more likely to adopt hospice-like values due to their exposure and socialization to these values. The same would be true with respect to the expectations adopted by patients and families in conventional programs. Health professionals would be expected to adhere to the values of their type of program for the same reason. The findings, therefore, appear to substantiate this theory. Another reason for differences in the health professionals' expectations is plausible as well, however: that of self-selection, particularly for professionals working in hospice programs. An interesting

possibility is that the reported conflicts in the professional socialization received by health professionals may have beneficial aspects as well as the negative outcome of role strain: these conflicts may serve to sensitize professionals to expectations consistent with both models of health care provision, allowing the professional to choose the set of role expectations most appropriate to a given situation.

Additional Comments. It is important to remember that the patients, and many of the family members, whose interviews were analyzed as part of this study were elderly. A "cohort effect," therefore, is probable. These individuals are likely to have been more "old school," more likely to have role expectations consistent with the medical model for health care provision, and less likely to have been influenced by recent cultural swings to the "pro-truth" mood (Veatch & Tai, 1980) and by the challenges posed to professional authority by the consumer rights and self-help movements. Indeed, Haug (1979) found that elderly patients were less likely to challenge professional authority than were younger patients. The reticence of older patients also was noted by some family members and health professionals. Traces of this phenomenon were evident in the remarks of a few patients, who clearly were reluctant to complain about their care. This possible "cohort effect" has particular relevance for patients' involvement (Indicator 4C) in their

own care. Especially for this generation of elderly patients, then, the hospice precepts of patient involvement in care-related decision-making may be premature, pointing to the need for active encouragement, particularly of elderly patients, to participate in their own care.

Active encouragement of family members to become more involved in the patient's care, however, may be counter-indicated, especially with respect to encouragement to care for the patient at home. Nearly without exception, the family members who were interviewed had attempted or were continuing to provide care for their ill relative at home. The physical and emotional strain imposed on the family member by such care was quite evident. A particularly valuable insight provided by these data is that health professionals may sometimes push family members too hard, making them feel guilty for their inability to care for the patient at home, ignoring the needs of the family members, many of whom (a) are themselves in poor health, especially the spouses of elderly patients, or (b) have families of their own to attend to.

As noted above in the discussion of the findings with respect to Research Question 1, the importance of the physician's role was evident in many patients' and families' comments, particularly with regard to his or her availability to patients and families (2A), the following of the doctor's orders concerning treatment procedures and

especially pain control (4B), and the physician's responsibility to provide information (mostly concerning diagnosis and prognosis) to patients and families (4C and 4D). Some nurses, too, felt that it was the physician's, not the nurse's, duty to provide information regarding patients' diagnoses or diseases and their prognoses. Some nurses also indicated that physicians' failure to provide such information made the job of the nurse more difficult because the nurse was then unable to talk openly with the patient and the patient was afraid of the unknown, not knowing why he or she was experiencing certain symptoms.

One surprising finding was that patients and families, while still desiring affective involvement (1A) on the part of the health professionals, tended to expect a less intense level of personal involvement than health professionals expected of themselves. It seems that health professionals may put more pressure on themselves to establish a more personal relationship with the patient than is expected by either families or patients, or at least to convey the impression of a more personal relationship. This latter possibility is suggested because of the use of such words as "convey" in health professionals' responses (e.g., "the health professional should convey true caring to the patient"). The literature on physician and nurse socialization and many respondents, including health professionals themselves and even a few patients and

families, however, caution against "overinvolvement" due to the increased likelihood of "burnout" for health professionals. The optimal level, in the view of most of the respondents, seems to be that of genuine personal warmth and caring, which may need to be conveyed in different ways for different patients.

As mentioned above in the discussion of the findings concerning Research Question 1, the socialization literature as well as some of the health professionals interviewed noted that patients and families sometimes are reluctant to give up active treatment for the patient's disease. An additional observation stemming from the interview data relates to this point: a given treatment, such as intravenous feeding, can be provided for different purposes, such as either to prolong life or to provide comfort. That is, there appear to be frequent differences of opinion as to which measures constitute appropriate "comfort" measures and which are extraordinary, life-prolonging measures. Conflict among health professionals themselves, as well as among health professionals and patients and families, then, appears likely with respect to issues concerning appropriate treatment measures.

Concerning pain control practices, a related area, a health professional made an interesting comment that may provide an explanation for health professionals' inability to control some patients' pain. He noted that there are

various kinds of pain, and that efforts to control physical pain may be ineffective, or counterindicated, when the patient's pain is of a spiritual or psychological nature.

Another theme that emanated from the interview data was related to this issue of expectations concerning the appropriate treatment goal (4A) and also to the issue of expectations for patient-professional continuity (5D). Specifically, the timing of the change from a goal of "cure" to a goal of "comfort" and "quality of life" is noteworthy. While it seemed that most health professionals eventually changed their treatment goal for the terminally ill patient, sometimes this change did not occur until quite late. In other words, the terminally ill patients continued to be treated as occupants of the "sick role" as opposed to occupants of the "dying role" until quite late in their lives (Noyes and Clancy, 1977). At issue here is the point at which someone should be considered as being "terminally" ill, or ill beyond hope of recovery. From the perspective of several of the health professionals in hospice programs, the switch to treating the patient in the "dying role" often did not occur soon enough; these professionals felt that patients frequently were referred to the hospice program with so little time left to live as to make it impossible for the health professionals to achieve their goals of making patients comfortable, helping them to improve or maintain their quality of life, and helping their families

to cope with the impending death. It seems that inappropriate timing of the switch between the two goals of treatment, then, can result in a failure on the part of the health professional to achieve either of the two treatment goals. Additional research into the question of just when someone should be viewed as "terminal" seems warranted.

Another theme that emerged from the interview data was that of the importance of the role of the family as an advocate and watchdog for the patient. Families and health professionals alike were aware, however, of the fine distinction between the family's fulfillment of this advocacy role and being overly critical and interfering. Respondents pointed out that families who were perceived as being overly critical were actually likely to have a negative impact on the care, as health professionals would be more inclined to avoid these patients.

An important point having relevance not only for the potential advocacy role that may be played by families (4D), but also for their treatment as recipients of care (Indicator 2B: Unit Of Care), was made by a few health professionals with respect to the provision of information to families. The point made was that families, like patients, may not ask for information, especially for information concerning available resources for financial assistance or home care supplies or for specific information regarding what exactly they should do if the patient dies at

home, how to make funeral arrangements, etc. One health professional asserted that while families generally will not ask for such information, and that while somehow the necessary activities surrounding a death do get done, the experience could be a much less traumatic and stressful one for the family if the health professional were to initiate discussion of these issues. Provided that this were done with sensitivity, the recommendation seems to be a worthy one.

In the original formulation of the analytical model which provided the basis for the analysis of data reported on here, one additional indicator, "Ability to Pay," was included. This indicator ultimately was eliminated from the model because its unit of analysis was not the health professional but was instead the organization or system in which care was to be provided. Nonetheless, a few remarks should be made with respect to this issue.

Six of the 17 patients (35%) (two conventional, four hospice) described concerns relative to their ability to pay for the care they were receiving or had received to date. Twenty-six family members (68%) described such concerns, either their own or their ill relative's (75% of those in conventional programs, and 61% of those in hospice programs). Most of these persons expressed concerns that related to services that were not covered by Medicare, or that had to do with care recipients needing to pay bills

themselves and be reimbursed by Medicare. Some were thankful that they or their ill relative had been able to stay at home because it was less expensive. Some reported with gratitude instances in which needed supplies had been provided free of charge. Twenty-eight health professionals (72%) discussed either matter-of-factly or with frustration situations in which adequate services could not be provided given the lack of reimbursement for such services. Several families and professionals noted that even those families with substantial resources at the outset of a terminal illness frequently find their reserves severely depleted by the time the patient dies.

Ideally, nearly all of these respondents probably would agree that terminal care should be available to patients regardless of their ability to pay. This ideal, like immediate availability of the health professional (Indicator 2C), however, appears to be far from realization. In planning services for terminally ill patients, it would appear prudent to bear in mind the high degree of concern expressed by patients and families with regard to cost of care and to make provisions for those who cannot afford to pay for these services. A minimal prescription for the individual health professional would be to keep in mind the fear and anxiety associated with financial worries that are experienced by many patients and families due to the high costs of health care.

A final finding derived from the interview data bears examination: that of the existence of needs on the part of health professionals that, at least as argued by some, must be met in order for health professionals to forestall burnout and, therefore, to be better able to serve their patients. The specific types of needs mentioned were those for time off, support, opportunities for continuing education, ventilation, and for pursuit of activities outside of work. As discussed above, this finding calls into question the very definition of a professional as one who has a service, not a self, orientation. An argument could also be made that a role expectation of this nature maintains its consistency with the service orientation but simultaneously embraces the self orientation. In either case, the definition of the professional role may require revision.

Research_Question_3

This question asked how the role expectations of the respondents interviewed compared with those to which physicians and nurses have been socialized.

Finding_1:___Comparision_Of_Findings_From_Research_
Questions_1_And_2. As noted in Finding 1 of Research Question 2, the ideal expectations of respondents who made comments relevant to the various indicators of role expectations were more consistent with the holistic

(hospice) model of care. In contrast, as noted in Findings 1 and 2 of Research Question 1, physicians and nurses appear to be socialized more to the medical model and/or to receive conflicting socialization, that is, socialization to aspects of both the medical model and the holistic model. The general conclusion that can be drawn, therefore, is that (a) respondents' expectations, as a whole, are not consistent with those to which physicians and nurses are socialized and are not likely to be met, or (b) for those role expectations with respect to which physicians and/or nurses receive conflicting socialization, respondents' expectations are likely to be met only sometimes.

