GUIDELINES TO ASSIST ADVANCED PRACTICE NURSES IN DISCUSSING END-OF-LIFE DECISIONS WITH CHRONICALLY ILL ADULTS AND FAMILIES

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By

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ABSTRACT

GUIDELINES TO ASSIST ADVANCED PRACTICE NURSES IN DISCUSSING END-OF-LIFE DECISIONS WITH CHRONICALLY ILL ADULTS AND FAMILIES

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The purpose of this project is to provide clinically useful guidelines to assist APNs, serving in the role of primary care provider, in discussing end-of-life treatment decisions with chronically ill adults and their families. A majority of patients want to participate, with their families and health care providers, in making decisions about their end-of-life care. Primary care provides an ideal setting for ongoing discussions of end-of-life treatment options.

Patients and families need a framework for the consideration, discussion, and documentation of treatment options in advance of a medical emergency. Decision making and the completion of advance directives, prior to an onset of incompetence, can help relieve families from making difficult decisions under duress, and increase the likelihood that medical treatment will be provided according to the patient's wishes. APNs have the expertise and the opportunities to assist patients and their families throughout the process of end-of-life decision making. The literature, however, provides few guidelines to assist the practitioner in this endeavor. This expanded nursing role needs to be recognized, developed further, and evaluated for its impact on the end-of-life care provided for chronically ill adults.

To my parents,
for their ongoing love and support.

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We do not see things as they are.
We see them as we are.
-- The Talmud

TABLE OF CONTENTS

CHAPTER I

CHAPTER II

CHAPTER III

CHAPTER IV

CHAPTER V

APPENDIX

CHAPTER I

Statement of the Problem

Problem Identification

The process of coping with chronic illness is ongoing, and requires individuals to confront, however reluctantly, both their own mortality and the concept of quality of life. Chronically ill patients often experience a long period during which further diagnosis and treatment either improves or maintains quality of life, or just adds unnecessary burden. Most patients want to be told the truth about their condition, and they want to participate, with their families and health care providers, in decisions about their end-of-life care (Johnson & Justin, 1988). Although it is difficult to define the "end-of-life" prospectively for any given patient, for the purpose of this project the concept is intended to represent the end stage of a chronic illness. This stage may encompass the final days, weeks, or months of a person's life, and is typically characterized by a downward trajectory of debilitation. End-of-life decisions are the choices made by an individual regarding his or her continuing care or treatment options for this end-of-life stage (Wesley, 1996).

Those who wish to direct the treatment they will receive at the end of their life must spell out their wishes clearly, convincingly, and in advance. (Hill & Shirley, 1992). Too often, families are pressured to make complex decisions at the bedside of their hospitalized, severely ill loved one, during the last days of his or her life. Decision making prior to a possible onset of incompetence can help relieve families from making difficult decisions in a crisis situation, and better assure that medical treatment is customized according to individual preferences.(Americans for Better Care of the Dying [ABCD], 1997).

Primary care assumes a continuum of care, and provides an ideal setting for ongoing discussions of end-of-life issues (Schlenk,1997). Patients and families need a framework for the consideration, discussion, and documentation of these issues in advance of a medical emergency. Advanced Practice Nurses (APNs) have the expertise and the opportunities to provide assistance to patients and families throughout this decision making process, however there is little information in the literature to guide them in this endeavor. The purpose of this project is to develop guidelines to assist APNs, in the role of primary care provider, in discussing end-of-life treatment decisions with chronically ill patients and their families.

Background of the Problem

America is a death-denying culture. Much of our individual and communal energy is spent in trying to shield ourselves from the understanding of death as a natural part of life (deBlois, 1994). In today's society, death is regarded as a medical event, managed by health care professionals, and taking place primarily in institutional settings (Matzo, 1997). While technology has introduced the means to prolong life for many people, it has also created new possibilities for how death occurs, resulting in both a change in societal attitudes, and confusion about the act of death itself (Haisfield-Wolfe, 1996). Whereas in the past death occurred most often as a result of an acute illness or sudden event, today's death is likely to come only after a long series of attempts to forestall the inevitable. In the

1990's most Americans die as a result of withholding or withdrawing some form of treatment, often after aggressive methods have been exhausted (Webb, 1997). As a society, we choose to ignore the fact that while medical technology can sometimes prolong life, it cannot prevent death (Haisfield-Wolfe, 1996).

Too often, medical technology, rather than sustaining life, merely prolongs the dying process. Often, the burden of treatment seems to outweigh its benefits. When this occurs, important questions are raised regarding the quality and meaning of life, concepts patients and their families may be confronting for the first time. Nurses and physicians in acute care settings, are all too familiar with the anguish families express when they are confronted with the necessity of making difficult decisions at the bedside of their critically ill family members. Anxious and confused, families attempt to sort through complex information, while at the same time trying to cope with the potential loss of their loved one.

When patients are unable to participate in decisions related to their care, families agonize over questions about what their relative would want done. Research demonstrates that most people, even with the best of intentions, cannot reliably predict which interventions their family members would have chosen (Perrin, 1997). When patients and families discuss these issues prior to a medical crisis, there is a greater likelihood that end-of-life care will be provided in accordance with a patient's values, wishes, and treatment goals (ABCD, 1997).

The issue of self-determination is central to end-of-life decision making. Patients who are conscious and mentally competent have long had the right to make decisions concerning their own medical treatment. Court cases and common law have repeatedly upheld the right of the individual to make his or her own medical decisions, even when family members and health care providers disagree with those decisions, or when those decisions may result in death (Webb, 1997). The right of a person to make decisions and act in accordance with his or her own values and belief systems underlies all debate, with most people concerned not only about avoiding suffering in the last stages of life, but also about maintaining dignity and some level of control (Wesley, 1996). In an attempt to guarantee that their wishes will be followed, approximately 15 % of Americans have completed some type of advance directive, or "living will". Although it is not the intention of this project to examine the legal and bureaucratic issues surrounding advance directives, it is recognized that documenting advance directives is an important component surrounding the end-of-life decision making process.

Family members need understanding and support as they work through the end-of-life decision making process with their loved one. They need time to come to terms with the approaching death of their family member, and to begin to adjust to how that death will affect their own lives. The emotional work of the family members includes an intense search for the meaning of the dying person's life, and of their own life in relation to that person (Swigart, Lidz, Butterworth, Arnold, 1996). As part of the anticipatory grieving process, patients and family members begin to move through a period of preoccupation with the disease state and ways to fix it, and then towards a gradual realization that loss is inevitable. For the purpose of this project, the term "family" will refer to whoever the patient defines as such, without restriction to conventional social norms.

Making end-of-life decisions in a crisis situation is extremely stressful for both patients and their families, and there can be long term consequences for individuals who later regret decisions made in haste or under duress. The stress escalates if there has been family conflict and dissent surrounding these decisions, and relationships can become permanently strained. Advanced Practice Nurses can be an important source of information and support throughout the decision-making process, in part by promoting honest, open communication between patients and their families prior to such a crisis situation.

A discussion of patient's preferences for end-of-life care is an important component of health maintenance, and should be routinely integrated into the annual physical exams of all adults. This project, however, will focus specifically on the discussion of these issues with chronically ill adults who are in the later stages of their illness trajectory, within the context of the primary care relationship.

A majority of Americans today die as a result of chronic illness, primarily heart disease, cancer, cerebrovascular disease, and lung disease (U.S. Bureau of the Census, 1997). For most people with chronic disease, death occurs after a long-term, debilitating decline (Webb, 1997). Too often, health care providers seem to forget the "whole" patient, providing treatment system by system, organ by organ, and viewing death as the ultimate medical failure. Modern medical textbooks emphasize treatment, not the normal course of disease, as if each individual crisis, if treated correctly, would somehow not lead to death eventually (Webb, 1997). An unfortunate result of this perspective is that patients themselves are often not told, and therefore do not understand, the natural course of their illness. Patient's may therefore be unprepared to make treatment choices in the context of what is appropriate or beneficial at a particular stage of their disease. Patients and families need to understand both the burdens and the benefits of treatment options in order to determine what is most likely to result in an improved quality of life, not just a prolongation of dying.

As primary care providers, APNs possess the expertise necessary to help patients and families understand the natural course of an illness, the possible treatment options, and the potential risks and benefits of these options (Given, 1995). Equipped with this information, patients can make informed decisions about their care consistent with their individual preferences, values, and treatment goals.

Purpose of the Project

The purpose of this project is to develop guidelines to assist APNs, in the role of primary care provider, in discussing end-of-life treatment decisions with chronically ill adults and their families. These guidelines are intended to provide a context for decision making, in order to help patients and families begin to consider these difficult decisions. Using Peplau's theory of interpersonal relationships as a framework, these guidelines were developed from a literature review of the concepts of chronic illness, quality of life, decision making, and end-of-life treatment options and goals. Using the guidelines presented here, APNs can help their patients to contemplate the concept of quality of life, to better understand their disease trajectory and the implications of treatment options, to formulate decisions within the context of their treatment goals, to discuss their wishes with their providers and the important people in their life, and to document their wishes appropriately. The underlying principles of these guidelines are intended to respect and preserve the patient's right to self-determination, to help clarify patient's individual treatment goals, and to reduce conflict among patients, families, and health care providers.

Advanced Practice Nursing and Primary Care

In 1993, the American Nurses Association defined Advanced Practice Nurses as "professional nurses who have successfully completed a graduate program of study in a nursing specialty or related health care field that provides specialized knowledge and skills forming the foundation for expanded practice roles in health care" (American Nurses Association, 1993). Although roles and titles vary, for the purpose of this project the umbrella term "Advanced Practice Nurse" will refer to a Master's prepared Nurse Practitioner or Clinical Nurse Specialist who is licensed as a Registered Nurse, and certified by a national nursing organization and/or a State Board of Nursing. In the past, it is primary care that has made the most effective use of non-physician practitioners (Havens & Evans, 1995). While APNs in primary care have been shown to mirror the diagnostic and management effectiveness of primary care physicians (OTA, 1986), they also have strengths in nursing areas that are traditionally lacking in the medical model, such as a more holistic paradigm that focuses on prevention, adaptation, education, counseling, access to community resources, and health promotion (Mudinger, 1994).