This conclusion, however, represents a broad generalization that does not take into account the differences that were found between each of the three groups of respondents (patients, family members, and health professionals) in their expectations with respect to four of the indicators and with respect to their varying rates of response to several of the indicators (see Research Question 2, Finding 2). This finding also does not consider the differences in expectations that emerged within each group of respondents, i.e., for respondents in conventional as compared with hospice programs (see Research Question 2, Finding 3). As a result, this conclusion, while accurate at a general level, oversimplifies the findings.

Implications

Keeping in mind the qualifications stated above, this conclusion has a number of practical implications. The hospice model of care appears to have a fairly broad base of support: the ideal expectations for the role of the health professional of the terminally ill patients, family members, and health professionals themselves were consistent with the majority of the hospice principles. At the same time, if the hospice model is to be implemented successfully in its entirety, based on the responses of those interviewed, it appears that health professionals currently practicing in conventional programs may require socialization to its principles with respect to the appropriate goal of treatment (4A), pain control practices (4B), patient involvement (4C), family involvement (4D) and interprofessional decision-making practices (5C). In addition, programatic and policy changes appear to be called for. Specifically, in order for health professionals to be able to address patients' (and families') psychosocial care needs (2A and 2B), health professionals need to have more time; such time is likely to be available only with the hiring of additional staff. Also, third-party reimbursement for the provision of psychosocial care only is indicated.

Furthermore, some education of patients and family members, that is, lay people in general, appears to be necessary for full and successful implementation of the

nospice model, especially for those who have had no prior exposure to or experience with hospice concepts. Specific areas seeming to require attention are: the unit of care (2B), the appropriate goal of treatment (4A), appropriate pain control practices (4B), involvement of the patient in care-related decisions (4C), involvement of the patient's family in the care (4D), and interprofessional decision-making (5C). Especially given the gradual movement toward holistic care and toward greater participation of lay persons in their own care, the hospice concept, in general, appears to be viable over the long run.

Even with such socialization and education, however, it is the opinion of this researcher that the basic American cultural predisposition to "not give up" hope of a cure is unlikely to be supplanted. In addition, it seems probable that some patients and families will continue to not want to know, or to have patients know, their diagnosis and prognosis. Furthermore, fears of patients' becoming drug-dependent and of medications losing their effectiveness if administered over a long period of time seem unlikely to be easily assuaged, especially among middle-aged and elderly patients and families. In sum, full adoption of all hospice precepts for care of the terminally ill may not occur for some time. Moreover, this may not even be desirable; if such precepts are adhered to on a broad scale and applied indiscriminately to all terminally ill people and their

families, what might be considered the most basic of all the hospice tenets will be violated: that the care of each patient and his or her family must be approached on an individual, case-by-case basis.

Evaluation Of The Utility Of Parsons' Pattern Variables

In general, Parsons' pattern variables as applied to this problem of identification of the role expectations for health professionals in the provision of quality terminal care proved quite useful for pointing to the major areas of role expectations. Although the names of the pattern variables and the language used to describe them were found to be cumbersome and obscure, the pattern variables were extremely valuable in signaling important areas for this role analysis.

One problem encountered was the overlap between the pattern variables; they do not appear to be mutually exclusive of one another, thereby making classification of certain role expectations difficult. Considerable benefit could be derived from further study of the interrelationships between the five variables.

Nevertheless, the pattern variables did appear to be reasonably comprehensive and capable of differentiating between role expectations prescribed by the two major models for the provision of health care (the medical and the holistic models) as well as between the roles of the

physician and the nurse. To maximize the usefulness and clarity of the pattern variable framework for the problem addressed in the present study, an elaboration of the pattern variables, in the form of development of various "indicators," was undertaken (see Chapter VI, Analytical Model).

One pattern variable and, particularly, one of the indicators developed could benefit from further study: the "achievement-ascription orientation" pattern variable and the indicator, "criteria for evaluation of the health professional" (4F). Just what characteristics constitute a performance-orientation as opposed to an ascription-orientation is highly debatable. For example, personal characteristics such as being "compassionate" or "having a talent for caring for old people" can directly affect the health professional's performance capacity, yet they may also be considered as ascribed characteristics (see Chapter VII, Results, Research Question 2, Indicator 4F). Some additional recommendations for future research follow.

RECOMMENDATIONS FOR FUTURE RESEARCH

A number of areas of inquiry related to the problem addressed in the present research appear to be fruitful and deserving of future study.

1. Systematic empirical study of medical and nursing schools is recommended in order to determine empirically the

norms to which physicians and nurses in training are professionally socialized. The present study found that physicians appear to be socialized to role expectations most congruent with those of the medical model. With respect to nurses, however, changes seem to be underway in the values and role expectations imparted through socialization, and it was not possible to characterize nurses as being socialized to either the medical model or the alternative holistic model. A trend toward the holistic model of care, however, appears to be evident. Also evident is the emerging role of the nurse in the provision of terminal care, possibly to a position of dominance. It is important to monitor these changes over time. A longitudinal study would be most useful in this regard.

Moreover, as noted earlier, much of the existing literature on the socialization of physicians and nurses with respect to issues surrounding the care of the dying does not appear to be empirically-grounded. Additional systematic work in this area is called for.

Accompanying this large-scale, systematic study of the norms to which physicians and nurses in training are socialized should be research addressing the relationship between socialization for the health professional role and behavior in that role. Ideally, such research would follow a group of medical and nursing students through their formal schooling and into the workplace. Participant observation

might be a particularly useful technique for assessing the health professionals' role behavior.

2. Extension of the present study to overcome its numerous design limitations is necessary in order for valid, generalizable findings to be obtained with respect to the ideal expectations for the health professional role. Particularly, the number of patients, family members, and health professionals interviewed should be increased. In addition, a greater ethnic mix of respondents should be obtained, and the sample should be national, not primarily local, in scope. Furthermore, respondents, particularly patients and families, should be of various ages. An age-stratified cross-sectional design would minimize any cohort effects obtained with respect to expectations for the health professional role to which patients and families may have been socialized. Alternatively, a longitudinal design would enable the monitoring of changes in role expectations over time. Similarly, study of prospective patients to determine their expectations for the health professional role in the provision of quality terminal care with followup interviews of patients who became terminally ill would be enlightening as to changes in perspective that may occur once an individual has been diagnosed as having a terminal illness. The health professionals interviewed should be physicians and nurses, some of each gender. With the expansion, in the holistic model of care, of the scope of care to include the

meeting of psychosocial as well as physical needs through the use of an interdisciplinary team of professionals, the addition of social workers and psychologists to the sample would be beneficial.

3. Further study of the decision-making process concerning designation of a patient as being "terminally ill" is warranted. The point at which a patient is seen as "terminal" affects the timing of the switch from the "sick role" to the "dying role" and the attendant expectations held by and for the patient occupying this role. The timing of this change in role expectations has implications for the health professional's ability to achieve either of the two major treatment goals (life prolongation or quality of life and comfort).

4. The present study focused only on the role of the health professional in the provision of quality terminal care. This role is just one of those in the role set. However, expectations associated with the roles of the patient and the family are equally important. A number of indications were given by health professionals, patients, and family members alike that there is a set of expectations for the "good" patient or the "good" family member. The role expectations for patients and family members in the terminal care situation should be systematically explored.

5. Treatment of the patient and the family as the unit of care is one of the key precepts of the hospice model

of care, yet little attention has been devoted to the question, "Who is the family?"; that is, "Which family members should receive treatment?" Underlying this precept is a perspective of the family as a system, as a functioning whole comprised of many parts. How realistic is it to expect the health professional to address the needs of all those family members involved with the patient? Future research should begin to examine this issue.

6. Systematic empirical study of the needs of terminally ill patients and their families is imperative. Much of the existing literature is impressionistic, yet entire treatment regimes are planned upon health professionals' perceptions of the various needs of patients and families.

7. Further refinement of the indicators of role expectations that were developed as part of this study is critical. These indicators have potential utility for the development of assessment tools to measure quality of terminal care and for recruitment and selection of health professionals to provide care for the terminally ill. Both process and outcome measures for assessing quality are necessary. Building upon the exploratory work done in the present study, development of closed-ended questions, perhaps in a checklist format, should be initiated. To avoid the pitfalls associated with the checklist used in the present study (e.g., misunderstandings of terms such as

"services," being overly long, having a confusing response format--see Chapter V, Research Design and Methods, Quality and Limitations of the Interview Data), items should be carefully pretested.

8. Additional consideration should be given to the issue of "who is right?", that is, whose viewpoint should be honored in instances of conflict between members of the role set, including the patient, the family, and the health professionals.

9. Finally, the present study has demonstrated that a redefinition of the role of the "professional" may be required. Further study of the distinction between "professionals" and "lay" people and their respective roles in the realm of American health care is needed.

For example, with increasing participation of patients and families in treatment-related decisions and the attendant erosion of the authority of the health professional, how will the roles of the lay person and the professional be differentiated? Also, what are the implications for the increased attention and openness to the needs of health professionals who traditionally have been viewed as sacrificing their own needs in order to meet those of the patients whom they serve?

CONTRIBUTIONS OF THE PRESENT STUDY

In summary, this study has made some methodological, theoretical, and practical contributions, including:

1. The application of Parsons' pattern variables, which were first conceptualized as dimensions which would describe ways role could vary (Parker, 1978), in an analysis of the expectations associated with a particular role. Typically, when the issue of expectations for a given role is raised, one or two types of role expectations may be addressed or focused upon; rarely is an attempt made to examine comprehensively the expectations associated with a particular role. This study demonstrates the value of Parsons' pattern variables: as offering a fairly comprehensive framework, a broad perspective, within which the various expectations associated with a given role may be viewed.