Primary care is defined as the basic level of care, providing preventive, curative, and rehabilitative services to maximize health and assist individuals toward their optimal level of well-being (Starfield, 1992). Seeking to integrate multiple health problems, primary care addresses the context in which illness exists, and strives to influence individual responses to health problems. Primary care assumes the responsibility for managing and coordinating an individual's care throughout the entire health care process, assuming responsibility for continuity as well as continuum of care: from health maintenance to symptom management or referral (Michigan Primary Care Association, 1991). Primary care delivers a range of basic health care services, treating self-limiting illnesses and minor disability, as well as chronic and incurable health problems. Primary care is intended to fulfill the patient's potential for physical, social, spiritual and emotional well-being, providing the stabilizing human support needed by patients and their families in times of health-related crisis (Given, 1995). Not limited to the course of a single episode or illness, primary care implies a continuing responsibility, in which the relationship between patient, family, and health care provider is paramount, and ongoing.

Advanced practice nurses possess the knowledge base, clinical expertise and holistic perspective necessary to play an integral role in helping chronically ill patients begin the process of end-of-life decision making. Research demonstrates that the discussion and development of an end-of-life treatment plan can help decrease patients depression, and enhance patients perception of being cared for, and in control (Miles, Koepp, Weber, 1996). Because of the continuity of care intrinsic to primary care, the primary care setting provides an ideal opportunity for APNs, who have formed ongoing, trusting relationships with their patients, to assist patients and families through the end-of-life decision making process.

CHAPTER II

Review of the Literature

The focus of this project is on the development of clinically useful guidelines to assist APNs to help chronically ill adults and their families in the process of making decisions about end-of-life care. Included in the foundation of these guidelines, are the concepts of chronic illness, quality of life, decision making, and end-of-life treatment options and goals. In order to accomplish the goals of this project, the above concepts were reviewed from the perspective of both nursing and medical literature, and examined within the context of Peplau's theory of interpersonal process. The literature review that follows will include information relevant to these issues, which have been identified by the author to be important components of the end-of-life decision making process.

Chronic Illness

Over the past century, advances in medical technology have resulted in a dramatic decrease in mortality from communicable and other acute diseases. This decrease in mortality from acute illness has led to longer life spans, which in turn leads to greater vulnerability to accident and disease events that result in chronic conditions (Lubkin, 1995). Because of this, the prevalence of chronic disease has increased dramatically, and is now the leading cause of morbidity and mortality in the United States. Nearly 50% of the population has one or more chronic conditions, with the greatest proportion of chronic illness affecting the older population. Almost 85% of those over 65 in the United States suffer from one, or more, chronic disorder (Hymovich & Hagopian, 1992).

The literature reveals a variety of definitions for the term chronic illness, with some too simplistic i.e. "a degenerative illness", and others so complex or narrow, that they are difficult to apply to diverse situations (Lubkin, 1995). For the purpose of this project, chronic illness will be defined as: a state of unwellness produced by disease or disability, which requires medical and social intervention over an extended interval, and affects myriad aspects of an individual's life (Lubkin, 1995). Chronic illness will be discussed in the context of individual adaptation and decision-making, rather than as it relates to a specific diagnosis. The need for health care professionals to see chronic illness as more than its pathology is essential for providing optimal support and interventions.

Chronic conditions are long term by nature and, as such, they require repeated interactions over months and sometimes years, between patients and their health care providers. Successful management of chronic illness requires the establishment of a collaborative patient/family/provider relationship that is based on mutual trust and respect (Meyer, 1993). APNs should make every effort to empower patients and their families to develop a high level of responsibility and involvement in the management of chronic illness, including them as primary participants in every aspect of the information gathering and decision-making process. This partnership of care requires an ongoing information exchange between all members of the triad. Chronic illness was chosen as a focus for this project, in part, because of the relationship between patients, families, and providers that results from the long term nature of the disease, and, in addition, because a chronic illness trajectory often presents frequent junctions that require decisions about treatment options and goals.

Unlike medical emergencies or curable diseases, chronic illnesses are usually long-lasting and without cure. The course of chronic illness, its severity, how often it will require treatment, and how limiting it will be from day to day, is unpredictable and varies from patient to patient. Because of its duration and its limiting nature, a chronic illness tends to affect all aspects of a person's life: self-esteem, relationships with others, and hopes and dreams for the future, as well as functional abilities and physical well-being. Problems that are frequently faced include intrafamily stresses, social isolation, fears of dependence, economic stresses, and the threat of death (Lubkin, 1995).

The course of any disease follows some type of general trend or trajectory, depending on the specific disease entity, its severity and rate of progression, and an individual patient's unique response to the disease. In the past, illness trajectories were fairly predictable, but the advent of new technology has dramatically altered such courses. Because of the dynamic nature of illness, trajectories can never be predicted with certainty; however, each type of disease has some general characteristic shapes and patterns associated with its projected course (Hymovich & Hagopian, 1992). For example, in some diseases a downward trajectory is typical, varying in speed but progressing steadily in severity, with few periods of relief. In other cases, the trajectory varies up and down, with episodic periods of exacerbation and remission, followed by gradual or dramatic decline. The latter can be especially stressful because of the uncertainty surrounding when relapses will occur, and what the residual damage will be.

Understanding the general characteristics of an illness trajectory is important for patients and families, because it provides a context from which end-of-life decisions can be made.

Trajectory projection is a concept which refers to the vision of an illness course, and is perceived differently by each individual who is involved in the illness and its management. This projection is an attempt to predict the way an illness is likely to progress, what will happen in the future, how long it will take, and what actions will be taken as a result of the projected trajectory (Corbin & Strauss, 1993). Trajectory projection provides the basis for the development of a prognosis, which has been shown to be a key factor in public opinion regarding end-of-life decisions. For example, in one study, 85% of respondents supported laws permitting decisions to forego life-sustaining treatment, and assisted suicide, for patients who have a poor prognosis for recovery (Singer, Choudrey, Armstrong, Meslin, Lowy, 1995).

Since perceptions are unique to the individual, and depend, in part, on a knowledge base gained from one's own experience, or the experiences of family members or acquaintances, there is often a difference between the professional's view of the projected course and the patient's view. The patient is less likely to focus on pathophysiology, and more likely to focus on the effects and burdens of symptoms, and on anxieties and concerns about the future (Lubkin, 1995). Family members have their own trajectory projection, which may be entirely different from the patient's, or the provider's, sometimes resulting in intrafamily conflict regarding treatment goals and decisions. APNs must be sensitive to the differing perceptions of providers, patients, and family members, facilitating open and ongoing discussions with all participants in the end-of-life decision making process.

The role of the APN in the care of their chronically ill patients is complex, and may vary throughout the phases of an illness. There should, however, be a consistent focus on the exchange of information between members of the patient/family/provider triad. Educating patients and their families about the disease process, the illness trajectory, and the risks and benefits of treatment options is an important role for the APN as primary care provider. For example, helping patients and families understand the process of CPR, and the odds of surviving neurologically intact for patients in the end stages of chronic illness, is essential prior to decision making about patient's resuscitation preferences (Puopolo, et al., 1997). However, only the patient can determine which treatments offer the wished for benefits, at an acceptable level of risk and burden (Lubkin, 1995). APNs must support their chronically ill patients in asserting their right to define their own concept of quality of life, and to make treatment decisions accordingly.

Quality Of Life

An analysis of quality of life, both present and future, is intrinsic to the process of end-of-life decision making. Although the term "quality of life", in itself, does not appear in dictionaries, the phrase is common to everyday conversation in American culture. There are multiple references to quality of life in the psychology, sociology, and health care literature, where it often serves as a standard to evaluate, or validate, certain practices and outcomes (Draper, 1992). Quality of life measurements are used to justify or refute different forms of medical treatment, and to provide a basis for allocating resources to those treatments judged to be most cost-effective (Goodinson & Singleton, 1989). Additionally, the phrase "quality of life" seems to come up whenever ethical issues in health care are discussed, particularly when the issue is euthanasia, or the withdrawal or withholding of medical treatment. In fact, Brody (1990) identified the quality of patients' lives to be one of the most crucial issues in medical ethics. Recurrent references to quality of life in the health care literature reflects a growing realization that the well-being of patients is an equally important consideration when treating them as are cure and sustainment of life (Meeberg, 1993). The frequent use of the term "quality of life" would seem to indicate a commonly understood concept of its meaning; review of the literature, however, indicates otherwise.

An extensive concept analysis of "quality of life" reveals no clear or consistent definition of the term. This lack of a singular definition leads to inconsistencies in interpretation, and makes it difficult to separate the concept from related concepts, or to measure it accurately (Bond, 1996). In general, the term quality of life implies the value or excellence of life. The word quality is used in an evaluative sense, and there is an implied comparison to the quality of life of others, or to one's earlier life. Quality of life, therefore, exists in varying degrees, and contains both subjective and objective elements (Bond, 1996). The objective attributes relate primarily to quantity of life, whereas subjective attributes are more likely to address the self-assessment of life satisfaction and well-being as components of quality of life.