2. The use of Parsons' pattern variables specifically to: (1) to identify (a) the role expectations to which health professionals (physicians and nurses) are socialized with respect to the provision of quality terminal care and (b) the ideal expectations for the health professional role in the provision of quality terminal care as held by a group of terminally ill patients, family members, and health professionals; and (2) compare (a) and (b). The pattern

variables were found to be useful vehicles for viewing and discriminating between role expectations associated with the current dominant model of health care provision in America today, the medical model, and an alternative model, the holistic care model, which, in the specific case of terminal care, is embodied in the hospice model. To date, no such systematic analysis has been made of the expectations associated with the role of the health professional in the provision of quality terminal care.

3. A call for reexamination of the definition of a "professional." This research demonstrated that the role of the health professional within the medical model differs from that of the health professional within the alternative, holistic model, and specifically, the hospice model. Either professionals within the alternative model are not really professionals or a redefinition of the role of the professional is required.

4. The generation of specific indicators of role expectations, elaborating upon Parsons' pattern variables. Following further refinement, these indicators can be used: (a) to develop instrumentation for assessing the quality of terminal care; and (b) for recruiting and selecting health professionals for the provision of quality terminal care.

5. The shedding of light onto some specific areas of role expectations in which there appear to be conflicts in socialization of physicians and nurses. These conflicts may

result in role strain and, therefore, may signal areas in which changes in socialization practices may be indicated in order to reduce such role strain and conflict.

6. The provision of insight into the specific ways in which terminally ill patients', family members', and health professionals' perspectives may be similar and different, and also the ways in which the views of persons associated with conventional programs may compare with those of persons giving or receiving care in hospice programs. These findings have implications both for role theory and for socialization theory as well as practical implications related to the reduction of conflict between members of the role set so as to enhance perceived quality of care.

BIBLIOGRAPHY

- Advancing the quality of health care. (1974, August).
Washington, DC: National Academy of Sciences,
Institute of Medicine.
- Alexy, W. D. (1981-82). Perceptions of ward atmosphere on
an oncology unit. International Journal of Psychiatry
in Medicine, 11(4), 331-340.
- Alutto, J. A., Hrebinisk, L. G., & Alonso, R. C. (1971).
A study of differential socialization for members of
one professional occupation. Journal of Health and
Social Behavior, 12(2), 140-147.
- Barnard, C., & Pellegrino, E. (1976). The right to die:
Two views. Current, 180.
- Becker, H. S., Geer, B., Hughes, E. C., & Strauss, A. L.
(1961). Boys in white: Student culture in medical
school. Chicago, IL: University of Chicago Press.
- Benoliel, J. Q. (1979). Dying is a family affair. In E.
R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A.
H. Kutscher, & I. B. Seeland (Eds.), Home care:
Living with dying, (pp. 17-34). New York: Columbia
University Press.
- Beverly, E. V. (1976). Understanding and helping dying
patients and their families. Geriatrics, 31(3):
117+.
- Biddle, B. J. & Thomas, E. J. (1966). Role theory:
Concepts and research. New York: John Wiley & Sons,
Inc.
- Block, D. (1975). Evaluation of nursing care in terms of
process and outcome: Issues in research and quality
assurance. Nursing Research, 24(4), 256-263.
- Bloom, S. W. (1979). Socialization for the physician's
role: A review of some contributions of research to
theory. In E. C. Shapiro & L. M. Lowenstein (Eds.),
Becoming a physician: Development of values and
attitudes in medicine, (pp. 3-52). Cambridge, MA:
Ballinger Publishing Company.

- Bloom, S. W. & Summey, P. (1976). Models of the doctor-patient relationship: A history of the social system concept. In The doctor-patient relationship in the changing health scene, (pp. 17-41). Washington, DC: National Institutes of Health, U.S. Department of Health, Education, and Welfare.
- Blumenfield, M., Levy, N. B., & Kaufman, D. (1979). Current attitudes of medical students and house staff toward terminal illness. General Hospital Psychiatry, 1(4), 306-310.
- Bowers, J. W. (1970). Content analysis. In P. Emmert & W. D. Brooks (Eds.), Methods of research in communication, (pp. 291-314). Boston: Houghton Mifflin Company.
- Breindel, C. L. & Acree, C. L. (1980). Estimates of need for hospice services. Death Education, 4(3), 215-222.
- Brim, O. G., Jr. (1976). Adult socialization. In R. Atchley & M. Seltzer (Eds.), The sociology of aging: Selected readings (pp. 81-94). Belmont, CA: Wadsworth Publishing Company, Inc.
- Brook, R. H. & Davies-Avery, A. (1977). Mechanisms for assuring quality of U. S. medical care services: Past, present, and future (Report No. R-1939-HEW). Washington, DC: Department of Health, Education, & Welfare.
- Brook, R. H., Davies-Avery, A., Greenfield, S., Harris, L. J., Lelah, T., Solomon, H. E., & Ware, J. E., Jr. (1976). Quality of medical care assessment using outcome measures: An overview of the method (Report No. R-2021/1-HEW; Contract No. HRA 230-75-0112). Washington, DC: National Center for Health Services Research, Health Resources Administration, Department of Health, Education, & Welfare.
- Buckingham, R. W. & Lack, S. A. (1977). Final report to the National Cancer Institute.
- Buckingham, R. W., Lack, S. A., Mount, B., Maclean, L., & Collins, J. (1976). Living with the dying: Use of the technique of participant observation. Canadian Medical Association Journal, 115, 1211-1215.

- Buckley, I. G. (1979). Fulfillment of life in the presence of death. In E. R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A. H. Kutscher, & I. B. Seeland (Eds.), Home care: Living with dying (pp. 199-204). New York: Columbia University Press.
- Budner, S. (1979). Shall we look before we leap? In E. R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A. H. Kutscher, & I. B. Seeland (Eds.), Home care: Living with dying (pp. 37-48). New York: Columbia University Press.
- Butterfield-Picard, H. & Magno, J. (1982). Hospice the adjective, not the noun. American Psychologist, 37(11), 1254-1259.
- Callan, J. P. (1979). The hospice movement. Journal of the American Medical Association, 241(6), 600.
- Clifford, I. M. (1979). Comprehensive planning for care and the home health agency. In E. R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A. H. Kutscher, & I. B. Seeland (Eds.), Home care: Living with dying (pp. 223-231). New York: Columbia University Press.
- Cohen, K. P. (1979). Hospice: prescription for terminal care. Germantown, MD: Aspen Systems Corporation.
- Colen, B. D. (1976, October 31). Ten bad days among the dying. Washington Post.
- Conway, M. E. (1978). Theoretical approaches to the study of roles. In M. E. Hardy & M. E. Conway (Eds.) Role theory: Perspectives for health professionals (pp. 17-27). Norwalk, CT: Appleton-Century-Crofts.
- Coombs, R. H. (1978). Mastering medicine: Professional socialization in medical school. New York: The Free Press.
- Coombs, R. H., & Powers, P. S. (1975). Socialization for death: The physician's role, Urban Life. 4, 250-271.
- Coppens, M. (1979, Fall). Intervention through sexuality counseling. In Oregon Comprehensive Cancer Program, The cancer newsletter (pp. 7-10). Portland, OR.

- Cox, J. (1978). Springfield (1978)--St. John's Hospice. In G. W. Davidson (Ed.), The hospice: development and administration (pp. 83-95). Washington, DC: Hemisphere Publishing Corporation.
- Craven, J. & Wald, F. S. (1975). Hospice care for dying patients. American Journal of Nursing, 75, 1816-1822.
- Craytor, J. K. (1979). Working with dying patients and their families. In E. R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A. H. Kutscher, & I. B. Seeland (Eds.), Home care: Living with dying (pp. 37-48). New York: Columbia University Press.
- Davidson, G. W. (1978a). Preface. In G. W. Davidson (Ed.), The hospice: Development and administration (pp. v-vii). Washington, DC: Hemisphere Publishing Corporation.
- Davidson, G. W. (1978b). In search of models of care. In G. W. Davidson (Ed.), The hospice: Development and administration (pp. 145-161). Washington, DC: Hemisphere Publishing Corporation.
- Dickenson, G. E. (1976). Death education in U.S. medical schools. Medical Education, 51, 134-136.
- Donabedian, A. (1966). Evaluating the quality of medical care. Milbank Memorial Fund Quarterly, 44(3), Part 2, 116-323.
- Donabedian, A. (1969). A guide to medical care administration. In his Medical care appraisal: Quality and utilization (Vol. II). New York: The American Public Health Association.
- Donabedian, A. (1978). The quality of medical care. In P. Abelson (Ed.), Health care: Regulation, economics, ethics, and practice (pp. 12-20). Washington, DC: Hemisphere Publishing Corporation.
- Donabedian, A. (1980). The definition of quality and approaches to its assessment. In his Explorations in quality assessment and monitoring (Vol. I). Ann Arbor, MI: Health Administration Press.

- Dowsett, E. G. (1972, December 30). The dying patient. Lancet, 2, 1416.
- Dubin, R. (1960). Parsons' actor: Continuities in social theory. American Sociological Review, 25(4), 457-466.
- Dubois, P. M. (1980). The hospice way of death. New York: Human Sciences Press.
- "The dying patient." Lancet, 1972, 2, 1238-1239.
- Epstein, F. H. (1974). The role of the physician in the prolongation of life. In F. J. Ingelfinger, R. V. Ebert, M. Finland, & A. S. Relman (Eds.), Controversy in internal medicine, II (pp. 103-109). Philadelphia: W. B. Saunders.
- Feifel, H. (1963). Death. In N. L. Faberow (Ed.), Taboo topics. New York: Atherton Press.
- Field, M. (1953). Patients are people: A medical social approach to prolonged illness. New York: Columbia University Press.
- Fox, R. (1957). Training for uncertainty. In R. K. Merton, G. Reader, & P. K. Kendall (Eds.), The student-physician (pp. 207-241). Cambridge, MA: Harvard University Press.
- Frank, A. W. (1974). Role. Encyclopedia of sociology (p. 246). Guilford, CT: Dushkin Publishing Group, Inc.
- Freidson, E. (1961). Patients' views of medical practice. New York: Russell Sage Foundation.
- Freidson, E. (1970a). Profession of medicine: A study of the sociology of applied knowledge. New York: Dodd, Mead & Company.
- Freidson, E. (1970b). Professional dominance: The social structure of medical care. New York: Atherton Press.
- Freihofer, P., & Felton, G. (1976). Nursing behaviors in bereavement: An exploratory study. Nursing Research, 25(5), 332-337.

- Germain, C. P. (1980). Nursing the dying: Implications of Kubler-Ross' staging theory. Annals of the American Academy of Political and Social Science, 447, 46-58.
- Gideon, M. (1979). The hospice movement. Journal of the American Medical Association, 242(12), 1258.
- Glaser, B. G. & Strauss, A. L. (1965). Awareness of dying. Chicago: Aldine.
- Glaser, B. G. & Strauss, A. L. (1968). Time for dying. Chicago: Aldine.
- Glick, J. H. (1975). A doctor's prescription for mercy. Good Housekeeping, 181, 67+.
- Gliebe, W. A. (1977). Faculty consensus as a socializing agent in professional education. Nursing Research, 26(6), 428-431.
- Goode, W. J. (1960). Encroachment, charlatanism, and the emerging profession: Psychology, medicine and sociology. American Sociological Review, 25 (902) (cited in Robinson, 1974)
- Gordon, G. (1966). Role theory and illness: A sociological perspective. New Haven, CT: College & University Press.
- Greer, D. S. (1983). Hospice: Lessons for geriatricians. Journal of the American Geriatric Society, 31(2), 67-70.
- Hackley, J. A., Farr, W. C., & McIntier, Sr. T. M. (1978) Tucson (1977)--Hillhaven Hospice. In G. W. Davidson (Ed.), The hospice: Development and administration (pp. 63-82). Washington, DC: Hemisphere Publishing Corporation.
- Halper, T. (1979). On death, dying, and terminality: today, yesterday, and tomorrow. Journal of Health Politics, Policy and Law. 4(1), 11-29.
- Hampe, S. O. (1975). Needs of a grieving spouse in a hospital setting. Nursing Research, 24(2), 113-120.
- Hardy, M. E. (1978). Perspectives on knowledge and role theory. In M. E. Hardy & M. E. Conway (Eds.), Role theory: Perspectives for health professionals (pp. 1-15). Norwalk, CT: Appleton-Century-Crofts.

- Harman, M. S. (1971). Medical education and the social-psychological care of dying patients. (Doctoral dissertation, University of California, Los Angeles.) Dissertation Abstracts International, 3209-A, p. 5356. (University Microfilms No. 72-90225).
- Haug, M. (1979). Doctor-patient relationships and the older patient. Journal of Gerontology, 34(6), 852-860.
- Heiss, J. (1968). An introduction to the elements of role theory. In J. Heiss (Ed.), Family roles and interaction: An anthology (pp. 3-27). Chicago, IL: Rand McNally & Co.
- Hinton, J. (1979). Comparison of places and policies for terminal care. Lancet 29-32.
- Holden, C. (1976). Hospices: For the dying, relief from pain and fear. Science, 193 (4251), 389-391.
- Holden, C. (1980). The hospice movement and its implications. Annals of the American Academy of Political and Social Science, 447, 59-63.
- Holsti, O. R., Loomla, J., & North, R. C. (1968). Content analysis. In Lindzey, Gardner, & Aronson (Eds.), The handbook of social psychology (2nd ed., Vol. II) (pp. 596-692). Reading, MA: Addison-Wesley.
- Hover, J. & Zimmer, M. J. (1978). Nursing quality assurance: The Wisconsin system. Nursing Outlook, 26(4), 242-248.
- Huntington, M. J. (1957). The development of a professional self-image. In R. K. Merton, G. Reader, and P. K. Kendall (Eds.), The student-physician (pp. 179-187). Cambridge, MA: Harvard University Press.
- Hurley, B. A. (1978). Socialization for roles. In M. E. Hardy & M. E. Conway (Eds.), Role theory: Perspectives for health professionals (pp. 29-72). Norwalk, CT: Appleton-Century-Crofts.
- Jacox, A. (1974). Professional socialization of nurses. The Weather Vane, 43(2), 4-5, 27-34.
- Jette, P. R. (1974). Socialization. Encyclopedia of Sociology (pp. 272-273). Guilford, CT: Dushkin Publishing Group, Inc.

- Kanoti, G. (1975). Doctors, death and dying. Linacre Quarterly, 42(4), 262-267.
- Kaylor, C. (1979). Evaluation of home care for the terminal patient: A proposed model. In E. R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A. H. Kutscher, & I. B. Seeland (Eds.), Home care: Living with dying (pp. 247-259). New York: Columbia University Press.
- Kerlinger, F. N. (1973). Foundations of behavioral research (2nd ed.) New York: Holt, Rinehart and Winston.
- Kerr, M. & Trantow, D. J. (May, 1969). Defining, measuring, and assessing the quality of health services. Public Health Reports, 84, 415-424.
- Kerstein, M. D. (1972). Caring for the terminally ill: A hospice (Letter to the editor). American Journal of Psychiatry, 129(2), 151-152.
- Kerstein, M. D. (1973, April). Must medical progress leave the dying patient behind? Geriatrics, 28(4), 67-68.
- Klagsbrun, S. C. (1982). Ethics in hospice care. American Psychologist, 37(11), 1263-1265.
- Koff, T. H. (1980, November). Hospice or hospital: A concept paper. Paper presented at the meeting of the Gerontological Society of America, San Diego, CA.
- Krant, M. J. (1978). Caring for the terminally ill: Expectations of patient and family. Hospital Medical Staff, 7(2), 1-6.
- Kron, J. (1976, March). Designing a better place to die. New York Magazine, 43-49.
- Lack, S. A. (1978). New Haven (1974)--Characteristics of a hospice program of care. In G. W. Davidson (Ed.), The hospice: Development and administration (pp. 41-52). Washington, DC: Hemisphere Publishing Corporation.
- Lack, S. A. & Buckingham, R. W., III. (1978). First American hospice: Three years of home care. New Haven, CT: Hospice, Inc.

- Lamers, W. J. (1978). Marin County (1976)--Development of Hospice of Marin. In G. W. Davidson (Ed.), The hospice: Development and administration (pp. 53-62). Washington, DC: Hemisphere Publishing Corporation.
- Lamerton, R. (1976). Care of the dying. Westport, CT: Technomic Publishing Company.
- Lasagna, L. (1968). Life, death and the doctor. New York: Alfred A. Knopf.
- Lebow, J. L. (1974). Consumer assessments of the quality of medical care. Medical Care, 12(4), 328-337.
- Levinson, D. J. (1967). Medical education and the theory of adult socialization. Journal of Health and Social Behavior, 8, 253-264.
- Lief, H. I. & Fox, R. C. (1963). The medical student's training for detached concern. In H. I. Lief, V. F. Lief, & N. R. Lief (Eds.), The psychological basis of medical practice (pp. 12-35). New York: Harper & Row.
- Liegner, L. M. (1975). St. Christopher's Hospice, 1974: Care of the dying patient. Journal of the American Medical Association, 234(10), 1047-1048.
- Light, D., Jr. (1980). Becoming psychiatrists: The professional transformation of self. New York: Norton.
- Linton, R. (1936). The study of man. New York: Appleton-Century.
- Liston, E. H. (1973). Education on death and dying: A survey of American medical schools. Journal of Medical Education, 48, 577-578.
- Lurie, E. E. (1981). Nurse practitioners: Issues in professional socialization. Journal of Health and Social Behavior, 22(1), 31-48.
- Markel, W. M. & Simon, V. B. (1978). The hospice concept (78-2R-100M-9/79-No. 3403-PE). American Cancer Society, Inc.

- Maslow, A. M. (1943). A theory of human motivation. Psychological Review, 50, 370-396.
- Mayhew, L. (1968). Ascription in modern societies. Sociological Inquiry, 38, 105-120.
- McAuliffe, W. E. (1979). Measuring the quality of medical care: process versus outcome. Milbank Memorial Fund Quarterly, 37(1), 118-152.
- McClure, W. J. (1973). Four points on quality assurance. In Quality assurance of medical care (pp. 329-346). Washington, DC: Regional Medical Programs Service, Health Services and Mental Health Administration, U. S. Department of Health, Education, & Welfare.
- McNerney, W. J. (1976). The quandary of quality assessment. New England Journal of Medicine, 295(27), 1505.
- McNulty, B. J. (1974). The nurse's contribution in terminal care. Nursing Mirror & Midwives Journal (London), 139(15), 59-61.
- Merton, R. K. (1957a). The role-set: Problems in sociological theory. British Journal of Sociology, 8, 112.
- Merton, R. K. (1957b). Some preliminaries to a sociology of medical education. In R. K. Merton, G. Reader, & P. Kendall (Eds.), The student-physician: Introductory studies in the sociology of medical education (pp. 3-79). Cambridge, MA: Harvard University Press.
- Mitchell, J. A. (1973). Quality of medical care: Mutual responsibility of consumers and providers. In Quality assurance of medical care (pp. 83-96). Washington, DC: Regional Medical Programs Service, Health Services and Mental Health Administration, U. S. Department of Health, Education, & Welfare.
- Morison, R. S. (1974). Alternatives to striving too officiously. In F. J. Ingelfinger, R. V. Ebert, M. Finland, & A. S. Relman (Eds.), Controversy in internal medicine, II, (pp. 113-121). Philadelphia: W. B. Saunders.