The elements that comprise quality of life are complex and variable, and can be organized into broad classifications of function and perceptions. The following general categories are derived from the social science literature on life satisfaction and quality of life: memory, mood, physical health, functional ability, interpersonal relationships, psychological well-being, life satisfaction, participation in religious activities, environmental comforts, and amount of physical discomfort (Pearlman & Uhlmann, 1988). Meeberg (1993) identifies four critical attributes of quality of life based on characteristics that appear repeatedly in the literature. These attributes include: a feeling of satisfaction with one's life in general, the mental capacity to evaluate one's own life as satisfactory or otherwise, an acceptable state of physical, mental, social and emotional health as determined by the individual, and an objective assessment by another that the person's living conditions are adequate and not life-threatening. While an assessment of another person's quality of life can be, and often is, evaluated by others, the focus of this project is on the more important self-assessment aspect of quality of life, in which the opinions of others may be but one component of a more global definition of an individual's quality of life.

Based on an extensive concept analysis, quality of life is defined here as "the cognitive capability to evaluate one's own life, a satisfactory state of social, emotional, physical and mental health, and an acceptable feeling of satisfaction and well-being, despite physical limitations, by both subjective and objective criteria" (Bond, 1996). However, this author agrees with Bond (1997), who states that the simpler and more direct definition "quality of life is whatever the patient and family say it is", may be more appropriate, especially in end-of-life decision making.

There is much discussion in the literature regarding the value of objective criteria in defining quality of life. In general, objective criteria such as socioeconomic status, level of functional status, and adequacy of housing, has been thought to play a significant role in the measurement of quality of life, however, support for this opinion has been inconsistent in the literature (Goodinson & Singleton, 1989). Interestingly, the evaluation of subjective elements by another is considered to be an "objective" element of the definition (Bond, 1996). Quality of life is a value-laden concept, and it is important to be sensitive to the difficulties that can arise when one person attempts to define quality of life for another.

Research demonstrates that health care providers' perception of quality of life differs significantly from that of patients (Bond, 1996). Based on individual values, as well as past negative (or positive) experiences, health care providers may feel quite capable of judging their patients quality of life. Those patients deemed by others to have a low quality of life may be less likely to be offered certain treatment options at all. When advanced directives are absent, or unclear, physicians often try to consider patient quality of life in order to justify treatment decisions made without knowing their patient's wishes (Pearlman & Uhlmann, 1988). This situation becomes especially problematic because of the value-laden aspect of these decisions, and, in the absence of direct information, the potential for judgement errors regarding patient's wishes.

Successful adaptation to chronic illness includes a conception that one's quality of life is worth the struggle (Lubkin, 1995). Illness is only one of the multiple factors that influence an individual's perception of their quality of life, and, in fact, research has demonstrated that quality of life can be perceived as quite good despite declining physical health. In a study of elderly outpatients with five common chronic diseases, global quality of life was found to be good across the five disease states (Pearlman & Uhlmann, 1988). Approximately half of the patients cited at least one event that recently improved their quality of life. Characteristics of the illness, patient's age, degree of combined disability, and the extent of medical intervention required to maintain a condition, are some of the factors that had an impact on an individual's assessment of quality of life. In general, issues pertaining to emotional, social, and intellectual functioning, as well as financial status and housing, only marginally affect patient's perceived quality of life. It is interesting to note that, again, physicians rated their patients' quality of life as being significantly worse than their patients did (Pearlman & Uhlmann, 1988).

In another study, health care providers and patients with spinal cord injuries (SCI) answered the same questions related to quality of life. The results demonstrated few differences between the patients and providers in regard to perceptions of their own quality of life. However, when the providers answered questions about the quality of life for SCI patients, the results differed dramatically. Ninety-two percent of the SCI patients rated their quality of life in positive terms, whereas only 18% of the providers felt that there would be a positive quality of life after a SCI (Bond, 1996).

The concept of quality of life is often embedded in end-of-life treatment decisions, particularly in the risk-benefit component of the process. Because many medical treatments have the potential to impose burden, it seems reasonable to consider whether

When quality of life is used as a basis for treatment decisions, health care providers are cautioned to be cognizant of the subjective and value-laden nature of this assessment.

Many chronically ill patients perceive their quality of life to be quite good, despite hardships imposed by their illness. Patients who are relatively comfortable and who believe that there is some degree of high quality of life left may be willing to undergo a variety of possibly difficult medical treatments aimed at prolonging or improving their lives (Hill & Shirley, 1992). For others, quality of life may be poor and suffering excessive. These patients may prefer a goal of palliative care, refusing any medical interventions that they perceive will only prolong the dying process. Health care providers may believe it is their obligation to provide the intervention most likely to succeed in diagnosing and solving acute problems, and may not consider each decision in the broader context of burden versus benefit, as it relates to the patient's self-assessment of quality of life (Fried & Gillick, 1994). For the purposes of end-of-life decision making, the patient's subjective perceptions are considered the most appropriate measures of quality of life (Pearlman & Uhlmann, 1988).

Decision Making

Inherent in any end-of-life treatment decisions is the ability to form and express preferences. Decision-making is defined as the process of judging the best course of action, after the deliberation of alternatives (Radford, 1994). The essence of decision making, according to the literature, is the formulation of alternative courses of action and making, according to the literature, is the formulation of alternative courses of action and the act of choosing between these alternatives after an evaluation of their likely effectiveness in achieving the decision maker's objectives (Radford, 1994).

There are four basic considerations that must be taken into account in any decision situation. These include: (a) the information available to form a basis for decisions, (b) the costs and benefits of a course of action, (c) the number of objectives, or goals, involved in the decision, and (c) the number of participants that have an interest in the decision being made. Decision making can be straightforward when there is complete information, a single objective, the ability to evaluate benefits and costs in quantitative terms, and a single decision maker (Radford, 1994). Unfortunately, end-of-life decisions are rarely, if ever, this simple.

A fundamental component of any health care decision is information. Without knowledge and information, neither health care providers, nor patients and their families, are able to participate effectively in treatment decision making (Degner & Beaton, 1987). In order to make decisions about their care, patients and families need information about the illness, its expected trajectory, treatment options, and the likely benefits and burdens of these options. It is unfortunate that the majority of this information, by its very nature, is fraught with uncertainty, as this adds to the difficulty of any decision making process (Radford, 1994). Uncertainty is the inability to determine the meaning of events, and occurs in situations where the decision-maker is unable to assign definite values to events or is unable to accurately predict outcomes (Mishel & Braden, 1988).

When first diagnosed with a chronic illness, patients may feel too overwhelmed to ask questions of any kind. At this stage of the illness, the information received by the patient and family may depend entirely on what information health care providers choose to share (Lubkin, 1995). It is important for APNs to understand that patients and families usually begin the information seeking process with a knowledge base drawn primarily from the experiences family members or friends have had with a similar disease or treatment plan. This knowledge base will ultimately influence the perception of all information received, and every decision about treatment and treatment goals (Degner & Beaton, 1987).

A second component of the decision making process encompasses the weighing of costs and benefits. Costs and benefits that can be described in quantitative terms make decision making easier, but this is rarely the case in end-of-life decisions. Evaluating costs and benefits on the basis of nonquantitative terms, such as values and preferences, makes the process of decision making more complex (Radford, 1995). As part of the evaluation process embedded in decision making, there must be an assessment of the benefits and an estimate of the risks of each course of action, in relation to the objectives of the decision maker. The decision can then be made on the basis of the greatest benefit for a given cost, or the least cost for a particular benefit (Radford, 1995).

Risk-benefit calculations remain the most frequent approach to end-of-life decision making (Degner & Beaton, 1987). The treatment of cancer is one of the successes about which medicine is most proud, because it represents a triumph of medical technology over a previously fatal condition (Quill, 1993). The treatment course, however, can be brutal, and is presented here as an example of the kind of risk-benefit calculations that chronically ill patients must sometimes face.

Although treatment regimens vary with differing types of cancer, most patients diagnosed with this disease will face either radiation, chemotherapy, or both. Each of these treatments are harsh, with predictable, and sometimes severe, complications ranging from nausea, vomiting, and hair loss, to infection, bleeding and death (Quill, 1993). In most cases patients can expect to be hospitalized, for periods of days, weeks, or months. Oftentimes patients become extraordinarily sick and dependent on a large medical staff with varying levels of caring and competence (Quill, 1993). Although survival rates vary with different forms of cancer, the relative survival rate for all cancers, at this time, is 53% (American Cancer Society, 1995). For many patients, the ordeal of aggressive treatment is well worth the chance for survival. But not all patients feel this way. Although death is virtually certain if one forgoes treatment, many patients will live relatively comfortable lives for extended periods of time before they die (Quill, 1993). For some people, the chance to spend their remaining time at home with their family, living life as fully as possible, outweighs the perceived risks of spending their final days in an aggressive, and uncomfortable, battle against death. For these people, the risk, or burden, of treatment is perceived to outweigh its benefits. In this case, the primary goal shifts away from extending life, and toward decreasing physical and emotional suffering.

The assessment of the risks and benefits attached to various treatment options is often done by physicians talking amongst themselves, weighing relevant test results and physical findings in light of experience, current knowledge and research data, and then presenting their conclusions to patients and families. The focus of this process is on patient survival. Missing from the analysis, is input from patients and families, who are more likely to frame risk-benefit ratio in terms of burden-benefit, in the context of personal goals and values. For patients, a scientifically based risk-benefit perspective may be of limited value. Most patients are not concerned just with survival at any cost; for most patients the issue of quality of life is central to the cost-benefit component of decision-making (Hill & Shirley, 1992). For any choice, alternatives should be characterized in terms of likely outcomes and benefits as evaluated from the patient's as well as the provider's perspective (Council on Scientific Affairs, 1996).

A third component of the decision making process is the identification of objectives. The presence of multiple, rather than single objectives, can complicate the structure of any decision making. When multiple objectives exist, a choice can be called "subjectively rational" (Radford, 1995). A subjectively rational choice is not uniquely best, but is instead regarded as the best choice under the conditions in which it is made. In situations where there are multiple objectives and no clear best choice, elimination methods offer some capability of ordering alternatives by preference. In this case, alternatives are evaluated against a factor related to each objective in turn, starting with the objective of highest priority. Alternatives are then eliminated sequentially until the designated best choice remains. Perhaps the most common example of the multiple objectives inherent in end-of-life decisions occurs when patients strive to prolong life, avoid suffering, and refrain from burdening their families. These objectives often conflict, forcing patients and families to prioritize goals, and to both choose, and eliminate, various treatment options accordingly.