- Mount, B. M. (1976). The problem of caring for the dying in a general hospital: The palliative care unit as a possible solution. Canadian Medical Association Journal, 115(2), 119-121.
- Mullaly, R. W. & Osmond, H. (1979). Medical education and the dying patient. Southern Medical Journal, 72(4), 409-411.
- Myers, B. A. & Graham, R. (1973). Quality assurance: HSMHA interest and role. In Quality assurance of medical care (pp. 445-460). Washington, DC: Regional Medical Programs Service, Health Services and Mental Health Administration, U. S. Department of Health, Education, & Welfare.
- Myers, L. C. (1982). The socialization of neophyte nurses. Ann Arbor, MI: UMI Research Press.
- Noyes, R., Jr. & Clancy, J. (1977). The dying role: Its relevance to improved patient care. Psychiatry 40(1), 41-47.
- Olsen, M. E. (1978). The process of social organization: Power in social systems (2nd ed.) New York: Holt, Rinehart and Winston.
- Osterweis, M. & Champagne, D. S. (1979). The U. S. hospice movement: Issues in development. American Journal of Public Health, 69(5), 492-496.
- Park, P. (1967). Measurement of the pattern variables. Sociometry 30(3), 187-198.
- Parks, P. (1979a, March 16). Hospice care: Implications for hospitals. Hospitals, pp. 58, 62.
- Parks, P. (1979b, November 16). Evaluation of hospice care is needed. Hospitals, pp. 68, 70.
- Parsons, T. (1951). The social system. Glencoe, IL: The Free Press.
- Parsons, T. (1960). Pattern variables revisited: A response to Robert Dubin. American Sociological Review 25(4), 467-483.

- Parsons, T. (1975). The sick role and role of the physician reconsidered. Milbank Memorial Fund Quarterly, Health and Society, 53, 257-78. (Cited in Haug, 1979).
- Paulson, G. W. (1973, March). Who should live? Geriatrics, 132-136.
- Payne, B. C. (1973). From performance-measured to utilization review to quality assurance. In Quality assurance of medical care (pp. 241-260). Washington, DC: Regional Medical Programs Service, Health Services and Mental Health Administration, U. S. Department of Health, Education, & Welfare.
- Payne, B. C. & Lyons, T. F. (1969). Design issues in process-outcome studies of quality care (Contract No. HSM 110-170-69). Washington, DC: National Center for Health Services Research and Development.
- Pellegrino, E. D. (1973). The quality assurances of medical care: Analysis and reflection. In Quality assurance of medical care (pp. 461-483). Washington, DC: Regional Medical Programs Services, Health Services and Mental Health Administration, U. S. Department of Health, Education, & Welfare.
- Plant, J. (1977, July 1). Finding a home for hospice care in the U. S. Hospitals, 53-62.
- Quint, J. C. (1967). The nurse and the dying patient. New York: Macmillan.
- Reeder, L. G. (1972). The patient-client as a consumer: Some observations on the changing professional-client relationship. Journal of Health and Social Behavior, 13, 406-412.
- Reiss, K. (1982a). Hospice care: A federal role? (Report No. 82-49 EPW). Washington, DC: Congressional Research Service, The Library of Congress.
- Reiss, K. (1982b, August 26). Hospice care under H.R. 4961. Washington, DC: Congressional Research Service, The Library of Congress.

- Robinson, D. (1974). Patients, practitioners and medical care: Aspects of medical sociology. London: William Heinemann Medical Books, Ltd.
- Rodek, C. F. & Jacob, S. (1983, June). Perspectives on hospice. Cancer Nursing, pp. 181-185.
- Rogers, B. L. (1978). Using the creative process with the terminally ill. In G. W. Davidson (Ed.) The hospice: Development and administration (pp. 123-126). Washington, DC: Hemisphere Publishing Corporation.
- Rose, M. A. (1976, March). Problems families face in home care. American Journal of Nursing, 416-418.
- Rosenberg, P. R. (1979). Catch 22--The medical model. In E. C. Shapiro and L. M. Lowenstein (Eds.), Becoming a physician: Development of values and attitudes in medicine (pp. 81-92). Cambridge, MA: Ballinger.
- Rosenfeld, L. S. (1973). Standards for assessing quality care. In Quality assurance of medical care (pp. 9-34). Washington, DC: Regional Medical Programs Services, Health Services and Mental Health Administration, U. S. Department of Health, Education, & Welfare.
- Rosenthal, C. J., Marshall, V. W., Macpherson, A. S., & French, S. E. (1980). Nurses, patients, and families. London: Croom Helm Ltd.
- Ross, C. W. (1978). Nurses' personal death concerns and responses to dying-patient statements. Nursing Research, 27(1), 64-68.
- Ryder, C. F. & Ross, D. M. (1977). Terminal care--issues and alternatives. Public Health Reports, 92(1), 20-29.
- Salber, E. J. (1975). Caring and curing: Community participation in health services. New York: Prodist.
- Saunders, C. (1965). The last stages of life. American Journal of Nursing, 65(3), 70-75.
- Schram, R. B., Kane, J. C., & Roble, D. T. (1978). "No code" orders: Clarification in the aftermath of Saikewicz. New England Journal of Medicine, 299, 875-878.

- Schulz, R. (1976, June). Meeting the three major needs of the dying patient. Geriatrics, 132-137.
- Schulz, R. & Aderman, D. (1976). How the medical staff copes with dying patients: A critical review. Omega, 7(1), 11- 21.
- Scurry, M. T., Bruhn, J. G., & Bunce, H. (1979). The house officer and the dying patient: Attitudes, experiences, and needs. General Hospital Psychiatry, 301-305.
- Searle, M. (1981). Obsessive-compulsive behaviour in American medicine. Social Science & Medicine, 15E, 185-193.
- Sherman, S. R. (1968). Quality health care: What is it? (Keynote Address). National Health Forum report: Quality in health care: Challenges and definitions: Vol. 1. New York: National Health Council.
- Shimkin, M. B. (1973). Implementation of the hospice concept. Science and Cancer (DHEW Publication No. NIH 15-586). Washington, DC: U. S. Government Printing Office.
- Shortell, S. M. (1982). The contribution and relevance of sociology to health services research. In T. Choi & J. N. Greenberg (Eds.), Social science approaches to health services research (pp. 21-52). Ann Arbor, MI: Health Administration Press.
- Shuval, J. T. (1975a). Socialization of health professionals in Israel: Early sources of congruence and differentiation. Journal of Medical Education, 50, 443-457.
- Shuval, J. T. (1975b). From "boy" to "colleague": Processes of role transformation in professional socialization. Social Science and Medicine, 9, 413-420.
- Simpson, M. A. (1976). Planning for terminal care. Lancet, 2, 192-193.
- Sjoberg, G. & Cain, L. D. (1971). Negative values, countersystem models, and the analysis of social systems. In H. Turk & R. Simpson (Eds.) Institutions and social exchange (pp. 212-229). Indianapolis: Bobbs-Merrill.

- Starfield, B. (1974). Measurement of outcome: A proposed scheme. Milbank Memorial Fund Quarterly, 52(1), 39-50.
- Stoddard, S. (1978). The hospice movement: A better way of caring for the dying. New York: Vintage Books.
- Strauss, A. L. (February, 1968). Problems of death and the dying patient. In A. Simon & L. J. Epstein (Eds.) Aging in modern society. Psychiatric Research Report #23, American Psychiatric Association.
- Strauss, A. L. (1975). Chronic illness and the quality of life. St. Louis: Mosby.
- "Supporting hospice care." (1980). Science, 207(11), 160-161.
- Swift, J. K. (1976). The chaplain's role in care for the dying: Toward a new understanding. Canadian Medical Association Journal, 115(2), 100-103.
- Talbot-Ponsonby, R. (1979). Management of the terminally ill patient. Nursing Journal of Singapore, 19(2), 92-94.
- Thanatology Today. (1980, January). (Newsletter). 1(10).
- Thompson, A. (1977). Havens for the terminally ill. McCall's, 105, 56.
- Thornton, R, & Nardi, P. M. (1975). The dynamics of role acquisition. American Journal of Sociology, 80(4), 870-885.
- Thrush, J. C., Paulus, G. S., & Thrush, P. I. (1979). The availability of education on death & dying: A survey of U.S. nursing schools. Death Education, 3(2), 131-142.
- Tobin, S. & Lieberman, M. A. (1976). Last home for the aged. San Francisco: Jossey-Bass.
- Turner, J. H. (1974). The structure of sociological theory. Homewood, IL: The Dorsey Press.
- Vachon, M. L. S. (1978). Motivation and stress experienced by staff working with the terminally ill. Death Education, 1, 113-122.

- Varro, B. (1980, May 2). Hospice: Humanistic approach to dying. Los Angeles Times, pp. 19.
- Veatch, R. M. & Tai, E. (1980). Talking about death: Patterns of lay and professional change. Annals of the American Academy of Political and Social Science, 447, 29-45.
- Vicker, R. L. (1979). The hospice movement in the United States. Long Term Care Health Services Administration Quarterly, 3, 253-283.
- Waitzkin, H., & Waterman, B. (1976). Social theory and medicine. International Journal of Health Services, 6, 9-23.
- Wessels, V. G. (1979). The nurse and home care of the terminally ill. In E. R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A. H. Kutscher, & I. B. Seeland (Eds.), Home care: Living with dying (pp. 49-59). New York: Columbia University Press.
- Williams, C. A. (1982). Role considerations in care of the dying patient. Image (National Honor Society of Nursing), 14, 1, 8-11.
- Williams, R. M., Jr. (1959). Friendship and social values in a suburban community: An exploratory study. Pacific Sociological Review, 2(1), 3-10.
- Williamson, J. W. (1971). Evaluating the quality of patient care: A strategy relating outcome and process assessment. Journal of the American Medical Association, 218, 564-569.
- Wilson, D. C., Ajemian, I., & Mount, B. M. (1978). Montreal (1975)--The Royal Victoria Hospital Palliative Care Service. In G. W. Davidson (Ed.), The hospice: Development and administration (pp. 3-19). Washington, DC: Hemisphere Publishing Corporation.
- Wolfe, D. (1970). Dying with dignity. Science, 168 (3938), 19.
- Woodring, S. (1979). Hospice pilot project in an acute care general hospital, 1975-1976. In E. R. Prichard, J. Collard, J. Starr, J. A. Lockwood, A. H. Kutscher, & I. B. Seeland (Eds.), Home care: Living with dying (pp. 159-164). New York: Columbia University Press.

- Woodson, R. (1979). Hospice care in terminal illness.
In C. A. Garfield, (Ed.), Stress and survival: The
emotional realities of life-threatening illness (pp.
325-342). St. Louis: C. V. Mosby.
- Wylie, N. A. (1978). Halifax (1976)--Victoria General
Hospital: A nursing model. In G. W. Davidson (Ed.),
The hospice: Development and administration (pp. 21-
39). Washington, DC: Hemisphere Publishing
Corporation.

APPENDIX A: RESPONDENT SELECTION PLAN
AND RESPONDENT PROFILES

OVERVIEW OF THE RESPONDENT SELECTION PLAN

Step_1: Program/Sites Selection (n=10)

Ten urban programs/facilities providing care to patients having late stage disease or illness were selected so that a wide range of services, philosophies, and care environments would be represented in the study. Sites selected included:

- o Hospitals (units within) (n=3; 2 "hospice-like")
- o Nursing homes (n=4; 1 "hospice-like")
- o Home care programs (n=2; 1 "hospice-like")
- o Hospice facility (n=1; autonomous program-- inpatient and home care)

Step_2: Selection of Individual Participants from the Above 10 Programs (Proposed n=100; Actual n=94)

Interviews were conducted with five groups of individuals:

- o Administrators or supervisors of the programs/ units/facilities identified above (1 per program; proposed and actual n=10)
- o Staff persons heavily involved in care of patients with late stage illness (3 per program; proposed n=30; actual n=29)
- o Elderly terminally ill patients (2 per program; proposed n=20; actual n=17)
- o Family members of terminally ill patients (2 per program; proposed n=20; actual n=18)
- o Recently bereaved family members of patients who had been cared for in the program (2 per program; proposed and actual n=20)

PROFILE OF PROGRAMS/SITES

TYPE	AVERAGE NUMBER OF PATIENTS	PATIENT AVERAGE AGE RANGE	AVERAGE LENGTH OF STAY	NUMBER OF STAFF	SERVICES OFFERED	FUNDING	SPONSOR OR PARENT ORGANIZATION	AGE OF PROGRAM	COST/DAY BASIC SERVICES
HOME HEALTH AGENCY	200; 60-80 visits per week some seen 1/week some seen 1/month	newborn-90 years average: 60 years	not available	4 RN; 1 admin; 1 HH aide; 3 PT; 1 SW; 1 MSW; 1 speech; 2 part time OT	rehab; skilled nursing; social services	private non-profit; Medicare; Medicaid; fee for service; donations; private insurance	none/self	14 years	per visit RN, \$17; PT, \$17; OT, \$10; speech, \$15/hour; HH aide, \$20/hour
HOME HEALTH AGENCY	35-40 seen 1-5/week	15-90 years, with most 40-50 or 65-70 years	2-3 months	8 RN; 1 MSW; 1 OT + 1 PT part time; 1 HH aide; 1 director of volunteers; 18 volunteers	skilled nursing; rehab; social services; 25 hour availability	private non-profit; Medicare; private insurance; donations; UGN	parent private non-profit agency		\$36 per visit
NURSING HOME	100	19-100 years; average: 80+ years	18 days	4 RN (per shift); 1 GNP; 1 DNS; 1 assistant DNS; 7 LPN; 53 aides	rehab; skilled and intermediate care; OT, PT, MSW, priest	private non-profit; fee for service; Medicare; Medicaid	fraternal organization	8 years	\$35-50 per day
NURSING HOME	94	36-102 years; average: 83-87 years	125 days	41 RN; 15-21 support staff; 10 admin and clerical	nursing skilled intermediate OT, PT, social services; rehab	private non-profit; fee for service; Medicare; Medicaid	religious organization	2 years	\$33-58 per day
NURSING HOME	105	few under 50 years	not available	90 FTE; 1 GNP; 25 RN; 50 aides; 15 LPN	skilled and intermediate nursing; rehab specifically for elderly, chronic disabled	private non-profit; fee for service; Medicare	religious order	23 years	\$35 per day
NURSING HOME	133	24-100 years; average: 82 years	171 days (12 for Medicare patients)	95 nursing (full and part time); 7 PT; 1 MSW; total 120 full time staff (6.5 RN per shift day and evening; 3 RN per night shift) not including DNS, inservice director and nursing supervisory	skilled and intermediate nursing; rehab; social services	proprietary; Medicare; Medicaid; fee for service	locally owned corporation	4 years	\$39-45 per day
HOSPITAL WARD	24	15-90 years; average: 40-50 years	1 week	17 FTE RN; 1 LPN; 3 aides; 2 unit secretaries	medical nursing; rehab; social services; acute care and terminal care	state and federal grants; Medicare; Medicaid; private insurance; private non-profit	public medical center	12 years one phase; 6 years other	\$180-200 per day
HOSPITAL WARD	8-12	not available	1-1 1/2 months (in program including home stays)	2-3 RN per shift plus RN director; no aides; PT, OT; volunteers	specialized terminal care; medical; nursing; social services; rehab	private non-profit; Medicare; Medicaid; private insurance; fee for service	religious organization; medical center	1 month	\$186 per day
HOSPITAL WARD	18-20	16-100 years; average: 50-60 years	10-14 days	4-5 RN per shift; medical supervisor; no aides; nurse coordinator; OT, PT; MSW; recreational therapist; 1 volunteer	medical nursing; acute and terminal care; rehab; social services	private non-profit; fee for services; Medicare; Medicaid	religious organization; medical center	4 1/2 years	\$220 per day \$28 per week for team services
FREESTANDING HOSPICE	8-12	21-101 years; average: 67 years men, 72 years women	1 month in program; 16 days in-patient	35 RN; 15 other; 80 volunteers	terminal care (nursing, rehab, social services)	private non-profit; Medicare; Medicaid; grant money	private foundation	5 years	\$80 per day

PATIENT PROFILE

Age	Sex	Care Settings (*denotes place of interview)	Diagnosis	Length of Illness	Prognosis	Aware of Illness
70	male	Home *Hospital	CA: prostate	7 years	uncertain: has lived one year longer than expected	yes
70	male	Home *Hospital	CA: colon	4 1/2 years	uncertain	yes
About 70 ¹	female	Home *Hospital	CA: brain tumor	7 months	uncertain	unclear, appeared to deny
60	female	Home Nursing Home *Hospital	CA: pancreas	7 1/2 years	uncertain	aware, but not talking about her illness
78	female	Hospital *Nursing Home	CA: pancreas	3 weeks	limited: 6 weeks	yes
78	male	Hospital Board & Room *Nursing Home	CA: secum	1 year	uncertain: guarded	yes
60+	female	Hospital Home *Nursing Home	CA: liver	1 1/2 years	limited	no
85	male	Hospital Home *Nursing Home	CA: stomach	2 years	uncertain: stable	yes
83	male	Home Hospital *Nursing Home	CA: bladder	3 years	uncertain: has lived nearly one year longer than expected	yes

¹Based on staff estimate or on the basis of comments in the interviews.

Age	Sex	Care Settings (*denotes place of interview)	Diagnosis	Length of Illness	Prognosis	Aware of Illness
57	male	Hospital Home *Nursing Home	amyotrophic lateral sclerosis	6 years	uncertain	yes
86	female	Home Hospital *Nursing Home	CA: abdomen (widespread)	2 years	uncertain	unclear
83	female	Hospital Home *Nursing Home	Severe CVA (stroke)	5 1/2 months	uncertain	unclear
75	female	Home Hospital Hospice *Nursing Home	CA: breast	1 1/2 years	uncertain: has lived longer already than was expected	yes
76	male	*Home	CA: colon	2 years	uncertain	yes
60+ ¹	female	Hospital *Home	CA: breast metastasized to bone	5 years	uncertain	yes
84	male	Hospital *Home	CA: bowel	4 years	uncertain: "not good"	yes
75	female	Home Hospital *Hospice	CA: pancreas	1 year	"a few months"	yes

¹Based on staff estimate or on the basis of comments in the interviews.

FAMILY PROFILE

Relationship of Respondent to Patient	Approximate Age of Respondent	Diagnosis, Length of Illness, and Age of Patient	Care Setting of Patient at Time of Family Interview	Respondent's Involvement in Care and Current Situation
Wife	70	CA, colon. Ill approximately 4 1/2 years. Age 70.	Hospital	Has cared for her husband at home. Spends her days in the hospital with him now.
Daughter	30s	CA, liver. Ill approximately 8 months. Age 58.	Hospital/out-patient treatment	Visits frequently. Seeks information from medical staff. Keeps patient and siblings informed. Has a strong support group.
Husband	early 70s	CA, brain. Ill seven months. Age 70.	Hospital	Cared for wife at home. Visits her daily now. They live several hours from the hospital. Is staying with a nephew in town.
Wife	65+	CA. Ill approximately one year. Age late 60s.	Hospital	Cared for husband at home. Visits him daily in the hospital.
Nephew	mid 60s	CA, secum. Ill approximately one year. Age 78.	Nursing Home	Closest relative to the patient. Visits him in nursing home weekly. Takes care of finances.
Wife	mid 60s	CA, larynx; stroke. Length of illness unknown, less than year.	Nursing Home	Cared for husband at home until stroke. Visits husband daily. Has health problems herself. Needs transportation to get to nursing home.
Daughter	mid 40s	CA. Ill for 2 years. Age 78.	Nursing Home	Visits father daily, works in the facility. Provides information to her brothers and sisters.
Sister	64	CA, liver. Ill about 2 years. Age 66.	Nursing Home	Lived with patient prior to illness. Cared for her at home. Visits her daily with other siblings.