End-of-life decisions often reflect multiple and diverse objectives, making "subjectively rational" choices the norm, rather than the exception. Treatment decisions may be narrowly focused, as those directed toward symptom control, or larger and more complex, such as the decision to withdraw treatment or to forego life-sustaining procedures. There are myriad and often conflicting objectives that patients consider throughout the process of decision making. These commonly include retaining control, avoiding suffering, decreasing intrafamily conflict, and avoiding burden to others (Webb, 1997). Decision making can be further complicated when there is conflict between patients and families, or between patients and providers, as to what the objectives of the decision making should be.

A fourth factor taken into account in decision situations is the number of participants who have an interest in the decision-making process, or who share a common purpose. In the case of group decision making, each member of the group has the capability of making a decision alone but is committed to joint decision making in accordance with the mission of the group. The process of group decision making generally includes an exchange of information, a process of interaction, and a goal of unanimity. Oftentimes, group members will try to influence the opinions and preferences of others, resulting in either consensus or conflict. When opinions become polarized, subgroups may form, with views that are in conflict with each other. The extent and nature of this conflict can be a major factor in determining how the group will make decisions (Radford, 1995).

In 1995 the findings of a major research study on the end stage of dying in America were released. The Study to Understand Prognoses and Preferences for Outcomes and

Risks of Treatment (SUPPORT) demonstrated, amongst other things, that end-of-life treatment decisions are not made by the patient alone, but by whole families, in consultation with health care professionals. Contrary to popular belief, these decisions were not found to be patient-centered only, but rather were most often arrived at with the entire family's well-being in mind (Webb, 1997).

Group decisions, by their very nature are complex decisions, with each member bringing a unique background of knowledge, experience, values, and beliefs to the discussion. As a result, different perceptions may arise from different interpretations of the same information (Radford, 1995). In addition, these complex decisions require the interaction of participants who may each be pursuing a number of objectives simultaneously.

Participants rarely resolve complex decisions on the first attempt. More often, decisions are arrived at only after considerable interaction amongst the participants, taking place over a period of time. These decisions require information and reflection (Schlenk, 1997), and depend, in part, on patient readiness. The appropriate time to approach these difficult issues is prior to a medical crisis, or imminent death, when patients are feeling well and are of sound mind, and when anxiety and fear is not excessive (Johnson & Justin, 1988). Health professionals need to recognize that patients and families use the same decision making processes that they do. The fact that patients and families arrive at different decisions more likely results from the use of different criteria, than a different process of decision making.

End-Of-Life Decisions: Treatment Options and Goals

Although it is difficult to define the "end-of-life" prospectively for any given patient, for the purpose of this project the concept is intended to represent the end stage of a chronic illness. This stage may encompass the final days, weeks, or months, of a person's life, and is typically characterized by downward trajectory of debilitation. End-of-life decisions are the choices made by an individual regarding his or her continuing care or treatment options for this end-of-life stage (Wesley, 1996).

Advances in medical technology have provided patients and families with multiple options for life-extending therapies. Examples of these options include cardiopulmonary resuscitation (CPR), mechanical ventilation, dialysis, antibiotics, blood transfusions, and artificial nutrition and hydration. Treatment goals for these therapies are primarily directed toward either extending life, or providing palliative (comfort) care only. These goals are dynamic, may be implied or explicit, and are often intertwined. An overwhelming majority of patients prefer a goal of preserving quality of life, rather than to have an extended life without regard to quality (Schlenk, 1997).

The principles of self-determination and informed consent are paramount to any treatment decisions. Discussing treatment options, including life-prolonging treatment, with health care providers and family can assist patients in clarifying and prioritizing goals prior to making decisions (Schlenk, 1997). Research demonstrates that while physicians are fearful that discussions of end-of-life care will scare or depress patients, many patients have thought about these issues, discussed them with others, and wish that their providers would initiate these conversations (Ebell, Smith, Seifert and Poisinelli, 1990). Patients want to participate in decision making about their end of life care (Johnson & Justin, 1988), and feel it is important to make decisions about life-prolonging treatment with their family's involvement, and while they are still well (Puopolo, et al. 1997).

Patients and families need information about medical treatments in order to make informed decisions that are consistent with their individual goals. This information should include a description of the procedures and/or technologies indicated for the treatment under consideration, its generally accepted risks and benefits, and specifically how it might translate into burden or benefit for this patient. These discussions should be framed in the context of both the patient's illness trajectory and their assessed quality of life.

Patient preference regarding cardiopulmonary resuscitation (CPR) is one of the most commonly considered end-of-life treatment decisions and will be discussed here as an example of such. First introduced in 1960, CPR was intended as a treatment for victims of acute insults such as drowning and accidents, or the dysrhythmias associated with acute myocardial infarction. The 1960 guidelines specifically state that CPR should not be attempted on all dying patients, and that it is, in fact, contraindicated for patients in the terminal stages of a malignant or other chronic disease (Hamil, 1995). Unfortunately, current practice fails to meet this, and other, criteria set forth by these guidelines. In today's health care, and legal climate, CPR has come to be used on virtually anyone found in a pulseless or breathless state, unless they have specifically designated otherwise. Unlike other medical treatments, CPR can be administered without a physician's order, and, in fact, a physician's order is required to stop or prevent it from starting (Rubenfield, 1995).

It is important for patients and families to have at least a general understanding of what CPR is, when it is indicated, and what the outcome might be, prior to making a decision about resuscitation preference. Information regarding CPR should be presented in the same format as other treatment decisions, i.e. what the treatment entails, it's risks and benefits, when and why it might be indicated, and what the treatment goal would be. An additional, and essential, part of any treatment discussion should be how this treatment might translate into burden or benefit for this individual patient. For example, it is important for patients and families to understand that even in an acute event on an otherwise healthy person, the incidence of survival to discharge from the hospital after arrest is only 15%, with about one third of those surviving having evidence of neurological deficit (Hamil, 1995). For those patients over 70, and with one or more chronic illnesses, the survival rates are even more grim, with some sources placing the likelihood of survival to discharge in a neurologically functional state as less than 5% (Hamil, 1995), and as low as 0.0% (Ebell, et al., 1990). Certain conditions associated with poor response to CPR are age greater than 70, and chronic illnesses such as cancer, renal failure, congestive heart failure, hepatic failure, AIDS, and COPD, particularly when they are coexisting diagnoses (Rubenfield, 1995, Hamill, 1995). Although CPR may result in prolongation of life, as a treatment modality it appears to have little impact on improving or maintaining quality of life for the chronically ill.

It would be a mistake to assume that given these statistics, few chronically ill patients or their families would choose resuscitation as a viable treatment option. Research demonstrates that even when faced with the scenario of terminal illness (Rubenfield, 1995), or mental incompetence (Johnson & Justin, 1988), a significant number of patients want CPR (Garrett, Harris, Norburn, Patrick, Danis, 1993). In one study, 20% of elderly nursing home patients said that they wanted CPR, mechanical ventilation, and hospitalization even if they were terminally ill or permanently unconscious (Danis et al., 1991). These findings serve to caution health care providers not to think that a treatment modality which has been shown to be of little value, or even futile, will be viewed as such by patients. Providers must be careful not to project their own biases about the value of treatment modalities onto patients and their families, and they must also understand that these decisions are based on more than just statistical facts.

Ideally, family members are integrally involved in the decision making process, and understand and support the patient's decision. It is the discussion of the patient's goals, values, and desires during the decision making process that allows the family and health care provider to understand the patient's wishes. The role of the APN is to assure that patients and their families receive and understand the information necessary in order to make an informed decision. Beyond that, it is up to the individual patients to decide what is right for themselves, based on their unique concept of quality of life, and their individual treatment goals. There is no way to anticipate every situation that may arise during the course of a person's illness. That is why it is so important that patients discuss with their family, thoroughly and in advance, not only the treatments they do or do not want in the event they become incompetent, but also to discuss the reasons for their treatment choices (Hill & Shirley, 1992).

Summary and Critique of the Literature

There is an extensive body of literature on the topic of death and dying, most of it exploring the emotional responses and medical issues related to terminal illness. Notably lacking, is information about end-of-life care, more specifically, what people want, and how health care professionals can help to provide it. Although there are a number of studies on resuscitation decisions and the withholding or withdrawing of life-prolonging treatments, there is a lack of information directed toward assisting the practitioner in the process of discussing these, or related, issues with patients and families.

Media attention focused on Dr. Jack Kevorkian, and the high profile cases of Karen Quinlan and Nancy Cruzan, has brought concepts such as "vegetative state" and "heroic measures" into everyday conversation. The result is that more people are discussing, although not necessarily documenting, the extremes of care they know they don't want at the end of their lives. Still, there is very little research to demonstrate what kind of care and medical interventions people do want during their final days, and even less on how and when these decisions should be made.

By 1992, all fifty states had legalized some form of advance directives, yet at this time, only about 15 percent of Americans have completed legal documentation of their wishes (Webb, 1997). The Patient Self-Determination Act (PSDA) passed in 1991 requires all health care institutions that receive Medicare and Medicaid to inform patients on admission about advance directives; only a small minority of people, however, choose to complete them. Studies are needed to determine both why people don't complete advance directives, and how their end-of-life care is affected when they do. Despite the extensive history of legal battles preceding advance directive legislation, there has been little research since then to demonstrate that these documents have met their intended goals. And, in fact, the landmark SUPPORT study (1995) of 9,000 seriously ill patients across the country demonstrated that there were no differences in health outcome or medical treatment between those who had signed advance directives and those who had not. Findings from the SUPPORT study identified problems, but did not offer solutions. Again, further studies are indicated to determine what methods might be employed to assure that end-of-life care is provided in accordance with patient's wishes.