Relationship of Respondent to Patient	Approximate Age of Respondent	Diagnosis, Length of Illness, and Age of Patient	Care Setting of Patient at Time of Family Interview	Respondent's Involvement in Care and Current Situation
Wife	80+	CA, bladder. Ill three years. Age 83.	Nursing Home	Is herself disabled and also a resident in the nursing home. Her husband comes to see her daily.
Daughter	late 20s	Amyotrophic lateral sclerosis, dependent on a respirator. Ill six years. Age 57.	Nursing Home	Visits frequently. Runs her father's business.
Daughter	mid 50s	Severe stroke, limited prognosis. Length of illness unknown. Age 84.	Nursing Home	Came from out of state to be with her ill mother. Visits daily. Is assisting her father with house-keeping, etc.
Niece	50s	CA, widespread. Ill two years. Age 86.	Nursing Home	Came from out of state to be with her aunt. Visits daily.
Daughter	mid 40s	Severe stroke. Ill 5 1/2 months. Age 83.	Nursing Home	Cared for her mother in her (daughter's) home. Visits daily and is an advocate.
Daughter	53	CA, breast. Ill 1 1/2 years. Age 75.	Nursing Home (discharged from hospice)	Cared for her mother at home. Visits frequently. Is also caring for her husband at home who is quite ill.
Wife	65+	CA, prostrate, bone metastasis. Ill approximately five years. Age 82.	Home	Cares for husband at home. Has received some training for this. Has a strong support system.
Wife	60s	CA, colon. Ill approximately two years. Has refused treatment. Age 76.	Home	Cares for husband at home. Has support services, but respondent feeling worn down. Daughter recently died of cancer.
Wife	80s	CA, bowel. Ill four years. Age 84.	Home	Cares for her husband at home. Husband and wife interviewed together.
Husband	early 60s	CA, pancreas, followed by stroke. Ill for approximately one year. Age 63.	Hospice	Cared for wife at home. Is in poor health himself. Visits wife daily, often bringing food for both his wife and the staff.

BEREAVED FAMILY PROFILE

Relationship of Respondent to Patient	Approximate Age of Respondent	Patient's Diagnosis, Length of Illness, Place of Death, Age at Death	Respondent's Involvement in Care	Length of Bereavement
Husband	70s	CA. Ill seven years, last episode 10 months. Spent about one week in a nursing home prior to her death in the hospital. Age mid 70s.	Had cared for wife at home. Visited her frequently in the hospital, a distance of three to four hours from home.	2 months
Daughter	40	CA, pancreas. Ill for 1 1/2 years. Spent time in and out of hospital. Died in the hospital. Age mid 60s.	Saw to her mother's care at home. Was an advocate and involved as a member of the team of providers.	4-6 weeks
Wife	late 60s	80 year old man had not been feeling well for about one year. Leukemia diagnosed during hospitalization for broken hip. Cared for at home. Died in hospital within a month of diagnosis.	Cared for husband at home. She had cancer herself several years ago.	3 months
Wife	58	CA. Ill approximately one year. Cared for at home and in the hospital. Died in the hospital. Age 67.	Cared for her husband at home.	3 months
Wife	55	CA. Ill approximately three months. Cared for at home. Died in the hospital. Age 55.	Cared for husband at home.	5 months
Wife	mid 60s	Bone marrow failure. Ill nine months. Died in the hospital at age 62.	Cared for husband at home before hospitalization. Spent nights in hospital. Was the only one who could calm her husband when he had reactions to medications.	6 weeks

Relationship of Respondent to Patient	Approximate Age of Respondent	Patient's Diagnosis, Length of Illness, Place of Death, Age at Death	Respondent's Involvement in Care	Length of Bereavement
Husband	70s	Multiple myeloma. Ill two years. Died at age 70 in her home two weeks after discharge from nursing home.	Spent nights in nursing home and was an advocate. Cared for her at home previously.	7 months
Wife	early 60s	Leukemia. Ill 20 months. Cared for in several hospitals in different parts of the country. Died at home six days after last hospitalization. Age mid 60s.	Lived in the hospital room. Kept track of medications, care. Cared for her husband at home previously.	2 1/2 months
Wife	86	CA, just over one year. Lived in southwestern Oregon, coming to Portland for care. Spent some time in hospital. Died in son's home at age 86.	Cared for her husband at home.	8 months
Wife & Daughter	70s 40s	CA, colon. Ill for three years. Had episodes in hospital and spent two months in nursing home. Died in a private home after one month. About 80 years old.	Cared for husband at home with assistance of daughter. Became worn out from the care.	2 years
Husband	64	CA, breast. Ill seven years. Last episode seven months. Died in hospice at age 61.	Cared for his wife at home before hospice. Visited daily. Has a very strong faith.	6 weeks
Brother	70s	CA. Ill two years. She died in the hospice at age 74.	Visited daily, both at home and when she went to the hospice.	1 1/2 weeks

Relationship of Respondent to Patient	Approximate Age of Respondent	Patient's Diagnosis, Length of Illness, Place of Death, Age at Death	Respondent's Involvement in Care	Length of Bereavement
Daughter & Daughter-in-law	30s	Leukemia. Ill nine months. Most care received in her home or daughter-in-law's home. Died in the hospital at age 63.	Daughter helped her mother at home, assisted in obtaining resources. Daughter-in-law cared for patient in own home for some time.	3 weeks
Daughter	mid-late 50s	Mother in poor health several years. Died in nursing home 15 days after a stroke. Age 80+.	Patient lived with daughter 10 years. Daughter visited her mother in the nursing home daily.	one month
Daughter	63	CA. Ill 1 1/2 years. Died in a nursing home. Age 80+.	Visited mother in the nursing home. Wanted to take her mother home. Patient had lived with another daughter.	one month
Cousin	40s	Cirrhosis of the liver. Died in a nursing home. Age 47.	Took care of her cousin for seven months and then was an advocate for him while he was in the nursing home.	6 months
Wife	70	CA, colon. Ill approximately 4 1/2 years. Died in nursing home. Age 65.	Cared for husband at home.	one month
Daughter	50	Had been in nursing home 5 1/2 years. Diagnosed with CA urinary tract and died within a few weeks. Age 73.	Cared for her mother in her home. Later was contact person for her mother after she entered the nursing home.	2 months
Wife	75	CA, lung, prostate. Ill for four years. Cared for at home and in the hospital. Died in nursing home. Age early 70s.	Cared for husband at home previously. Visited daily in nursing home. Now a volunteer at the nursing home.	2 months

STAFF PROFILE

Care Setting	Position	Length of Time in Position
Hospitals (n=3)	RN*, special team	4 1/2 years
	RN*, head nurse, oncology unit	1 year
	RN, charge nurse, oncology unit	1 1/2 years
	RN, staff nurse, oncology unit	2 years
	RN, demonstration program	1 month
	RN, demonstration program	1 month
	Nurse's Aide, oncology unit	1 year
	MD, Medical Director, special team	5 years
	MD, senior resident, oncology unit	5 years
	MD*, Medical Director, demonstration program	6 months
	MSW, special team	6 months
	MSW, demonstration program	6 months
Nursing Homes (n=4)	Administrator*	7 months
	Administrator*	2 1/2 years
	Administrator* (RN)	1 1/2 years
	Administrator*	7 months
	Geriatric Nurse Practitioner	16 months
	RN, supervisor	4 months
	RN, supervisor	18 months
	RN, staff nurse	11 months
	RN, staff nurse	23 years
	RN, staff nurse	8 months
	RN, mental health specialist	3 years
	Nurse's Aide	7 months
	Nurse's Aide	7 months
	Social Service Director	2 years
	BSW	6 months
	Chaplain	8 years
Home Health Programs (n=2)	RN*, team manager	2 years
	RN*, supervisor	6 months
	RN	18 months
	RN	5 months
	Home Health Aide	5 1/2 months
	MSW	2 years
Freestanding Hospice (n=1)	BSW	10 months
	Administrator* (SW)	6 months
	RN, head nurse	4 months
	Medical Director	3 years, 3 months
	Family Service Worker	1 month

*Interviewed as program administrator or supervisor

APPENDIX B: INTERVIEW SCHEDULES

PATIENT INTERVIEW SCHEDULE

We're interested in learning more about the care of people who are seriously ill--things like what kinds of care are given, what makes care good, what makes it poor and the things about care that are most important to very ill people. Your thoughts as a person who is experiencing a serious illness will be of great value to us, and I appreciate your willingness to let me come and talk with you.

Because I want to be sure that I don't miss any of what you say or change your words somehow, I'd like to tape record the interview, if you don't mind. The tape and the interview are completely confidential, and they'll be used only by me and my staff. If at any time you would like for me to turn off the recorder, just let me know. Let me emphasize, though, that what you say will be kept confidential. In our report, neither your name nor any personal information will be used when we describe the study's findings.

Before we begin, I need to ask you to read and sign this form, which states that you agree to participate in the research. It's something the University requires us to do for your protection, to make sure we've explained to you what the study involves. (HAND RESPONDENT INFORMED CONSENT FORM; READ TOGETHER IF APPROPRIATE). Do you have any questions?

1. When someone has been ill for a period of time, he or she has usually received care in a number of places, such as hospitals, nursing homes, clinics, doctor's offices, and at home. Since you discovered you were ill, where have you received care? (PROBE: When was this?)

Settings

When There

2. Who are all the people who have been involved in your care, and what have they done? (PROBE: Let's start with where you are now and who is taking care of you here, and then we can work backwards).

Name/Position

Where/Care Setting

What Done

(PROBE: Who else has played a part of your care? IF HAVEN'T MENTIONED ONE OR MORE OF THE FOLLOWING, ASK: What about _____?)

What did (or do) they do?

Physician

Nurse

Nurse Aide

Volunteer

Social Worker

Physical, Occupational, or

Recreational Therapist

Home Health Aide or
Homemaker
Dietician
Clergy
Relatives
Friends

Anyone else? What did (or do) they do?

3. In general, we're interested in the characteristics and behaviors of these people that enable them to provide good care. Now that we've been talking about all the people who have been involved in your care, I'd like you to think about three you've liked particularly well. What about them do you like or did you like the most? (PROBE: IF DON'T MENTION BEHAVIORS, ASK: What did they do that you liked?)
4. What about three persons whom you have not liked so much or with whom you have been somewhat dissatisfied? What about them or what they did (or do) would you like to change?
5. For many people, where they are being cared for is very important. Where would you most prefer to be cared for?
6. (IF DIFFERENT THAN CURRENT SETTING, ASK: What would make it possible for you to be cared for at _____?)
7. You mentioned that you've been cared for (LIST PLACES, Q. 1--e.g., in the hospital, a nursing home, by doctors in their offices, in your own home)?

What are the best things about (PRESENT SETTING)?
What is most difficult for you about being here?

What were the best things about (ASK FOR EACH PREVIOUS CARE SETTING)?
What was most difficult about being cared for there?

<u>Type of Setting</u>	<u>Best Things</u>	<u>Most Difficult Things</u>
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8. We've been talking about people who provide care and places where care is given. Now I'd like to talk a little about the needs of people who are (seriously ill, have cancer--CHOOSE APPROPRIATE). If you were asked to give a talk to a group of medical and nursing students, what would you tell them about the needs of people who are (very sick, seriously ill, have cancer--CHOOSE APPROPRIATE)?
9. What would you say have been your greatest needs? (PROBE:
10. What are the things that are concerning you most right now?
11. Let's go back to the group of medical and nursing students. What would you tell them about the needs of the family of people who are very sick?

12. What needs of patients and families do you think staff are most likely to be unaware of or unresponsive to?
13. Some people have said that serious illness is often a "bringing together" time for families. Others have said that their family has fallen apart, that their relations with their family have broken down because of their illness. What has your experience been? (PROBE: What has happened with your family since you've been ill?)
14. In what ways may the needs of older people who are seriously ill differ from those of younger people who have a similar illness?
15. Some people feel that care provided to older persons who are very ill differs from that provided to younger people with the same illnesses. From what you've observed and experienced, how does a person's age affect the care provided to him or her? (PROBE: in terms of amount, kind, where it's provided, staff attitudes, etc.)
16. Looking back over what we've talked about, what would you say good care for people who are seriously ill consists of? (PROBE: What is involved in the provision of good care to people like yourself? If you had to decide whether the care given to someone who was seriously ill was good or bad, what things would you consider in your decision?)

17. I have one last set of questions which includes things which some people think are important for good care. (HAND-RESPONDENT SHEET) I'd like for you to tell me whether, in your opinion, each one matters a great deal, matters somewhat, or doesn't matter in the care of someone who's very ill. Do you think it matters a great deal, matters somewhat, or doesn't matter that...
- | | | | | |
|----------------------------|--|--------------------------|--|-----------------------------|
| MATTERS
A GREAT
DEAL | | MATTERS
SOME-
WHAT | | DOESN'T
MATTER
AT ALL |
|----------------------------|--|--------------------------|--|-----------------------------|

a. Care is available day and night, 7 days a week.				
b. Patients are kept informed of their condition and what's being done.				
c. Doctors and nurses sit, talk, and listen as well as attend to patients' physical needs.				
d. Care is given to patients in their own homes.				
e. Patients' families have a say in the patients' care				
f. Training is available for patients' families on home care techniques and equipment.				
g. Training is given to patients so they can care for themselves .				
h. Pain medication is given on a regular basis without patients asking for it.				
i. Patients' families help care for the patient.				
j. Several people, in addition to doctors and nurses, provide care such as a social worker, physical or occupational therapist .				
k. Friends visit often				
l. Patients decide who their visitors will be and when they can visit				
m. Patients decide how much and what kind of care they get				
n. Patients have activities and things to keep them occupied . . .				
o. Services be provided for patients' families as well as for patients				
p. A chaplain or other clergy person visits with the patient and the family often.				
q. Care is available to all, regardless of their ability to pay.				
r. Financial advice is available for patients and families				
s. Legal help is available for patients and families				
t. Patients' private physician is involved in their care throughout their illness				
u. Patients choose when and what they want to eat.				
v. Someone is responsible for keeping track of all the things that are going on regarding patients' care (no matter <u>where</u> they're being cared for).				

Those are all of the questions I have. Is there anything that you feel I should have asked or that you would like to add? You've been very generous to let me come to do this interview. I really appreciate your time and effort.

Thank you very much.

STAFF INTERVIEW SCHEDULE

We are interested in learning about caring for people who are terminally ill, that is, people who have a life-threatening illness with a limited prognosis. Specifically, we are trying to identify the types of care and services given to people who are terminally ill, the needs of these persons, the features of care most likely to meet their needs, and factors which facilitate or impede the provision of good care. Your thoughts and experiences as a staff person here will be of great value to us, and I appreciate your willingness to share them with me.

Because I want to be sure that I don't miss any of what you say or inadvertently change your words somehow, I'd like to tape record the interview, if you don't mind. The tape and the interview are completely confidential, and they'll be used only by me and my staff. If at any time you would like to turn the recorder off, all you have to do is press this button on the microphone and the recorder will stop. Let me emphasize that the interview and the tape are confidential; in our report, the findings will be reported in the aggregate and your responses will not be identifiable to you.

1. First, what exactly is your position and your title here?
2. Did you work with the (program/organization) before you became (JOB TITLE)?
 - 2.a. (IF YES, ASK:) How long and in what capacity?
3. How long have you been (JOB TITLE)?
4. What would you say are the goals of this (program/facility/ward)?
(PROBE: That is, what are its treatment aims or the desired outcomes?)
5. What are the training/experience requirements for a (POSITION/TITLE) here?
6. In your opinion, what characteristics should staff possess in order to be able to provide good care for the dying?
7. About how many patients, on the average, do you care for each week?
8. How many of these are terminally ill, that is, in danger of imminent death?
9. How many of your terminally ill (late stage disease) patients are elderly (65 and over)?
10. About what proportion of the elderly patients you care for have family members whom they see regularly? (PROBE: That is, at least once a week?)

Now I'd like to ask you to think in general about dying people and their families.

11. First, when do you begin considering someone as being "terminally ill?"
(PROBE: What factors are involved in this decision?)
12. From your observations both here and in other care settings, how is care given to terminally ill patients different from that given to those who may be seriously ill but who have more positive prognoses?
13. On the basis of your experience, what do you see as the greatest needs of persons who are terminally ill? (PROBE: How would you rank these needs-- what is most important, next most important, etc.?)
14. What about their families, what are their greatest needs? (PROBE: How would you rank these needs in terms of their importance?)
15. Which needs, of both patients and families, do you think they themselves would be less likely to perceive, and why is this so?
16. Which needs might they be less likely to admit, and why?
17. In what ways may the needs of older people who are terminally ill differ from those of younger people with similar illnesses?
18. Some of the people we've talked with have indicated that care provided to older persons (65 and over) who are terminally ill frequently differs from that provided to younger persons in similar situations. In your experience, how does a patient's age affect the care provided to him/her? (PROBE: How does care differ in terms of amount, kind, place of delivery, duration of service, staff attitudes, involvement of family, etc.?)
19. (IF NOT ALREADY INDICATED, ASK:) How do you feel about this?

Now I'd like to ask you to think about what things help and what things hinder the (program/facility/ward) in attaining its goals?

20. As (JOB TITLE) of this (program/facility/ward), what do you see as the greatest barriers to providing the kind of care you would like to provide?
21. (See next page.)
22. On a more positive note, what kinds of things facilitate provision of good care? (PROBE: What factors, things about the program, patients, enable you or other program staff to provide the kind of care you would like to see provided?)
23. I'd like you to think of three patients whose care you felt went particularly well and that left you feeling satisfied. What were the circumstances surrounding the care for each of these patients and what about their care satisfied you?

24. What about three patients whose care you feel did not go so well and that left you feeling dissatisfied? What were the circumstances surrounding the care for each of these patients, and why did you feel dissatisfied?
25. We've been talking about several factors which affect the provision of good care to people who are dying. What exactly would you say good quality care is? (PROBE: What elements comprise quality care?)
26. (IF MORE THAN ONE ELEMENT MENTIONED, ASK:) How would you rank these various elements in terms of their relative importance for the provision of quality care? (PROBE: Which is the most important, the next most important, etc.?)
27. What results would indicate that quality care was given? (PROBE: How would you determine whether the care provided was of high quality?)
28. We're almost done now. Patients, families, different care providers, including doctors, nurses, social workers, administrators, etc., may have different perspectives on what makes care good. In this study, we're talking with care providers, dying patients and their families about quality care. What differences in opinions about what quality care is do you think we can expect to find between these groups of people? (PROBE: How do you think patients' perceptions of quality care might differ from their families'? How do you think your perceptions of quality might differ from those of other care providers? Maybe it will help if you think about specific cases in which there have been disagreements about how the care should proceed--tell me about these cases.)
29. (See Q. 17, Patient Interview Schedule)
30. Finally, one last question: In general, what recommendations would you make for assuring that quality terminal care is provided by a program or facility? (PROBE: What policies should be followed? What regulations should be enacted?)

Well, I think we've covered everything that I had hoped to cover. Is there anything that you feel I should have asked or that you would like to add?

This has been very helpful and, again, thank you for taking the time to talk with me.