In a study that examined the concept of surrogate decision making, the results indicated that surrogate resuscitation decisions for incompetent patients often do not approximate the patient's wishes, even when the decision makers appear to know the patient well and believe that they are exercising substituted judgement (Uhlmann, et al., 1988). The authors concluded that the ability of physicians or spouses to predict what patients would want is limited by a lack of prior discussion. They hypothesized that discussion of resuscitation preferences between patients, surrogates, and providers would increase the accuracy of substituted judgments by allowing surrogates to better understand patient's values, and physicians to better inform patients and spouses about prognoses and other technical factors. Missing from the existing literature are studies that demonstrate whether discussing end-of-life decisions with family members and health care providers prior to the onset of incompetence has any impact on the care provided at the end of life.

Of the existing literature relevant to this project, two important points should be discussed. The first is that the role of advanced practice nursing in relation to end-of-life issues is not addressed in the research literature. Studies focus instead on the role of the physician. Because of the differing perspectives of nursing and medicine, it is not clear if the findings from these data can be generalized to advanced practice nursing. Nursing must take the lead in designing and implementing research studies that address the important contributions APNs can make in guiding patients and families through the end-of-life decision making process.

A second issue that warrants examination here, is that the preponderance of research literature related to end-of-life decisions is of quantitative design, although, in some instances, qualitative methods might be more appropriate. Brody (1990) states that it may not be possible to determine how patients make these difficult decisions, that is, how they reconcile personal values with clinical and prognostic facts, how they respond to situations in which tradeoffs between quality of life and quantity of life must be made, and why patients perceive certain persons to be helpful consultants in making these decisions. This author agrees with Brody's assertion that qualitative methods, such as the analysis of a small number of intensive discussions, might better answer these research questions than would larger quantitative studies. The fact that so little of the research related to end-of-life issues is qualitative, may reflect an institutional bias against qualitative research methodologies as not being scientific enough, however, the author believes the use of these methods, in conjunction with more traditional quantitative studies, could provide valuable information for assisting APNs and other practitioners in understanding the full complexity of end-of-life decision making.

CHAPTER III

Conceptual Framework

The study of interpersonal process is a developing body of scientific knowledge that can be used to explain observations and guide interventions, related to end-of-life decisions. Peplau's theory of interpersonal process is used as the conceptual framework for this project because it recognizes each person as a unique biological/psychological/spiritual/sociological individual, who will respond differently than any other person in a given set of circumstances (George, 1985). The process of making end-of-life decisions is complex and individual. One cannot overestimate the influence of the unique preconceptions and expectations that each participant brings to the decision making process.

Peplau identifies four sequential phases of the interpersonal process in which the nurse-patient relationship progresses from first encounter to the conclusion of that relationship: orientation, identification, exploitation, and resolution (George, 1985). While an awareness of the process Peplau describes is implicit in this project, it is not our intention to focus on the incremental phases of the nurse-patient relationship. However, it is understood that this component of the interpersonal process is an important and integral part of the ongoing APN/patient/family primary care relationship.

End-of-life decision making is a complicated process, in part, because of the differing perspectives of each participant in the decision making process. Peplau's conceptual framework recognizes the diverse perspectives that both nurse and patient bring to the therapeutic relationship as represented in the model (Figure 1). Expanding the model to include each individual family member or significant other as a distinct entity can be seen in Figure 2. In nursing today, the patient has come to be viewed as inclusive of family and community (George, 1985). We have adapted this model, however, to incorporate a recognition that family members have unique preconceptions and expectations of their own that differ from those of the patient and practitioner. Despite family members perceptions that they understand patient's preferences regarding end-of-life treatments, studies show that without prior discussion, and/or the completion of advance directives, family members cannot reliably predict which interventions patients desire (Uhlman, et. al. 1988, Johns, 1996, Perrin, 1997).

Peplau defines nursing as an interpersonal process that involves interaction between two or more individuals with a common goal (George, 1985).This goal provides the incentive for the therapeutic process in which, ideally, the patient, the patient's family, and the APN, respect each other as unique individuals, learning and maturing as a result of their interactions. In the case of end-of-life decision making, the common goal, in the conventional wisdom, is often stated as "what is best for the patient". Each participant in the decision making process will have differing perceptions that influence the interpretation of this goal. For example, "what is best for the patient" may be interpreted by the APN to be the avoidance of futile and uncomfortable treatments. For the patient, the avoidance of suffering may be paramount (Lynn, et al., 1997), and for families, the goal might be simply to prolong the life of their loved one. It is important to understand that each individual has learned differently from their background of environment, mores,

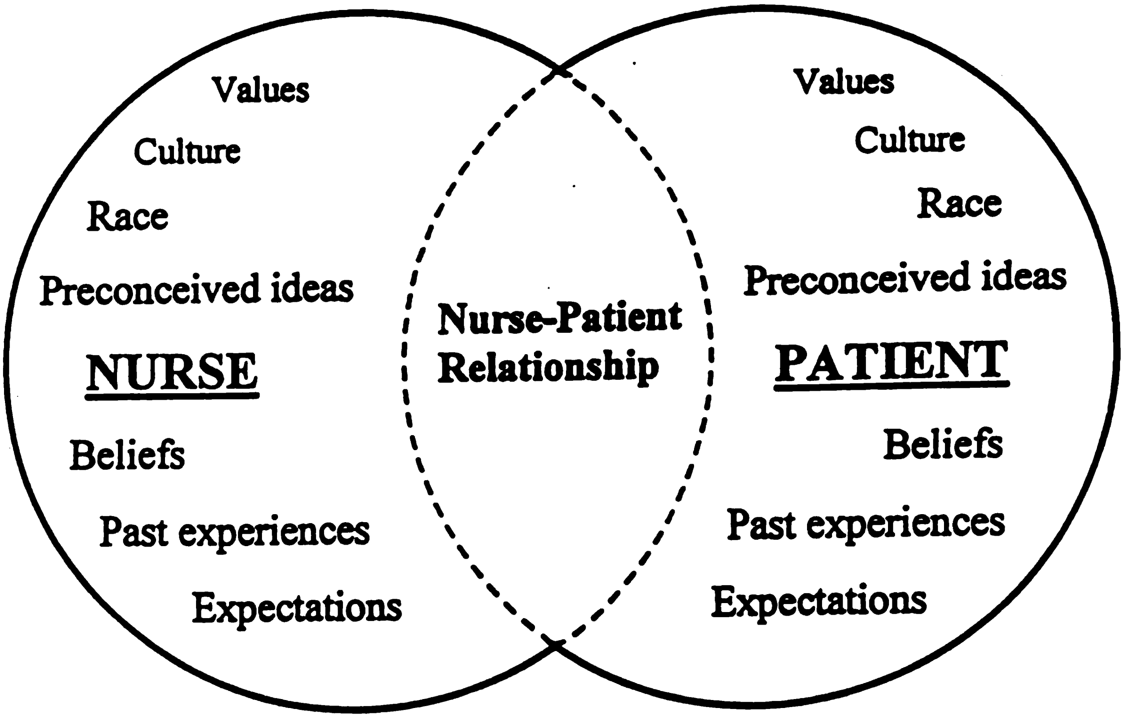

Figure 1. Peplau's factors influencing the blending of the nurse-patient relationship. (Adapted by George, 1985, p.54).

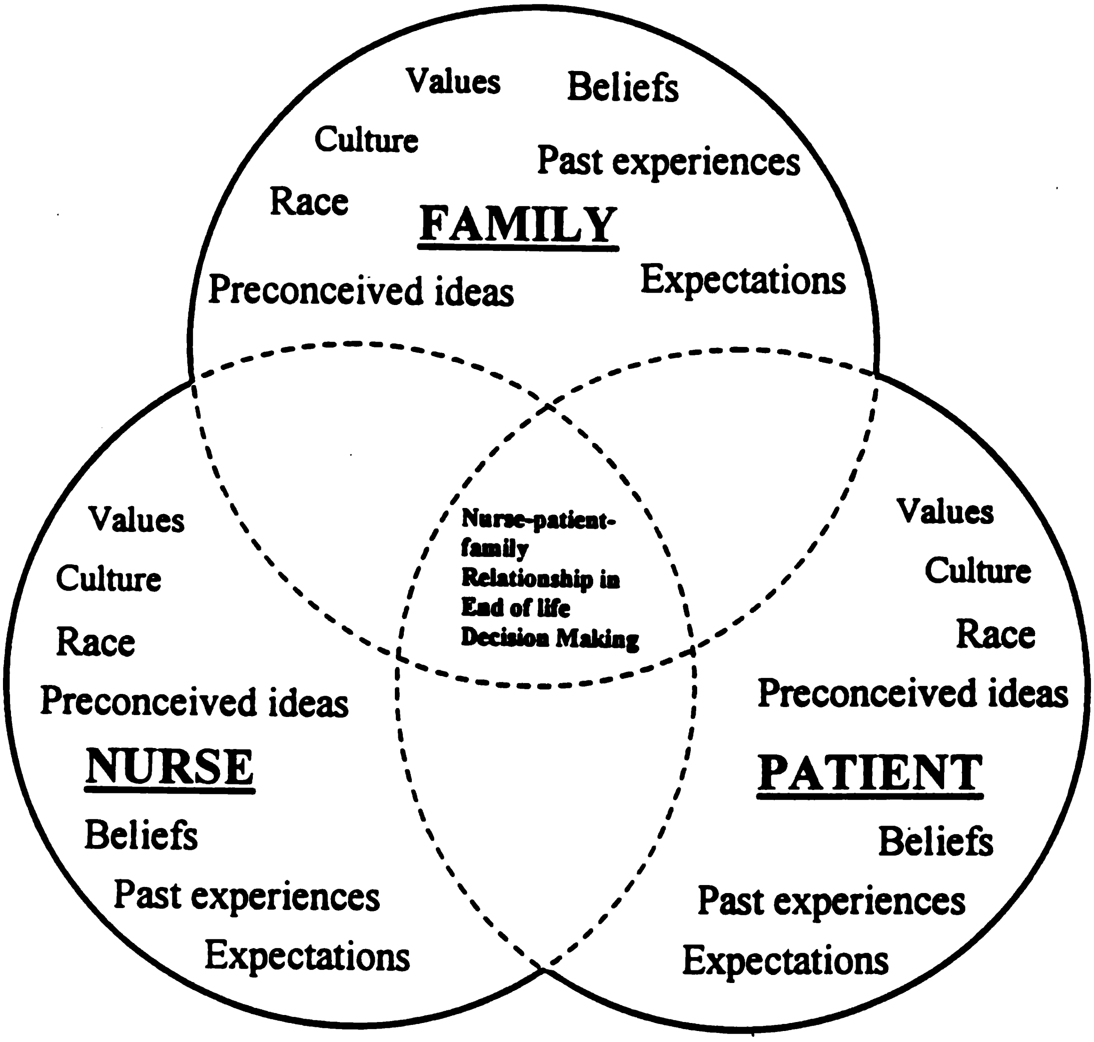

Figure 2. Factors influencing the nurse-patient-family relationship in end-of-life decision making. (Adapted by the author from George, 1985, p.54).

customs, beliefs, and experiences, and that each individual will therefore approach goals from a unique perspective.

Peplau views nursing as a "maturing force" and feels that, for the practitioner, nursing is a learning experience about his or her self as well as about others. As nurses guide patients and families through the decision making process, they gain knowledge and skill. As a result, the methods and principles utilized in this process become increasingly more effective. Therefore, each nurse-patient-family encounter provides experiences that influence the nurse's personal and professional development. Peplau believes that, in turn, the kind of person the nurse becomes influences the interpersonal relationships inherent in this and future interactions (George, 1985).

Peplau stresses the importance of self-knowledge, and it's impact on the interpersonal process. APNs must examine their own views, values, and biases, as they guide patients and families through the end-of-life decision making process. Research demonstrates that providers often have significantly different perceptions about what the patient would want or feel in a given situation. It is important to remember that health care providers may be influenced by social factors affecting the patient, such as alcoholism and substance abuse, which have little to do with patient prognosis (Rubenfield, 1995), that they may grossly underestimate the quality of life of their patients (Bond, 1996), and cannot reliably predict what patient's resuscitation preferences might be (Uhlman et al., 1988). Of note, are the findings of a study of a broad range of health care professionals that indicated that health care providers felt that too much care is provided to the terminally ill (Rubenfield, 1995).

Although APNs bring a greater knowledge of disease trajectories and medical technology to the interaction, they must remember that information is only one component of the decision making process, and is rarely the only relevant factor influencing these decisions. While APNs often have a broader range of experience with medical treatments and end-of-life issues, they must not assume that their perspective is more objective or valid than that of the patient or family. Thus, the conceptual framework used for this project takes as it's underlying assumption, an expanded form of Peplau's interpersonal process that asserts that the outcome of every therapeutic interaction is affected by the diverse perspectives, expectation, and life experiences of each of the participants in the decision making process.

CHAPTER IV

The Project

Project Development

The purpose of this project was to develop clinically useful guidelines that can be utilized by APNs as primary care providers to assist chronically ill adults and their families in making decisions regarding treatment options at the end of life. Using Peplau's theory of interpersonal process as a framework, these guidelines were developed from a literature review of the concepts of chronic illness, quality of life, decision-making, and end-of-life treatment options and goals. These guidelines are intended to be used as both a resource and a self-education tool for APNs in primary care practice. The goals of these guidelines include: increasing the frequency of provider/patient/family discussions related to end-of-life care, decreasing the discomfort APNs may feel in initiating these discussions, and enhancing the APN's ability to understand, and to support, chronically ill patients' preferences for end-of-life care.

These guidelines were based on the assumption that end-of-life decisions are best made in the primary care setting, when patients aren't critically ill or incompetent, and when they have time to reflect on their medical care preferences and to discuss their wishes with pertinent family members. They assume that a mutually trusting relationship between patient, family and APN, best facilitates discussion of end-of-life issues, and that this prior discussion will enhance the likelihood that end-of-life care will be provided in accordance with the patient's wishes. They assert that end-of-life decisions should be considered in the context of a patient-identified goal of either palliative care or aggressive medical therapy, and that appropriate treatment options are available to address either goal. They reflect a belief that it is important for patients and families to understand treatment options, and the potential consequences of those options in relation to quality of life, in order to make informed choices about end-of-life care. And they conclude that the medical treatment provided at the end of life is more likely to be in accordance with patients wishes when patients, families and providers participate together in the decision making process.

Implementation and Evaluation of the Guidelines

The guidelines presented here have not yet been tested. In order to determine their clinical usefulness it is first necessary to test and evaluate them in actual practice. Although every effort has been made to anticipate potential problems, unforeseen issues may arise when implementing the guidelines in a clinical setting. There is no substitute for knowledge gained from the actual use and subsequent assessment of any instrument. It is recommended, therefore, that a pilot study be carried out and fully evaluated prior to any wider distribution of these guidelines.

The purpose of the pilot study would be to obtain information for improving and refining the guidelines, by evaluating them for clarity, ease of use, applicability to practice, and general acceptance by the target population. For the purposes of the pilot study, a representative group of APNs in primary care practice should be selected for the initial test group. This target test group should be limited to APNs who work in practice settings that allow for ongoing relationships with chronically ill adults. Because it is not clear whether these guidelines can stand alone, or would be more effectively introduced as part of a broader educational structure that includes a review of the key issues involved, it is recommended that the study population be divided into two groups for the purpose of further evaluation of this question.

Data collected as part of the pilot study should include the individual reactions and impressions of participants after using the guidelines, as well as scaled response measurements of the guidelines in terms of ease of use, comfort level in use, and applicability and relevance to practice. The informed opinions and suggestions for revision by the APNs participating in the test are particularly important to a full evaluation of the instrument in the patient and family based relationship of actual practice. It is therefore recommended that the pilot study evaluation process include subjective interviews with each of the participant APNs, in addition to an objective measurement of the specific test criteria.

After the objective and subjective data from the pilot study have been collected and evaluated, the guidelines should be refined and revised as indicated to eliminate or reduce problems identified during the testing. If extensive revisions are necessary, it would be prudent to conduct a second pilot study that subjects the revised guidelines to clinical testing. Once the final revisions have been made, the guidelines should be made available for wider distribution in professional journals, as a part of inservice and continuing education programs, and through professional or associational seminars.

CHAPTER V

Implications for Advanced Practice Nursing

Primary Care

A position statement published by the American Nurses' Association states that "nurses have a responsibility to educate patients and families about all forms of life-sustaining treatment, and they should be involved in both the planning and implementation of resuscitation decisions" (Puopolo, et al., 1997). Primary care provides an ideal setting for discussions of end-of-life issues, not only because of the ongoing, established relationship between patients and practitioners, but also because of the opportunities to address this topic at routine visits, allowing patients the time to reflect on medical care preferences, and to discuss their wishes with family members. Advanced practice nurses in primary care should work in collaboration with patients and their families to clarify goals, and to identify and discuss treatment options, in order to develop a plan for end-of-life care that reflects patient autonomy and sound medical judgement. This process is influenced by the unique perceptions and pre-existing beliefs that all parties bring to the discussion, not only in relation to chronic illness and dying, but also about the meaning and value of life itself.

APNs should encourage patients to complete advance directives as a means for them to communicate their preferences and goals in the event that they become unable to speak for themselves. However, completing advance directives does not assure that patients will receive care in accordance with their wishes. Advance directives are unlikely to have an effect on end-of-life care unless family members and health care providers understand, support, and advocate for what they know to be the patient's preferences (Quill, 1993).

APNs may be uncomfortable initiating such conversations with their patients, in part, perhaps, because they haven't yet come to terms with their own feelings about death and dying. Prior to a discussion with their patients, nurses must examine their own values and cultural and spiritual beliefs about death, and attempt to integrate this awareness with knowledge gained from personal and professional experience. Nursing is an interpersonal process, with both the patient and the nurse having equally important parts in the therapeutic interaction. APNs should understand that the behavior of others is best understood in the light of self knowledge (George, 1985).

Nursing Practice

In the role of educator, APNs have a responsibility to address the learning needs of patients and families, community members, and other health care professionals (Given, 1995). The processes and issues related to educating patients and families about end-of-life decision making process are embedded throughout the body of this work and will not be reiterated here.

The scope of primary care includes responding to the needs of the community (Starfield, 1992). As educators, APNs should be prepared to take part in group discussions, organize seminars, or participate in other forums on end-of-life decision making, all of which can help prepare patients and families as they begin to think about these issues. Topics could include: (a) patient autonomy and the right to accept or refuse medical treatments, (b) advance directives, and their implications for end-of-life care, and (c) treatment options, what they are, and how they may translate into burden or benefit. At the conclusion of such programs, APNs could encourage participants to consider the concept of quality of life, and to discuss their thoughts about goals of care and life-prolonging interventions with their families and health care providers.

As primary care providers, nurses offer client-centered care in a family focused context, an advantage largely absent from that provided by other professionals (Given, 1995). Few physicians are educated to actively view patients as part of a larger family unit. APNs can play a vital role in medical education by assisting physicians to understand what patients and families want and need, in relation to end-of-life decision making, and how specifically to approach this process. Nurses and physicians who practice in acute care can profit from inservices designed to assist them in discussing these issues with patients and their families. Guidelines such as those presented here can be adapted in order to provide a useful framework for the discussion of patient-focused end-of-life decisions in acute care settings.

Educational interventions should focus on increasing the frequency of patient/provider discussions, decreasing the discomfort associated with initiating these discussions, and improving the health care professional's ability to understand, and support patient's preferences for end-of-life care. Additionally, it is the author's view that these topics should be incorporated into the curriculum of both medical and nursing school programs, in order to help prepare future doctors and nurses for the difficult situations they will inevitably face.

Nursing Education

Nursing schools continue to educate the next generation of health care professionals, those who will care for the rapidly growing chronically ill population of the future. Although many programs have increasingly incorporated information about chronic illness, death and dying, and medical ethics into their curriculum, most still provide too little information about the concept of palliative care, and the process of advance planning for end-of-life treatment decisions.

It is hoped that these guidelines will provide a useful framework for educating and preparing nursing students for their role in assisting patients through the process of end-of-life decision making. Each of the concepts (chronic illness, quality of life, decision making, and treatment options) should be discussed individually, and as they interrelate within the context of complex decision making related to end-of-life care, and examined within the broader context of Peplau's theory of interpersonal relations.

As part of the educational process, students should be encouraged to examine their own feelings about death and loss, and to contemplate both the concept of quality of life, and the potential burden versus benefit of the highly technical medical treatments available today. One method of generating contemplation and discussion of the concept of quality of life, is participation in an exercise that hospice volunteers are sometimes given to increase their understanding of the feelings people may have at the end of their lives (Hill

& Shirley, 1992). In this exercise, each person is asked to write, one at a time, the things they value most in life on ten separate pieces of paper. These things might include the names of people or special places, or physical activities such as hiking, camping, or traveling. They might include sensations or experiences such as listening to music, or watching a sunset, or characteristics of one's life such as independence, the ability to make decisions, the feeling of being part of a family, or the excitement of adventure and challenge. Each of the ten pieces are first held in one's hand, appreciated for a moment or two, and then one by one, thrown away. For the participants in this exercise, the feelings of loss and grief, and perhaps anger, that accompanies each of these losses, can trigger a deep appreciation for the experiences that people face at the end of life. An open discussion of the feelings generated by this exercise can help nursing students to better understand their own feelings, and how deeply personal and individual the concept of a life worth living can be.

If, as a society, we believe that all Americans who are near the end of their life deserve high quality palliative care, and respect and attention to their individual wishes regarding end-of-life treatment decisions, then it is essential that both undergraduate and graduate nursing programs provide students with the information necessary to enable them to guide and advocate for their patients as they make difficult end-of-life choices.

Research

In the role of researcher, APNs pursue scientific investigation of clinical problems, and test nursing theories, in order to advance nursing knowledge (Given, 1995). Nursing research related to the topic of death and dying should include inquiry into the role of APNs in assisting patients and their families to make end-of-life decisions. Using Peplau's Theory of Interpersonal Process as a framework, APNs can examine the many factors which contribute to diverse, individual perspectives related to end-of-life decision making, and how these decisions affect the care that patients receive in their final days.

The purpose of this project was to develop clinically useful guidelines to assist APNs, in the role of primary care provider, to discuss end-of-life decisions with chronically ill adults and their families. Further research is needed to evaluate these guidelines in terms of their ease of use, applicability to primary care practice, and value in achieving desired outcomes. In addition, it is important to examine whether outcomes are different when end-of-life decisions are made in a primary care setting as opposed to a crisis situation.

In addition to those discussed previously, the following implications for research are identified from the literature review as important for collaborative, interdisciplinary research. These research questions might best be addressed by using both quantitative and qualitative methodologies, in order to obtain a more complete picture of the many factors relevant to the issue of end-of-life care.

First, what kind of care do people want at the end of their lives, and what factors influence their responses to this question? For example, do people who are chronically ill feel differently than those that have not yet faced serious health problems? And, what does effect does culture, race, values, past experiences, and expectations have on preferences for end-of-life care? Although it has been stated here that optimal decision making requires decisions that reflect patient preferences and values, patient preferences for end-of-life care have been studied very little (Council on Scientific Affairs, 1996).

Second, the author would suggest investigation of which methods best assure that end-of-life care is provided in accordance with the patient's intentions. Although there has been a great deal of attention paid to the concept of advance directives, it is not clear whether this method will ultimately prove effective in realizing the underlying goal of end-of-life care that reflects the patient's wishes, or whether there might be better ways to ensure that these are carried out.

A third implication for research points to the need to identify and evaluate specific strategies that can guide practitioners in discussing end-of-life decisions with patients and their families.

Lastly, a central implication for future research would suggest an examination of the impact of end-of-life decision making on society. As medical technology progresses and life spans increase, so do the costs of end-of-life care. If people were given opportunities to understand and specify their choices for end-of-life care, how might this affect society, both in dollar costs, and in less tangible measures?

SUMMARY

The introduction of technology, and shifting societal expectations regarding death, have expanded the nursing role in the care of the dying. In this new and complex role, APNs can make an important contribution to the work their patients undertake as part of the end-of-life process. Using a foundation of knowledge and experience, APNs can help their patients contemplate a personal concept of quality of life, to better understand their disease process and the implications of treatment options, to formulate decisions within the context of their values and treatment goals, to discuss their wishes with their providers and the important people in their life, and to document their wishes appropriately.

All end-of-life decisions require information and reflection, and should be based on the unique beliefs of the individual who makes them. The nursing role should not be concerned only with what patients choose, but, instead, should focus on supporting them through the process of choosing, with the goal of enabling and empowering each person to make a plan for care at the end of life that is consistent with individual beliefs about life and how it should best be lived.

APPENDIX

GUIDELINES FOR END-OF-LIFE TREATMENT DECISIONS

1. Initiate a discussion of end-of-life issues.

Goal: To begin an open-ended discussion, in the outpatient setting, of patient preference regarding end of life treatment options, prior to a crisis situation.

Action: Discussions about end-of-life care should, when possible, be incorporated into the course of routine office visits. Hill, (1992), provides an example of what the APN might say:

> We have a little extra time today, and that gives me a chance totalk to you about some things that are clearly not immediately pressing questions, but about which I would like to know your thoughts. Then, if the time ever comes when together we're faced with these questions, I'll know what you think.

Patients should be encouraged to continue this discussion with their spouse/partner and other appropriate family members, and informed that the subject will be revisited at future appointments.

Rationale: Research demonstrates that a majority of older people have considered end-of-life care and wish to discuss this issue with their primary care providers, even though they may be reluctant to initiate the conversation themselves (Perrin, 1997). Although there is no specific time at which providers should broach the subject of end-of-life care, there is an advantage to discussing these issues when patients are not acutely ill, when they have time to think about medical care preferences, when they have opportunities to discuss their wishes with friends and family members, and when, as a result, they can be more reflective (Duffield, 1998). In this setting, both patient and provider can begin what should continue to be an ongoing, exploratory, conversation. As Hill (1992) states:

> One of the ways to lessen a patients discomfort with the discussion of treatment preferences and advance directives is to make it so routine that it is equivalent to asking the patient what his or her social security number is.

A discussion of patient preferences for end-of-life care is an important component of routine health maintenance, and should be integrated into annual physical exams for all adults. In reality however, many patients and families confront these issues for the first time only in the later stages of the chronic illness trajectory. Chronic conditions generally require repeated interactions between patients and their health care providers over the course of the illness. Many of these interactions provide ideal opportunities for the discussion of end-of-life issues, most notably when specific treatment options are under consideration, or when patients begin to report excessive suffering or a significant loss in their quality of life.

2. Encourage patients to explore the concept of quality of life.

Goal: To provide a context in which patients define the fundamental goals that will help identify appropriate treatment options.

Action: Prior to a discussion of treatment goals, or specific treatment options, patients should be encouraged to reflect on the elements that give their lives a sense of quality and value. One way to introduce and normalize the topic would be for the APN to say :

> Before we talk about specific treatment options, I've found it's often helpful for people to take some time to think about what kinds of things they value most in life. Some people feel they would be unwilling to do anything that would take away the things that are important to them, while others would be willing to do whatever it takes to prolong their life, no matter what. Making decisions about treatment options is often easier when people think about them in relation to what impact these choices might have on their quality of life. For example, for some people quality of life means independence, or the ability to work in their garden, or being able to make their own decisions.

Patients are thus encouraged to consider a personal definition of quality of life, and to begin to assess which potential losses or changes in their life might, or might not, be tolerable as the course of their chronic illness progresses.

Rationale: The concept of quality of life is embedded in end-of-life treatment decisions, particularly in the burden/benefit component of the process. Because many medical treatments have the potential to impose burden, it is important to consider them in the context of whether they will likely improve or detract from quality of life. Quality of life comprises more than physical comfort and symptom control; an important element seems to be living actively and positively until this is no longer possible. Patients who feel that there is some degree of high quality life left may be more willing to undergo a variety of medical treatments aimed at prolonging life, than might patients who feel that their quality of life is already poor, or that any loss or change in their current quality of life would be unbearable.

Each person has their own perception of what constitutes quality of life, and how much loss they are willing to endure in the interest of prolonging life. When patients are able to define a personal concept of quality of life, and to share their beliefs with their family, a framework for the consideration of treatment goals and options can be developed accordingly. And, in the event that the patient becomes incompetent at some point, this prior knowledge of the patient's wishes and beliefs can be helpful to providers and families when treatment decisions must be made.

3. Educate patients and families about the chronic illness trajectory.

Goal: To familiarize patients and families with the natural course of the disease process, so that they can make more informed choices in the creation of their treatment goals.

Action: Throughout the phases of a chronic illness, APNs should educate patients and families about the disease process, the illness trajectory, and the burdens and benefits of treatment options. Incorporated into routine office visits, these discussions should include the way an illness is likely to progress, what may happen in the future, and what actions and medical interventions may be indicated. For example, patients who suffer from chronic respiratory ailments should be prepared for the likelihood that they will develop chronic or episodic dyspnea at some point in the future, and that therefore they will need to consider their feelings regarding intubation and mechanical ventilation.

As part of the educational process, APNs should maintain a list of organizational and information resources, that may be useful in helping patients and families to understand the nature of a chronic illness. Reading materials such as pamphlets, and reprints of articles, can be distributed in primary care offices. Additionally, patients can be encouraged to investigate the extensive selection of illness-related books available at most libraries and bookstores.

Rationale: The course of any disease follows some type of general trend or trajectory, depending on the specific disease, its rate of progression, and the individual patient's unique response to the disease. The amount and type of information people want about their own or their family member's medical condition varies with individual coping styles and the context of the situation (Hymovich & Hagopian, 1992). Patients and family members generally want information that is of primary importance to them at the time, however, the APN should be prepared to respond to the changing concerns and questions of the patient and family as the disease progresses. Most patients need and want knowledgeable, experienced-based medical advice, and a realistic appraisal of their overall medical condition (Quill, 1993). Patients and families need information about an illness and its expected trajectory in order to participate in informed, shared decision making with health care providers. The patient's perceptions about his or her illness, however, must be explored before substantial efforts at patient education and informed decision making can proceed. It is important for APNs to remember that given the same information and prognosis, different patients will make different choices.

4. Help patients and families define treatment goals.

Goal: To establish a broad patient-defined therapeutic goal that can be used as a framework for discussion of treatment options.

Action: The APN should guide patients and families in using their understanding of the illness trajectory and their definition of quality of life as a basis for choosing between divergent goals of palliative care or aggressive medical therapy. To illustrate this, the APN might say:

> Keeping in mind what you have learned about your illness, and the things that are most important to you, the next thing we need toconsider is what your treatment goals will be. For instance, some people want to choose treatment options that focus primarily on prolonging life. Other people feel that keeping as comfortable as possible should be the main goal.

It is important for practitioners to reassure patients and families that these goals are flexible, and that they are free to reconsider them as the course of the illness progresses. APNs should also emphasize that there are treatment options available for either goal, and that, for instance, a goal of palliative care is not the same as "giving up".

Rationale: Treatment goals provide an important context for the consideration of specific treatment options, and the development of a plan for end-of-life care. These goals are generally directed toward either extending life, or providing comfort care only. There are multiple, and often conflicting, objectives that patients consider in the process of forming their treatment goals. These commonly include the desire to retain control, avoid suffering, decrease intrafamily conflict, and avoid burdening others (Webb, 1997). These goals are not formed lightly, rather they are most often based on knowledge and introspection. For many, treatment goals reflect an ability to make emotionally complex and highly consequential choices (Webb, 1997). These goals are dynamic, and, as such, may change as patients perceptions change. Using a foundation of knowledge and experience, APNs can help their patients to formulate realistic goals that are consistent with their unique values, beliefs, and expectations. In addition, when families and health care providers understand and support what the patient is trying to achieve, they are more likely to advocate for the patient's wishes in the event that they are unable to speak for themselves.

5. Address specific treatment options.

Goal: To identify appropriate treatment options, to educate patients about what these options entail, and to guide patients and families in evaluating each option for potential burden versus benefit.

Action: Using the patient-defined treatment goal as a framework for decision making, the APN should identify and discuss treatment options that are compatible with the patient's wishes. For instance, if the patient has decided that palliative care is the primary goal, methods of pain control are more likely to be the focus of discussion than are more aggressive interventions such as

CPR, chemotherapy, or hemodialysis. No matter which options are chosen, APNs need to educate patients and families about the specific details of medical procedures that may be relevant to their illness and their treatment goals. This information should include a complete description of the treatment in question, it's risks and potential benefits, and the reasons this treatment may or may not be appropriate. Patients and families might also need detailed information about why certain treatment options are not consistent with the patient-defined treatment goal. As part of this educational process, the APN should review with the patient their quality of life assessment, the illness trajectory, and how these might relate to the burden and/or benefit of options under consideration.

Rationale: The principle of informed consent is paramount to all treatment decisions. Patients and families need information about the specifics of treatment options in order to make informed decisions that are consistent with their individual goals. Many medical treatments, such as dialysis, chemotherapy, and surgical interventions, have the potential to impose great burden. It is, therefore, essential that patients and families understand what is involved in these options, and that medical professionals be realistic and honest about the potential burdens of treatment, and the odds of surviving either fully intact, or with added disability. Putting patients through medical interventions when the odds of meaningful survival are low, and the odds of great suffering are high, requires as much informed consent as is possible. Even when a less medically aggressive approach is chosen, patients must be informed about potentially difficult trade-offs such as that between pain and sedation, and choices about palliative interventions that, though well intended, may have undesirable outcomes.

6. Formulate and document a plan for end-of-life care.

Goal: To translate the patient's treatment goals into a plan for end-of-life care, and to document these wishes in the form of an advance directive.

Action: In an atmosphere of shared decision-making, the APN should assist patients and families in the process of reflection, discussion, and communication of the patient's treatment preferences. As a result of this process, a plan for end-of-life care can be developed that is consistent with the patient's goals, and which reflects the patient's beliefs about quality of life, their understanding of their disease process, and their assessment of the burden versus benefit of various treatment options. It is important for the APN to focus the conversation on what can be done, rather than what can't be done. For example, if patients choose palliative care as a treatment goal, a plan should be developed to address the symptoms that will likely occur during the course of an illness. If patients decide that the burden of mechanical ventilation outweighs its benefits, than a specific plan of action must be formulated to prepare families to respond with palliative treatment in the event of an acute exacerbation of dyspnea. In cases like this, patients and families can be instructed to administer aerosolized or sublingual morphine, and extra doses of diuretics, both which work effectively to counteract the symptoms and anxiety associated with shortness of breath. Having a plan like this in place helps to avoid the feelings of powerlessness that patients and families often have, and decreases the likelihood that patients will end up intubated and on mechanical ventilation despite their wishes, because they were offered no other alternative to relieve their symptoms.

Once patients and families have established treatment goals and formulated a plan for end-of-life care, they should be encouraged to document these wishes in the form of advance directives. Advance directive forms should be available for distribution within the primary care setting. APNs can also encourage and support patients who prefer to obtain legal counsel to assist in the completion of this document. Patients should be encouraged to make photocopies of completed forms, so that there is one on file at both the primary care office and the hospital, and extras for distribution to appropriate family members and friends.

Rationale: Research demonstrates that an end-of-life treatment plan results in decreased patient depression, and an enhanced patient perception of being cared for and in control (Miles, Koepp, & Weber, 1996). It is important to formulate a plan for end-of-life care that is consistent with the individual patient's preferences, values, and treatment goals. Patients and families need to know that regardless of whether the patient chooses a goal of palliative care, or one of aggressive medical therapy, that their health care provider will support them in their choices, and that there will be a plan of care in place to assist them in negotiating through the potentially difficult times ahead. APNs should make clear that the patient's plan for end-of-life care is dynamic, and that the topic can be revisited and revised at any time, in accordance with the patient's wishes. Many people have fears of losing dignity, and of not being able to cope (Quill, 1993). Patients and families need the reassurance of knowing that their primary care provider will listen to their fears, and be available to assist them throughout their illness, even if they cannot solve all the problems.

Those patients who wish to direct the treatment they will receive at the end of life, even if they are incapacitated by illness or trauma, should communicate their wishes in writing. Although one would hope that families, and primary care providers could successfully advocate for what they know to be the patient's preferences, without written advance directives, patients run the risk of having their treatment guided more by the goals and values of family members, consulting physicians, or the health care institution, than by their own values and wishes. Health care professionals are legally and ethically obligated to follow advance directives. However, written documentation of one's wishes is not enough; the most important aspect of advance directives is the dialogue and interaction that occurs in advance, between patients, families, and the patient's primary health care provider (Hill & Shirley, 1992).

7. Provide regular opportunities to review and revise the plan.

Goal: To assure that both the treatment goals, and the plan for end-of-life care, accurately reflect patients wishes throughout the course of the chronic illness trajectory.

Action: Initiated by the APN, patient, or family, a discussion of treatment goals and treatment options may appropriately be revisited, and the plan of care revised, throughout the course of the chronic illness trajectory. Within the context of the ongoing primary care relationship, these conversations may take place at routine office visits, following discharge from the hospital after an acute medical crisis, or prior to a planned surgical intervention or the initiation of a major treatment option such as dialysis or artificial nutrition. APNs should also consider initiating a discussion of treatment goals and options, whenever patients report a significant decrease in their quality of life. These discussions should be guided by the specific situation, but may typically include a discussion of the patient's illness trajectory, the treatment options under consideration, and the patient's perception of the burden versus benefit of these options.

Rationale: The goals of end-of-life care are dynamic, and may change as the chronic illness trajectory progresses. An important concern for those faced with interpreting advance directives is whether the stated choices are stable over time. The decision to continue aggressive medical intervention, especially under those circumstances where the odds of harm are high, needs to be constantly reexamined. Overall, patients do change their attitudes regarding end-of-life care as their disease progresses (Rubenfield, 1995). When a patient decides that the suffering which occurs is too much to bear, or when the odds of full recovery become too remote, then the goal of treatment may shift away from prolonging life, and toward promoting comfort and lessening suffering (Quill, 1993). Of note, is that among patients who initially choose minimal, or palliative care only, subsequent decisions for more care are extremely unlikely (Rubenfield, 1995). APNs are cautioned to remember that each participant in the decision making process will have their own perception of the advisability or futility of continuing treatment. However, under no circumstances should the wishes and requests of family members, health care providers, or others, take precedence over those of a competent patient.

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