BARRIERS TO TIMELY HOSPICE REFERRAL FOR CANCER PATIENTS ACROSS THE LIFESPAN:

IMPLICATIONS FOR THE FAMILY NURSE PRACTITIONER

By

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DEDICATION

I would like to dedicate this master’s project to everyone who has ever experienced the challenge of working with terminally ill patients and their families.
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ABSTRACT

Timely hospice referral is crucial for dying patients and their families to benefit from hospice services and increase the quality of end of life. Hospice is widely accepted and acknowledged as a valuable and appropriate intervention for dying patient, yet it is estimated that one third of patients will enroll in hospice in the last week of life (Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005). Unfortunately, barriers exist that prevent timely hospice referral. It is important for the FNP to identify barriers to timely hospice referral. Once barriers are identified, the FNP may develop interventions to decrease such barriers and facilitate timely hospice referral.

This Master’s Project identifies barriers to timely hospice referral found in the literature. A descriptive survey was developed to describe Tucson primary care provider’s experiences with hospice referral. Results from this survey, if conducted, will provide valuable information to the FNP working with terminally ill patients.
CHAPTER 1

Introduction

The family nurse practitioner (FNP) has the unique ability to work with patients across the lifespan, from birth to death. Although the FNP excels in health promotion and disease prevention, a majority of patients will become ill; some of these patients will even become terminally ill with cancer. For these patients, death may occur unexpectedly, shortening their life spans. This poses a special issue and opportunity for the family nurse practitioner, who may be caring for not only the patient, but also the entire family.

In the United States, despite concerted efforts among health professionals regarding cancer prevention, cancer remains a serious threat to health. Data from the National Cancer Institute, Centers for Disease Control and Prevention, and the North American Association of Central Cancer Registries, indicates that nearly 1.5 million Americans will be diagnosed with cancer in 2007. More than 500,000 cancer-related deaths are also expected in 2007 in the United States, according to mortality data from the National Center for Health Statistics. This startling statistic means that over 1,500 Americans will die each day from cancer (Jemal, Siegel, Ward, Murray, Xu, & Thun, 2007).

In the United States, the lifetime probability of developing cancer is 45% for men and 38% for women (Jemal et al., 2007). Women, however, have a greater chance of developing cancer before age 60 due to the common early age of breast cancer onset (Jemal et al.). Cancers of the prostate, lung and bronchus, and colon and rectum cancers
are projected to account for 54% of all new diagnosed cancers in 2007 in the United States. In American women, cancers of the breast, lung and bronchus, and colon and rectum are predicted to account for 52% of new cancers in women for 2007. Among these new cancer cases in American women, breast cancer is expected to account for 26%. Among men, cancers of the prostate, lung and bronchus, and colon and rectum account for an estimated 54% of all newly diagnosed cancers in the United States (Jemal et al.). Additionally, in the United States, cancer is the second leading cause of death among children between the ages of 1-14. Leukemia, nervous system cancers, sarcomas, non-Hodgkin lymphoma, and renal tumors are the most common cancers in children (Jemal et al.). In the United States, the number of newly diagnosed cancer patients is expected to more than double from 1.36 million in 2000 to almost 3 million in 2050 (Hayat, Howlader, Reichman & Edwards, 2007). Figure 1.1 (Jemal et al.) illustrates estimated new cancer cases and deaths, by sex, in the United States for 2007.
Figure 1.1

It is clear from the statistics that many patients each year will be diagnosed with cancer. The family nurse practitioner will be involved with caring for some of these patients. Even if the family nurse practitioner does not specialize in oncology, there will still be involvement with patients diagnosed with cancer who are facing the possibility of premature death. As a primary care provider, involvement and follow-up with patients undergoing treatment for cancer is likely. It is the FNP, as the primary care provider, who
may discover the cancer and make the referral to an oncologist. As the patient is seeking treatment from the oncologist, the relationship with the patient continues. Although the focus of this paper is the FNP as primary care provider, FNPs also have an option to specialize in oncology and may care for adults or children with cancer. As a family nurse practitioner specializing and working in oncology, it is important to develop a close, trusting working relationship with the patients and families. A trusting working relationship may facilitate communication needed to initiate difficult conversations regarding end of life and goals of care if the illness progresses.

Although there has been great advancement in the treatment of cancers, many cancers fail to respond to treatment. The experience of this author is that, in some cases, although the cancer may be responding to treatment, the patient may develop multi-system failure from treatment related toxicities. It is imperative that the family nurse practitioner assist patients and families in recognizing when treatment is no longer a viable option and inform patients and families about hospice. Timely hospice referral is crucial for patients and families to benefit from hospice services and increase the quality of end of life.

**Background and Significance of Hospice**

Hospice, an interdisciplinary concept of providing comprehensive care to terminally ill patients (Kinzbrummer, 2001), originated in England and came to the United States during the 1970s. The first American program opened in 1974 (National Hospice and Palliative Care Organization, 2005). In the 1980s, hospice was added as a Medicare benefit. Nursing care, spiritual and psychological counseling for both patient
and family, volunteer services, respite care, and family bereavement services following the patient’s death are all services provided by hospice (Jennings, Ryndes, D’Onofrio & Baily, 2003). Family bereavement services continue for up to one year after the death. The hospice philosophy of holistically caring for the patient and family is consistent with the care of the patient and family by the family nurse practitioner. An interdisciplinary team including nurses, social workers, clergy workers, nursing assistants and physicians (Jennings et al., 2003) provides hospice care. Primary care providers may continue to direct patient care when the patient is enrolled in hospice or the patient may be transferred to the care of a hospice provider. In 2005, Medicare proposed a rule to allow nurse practitioners to remain as attending provider once the patient has enrolled in hospice (Medicare Hospice Regulations, 2005). This truly allows the family nurse practitioner to provide comprehensive care for the patient and family until death.

Since its inception, hospice has evolved to include caring for patients of all diseases, socio-economic situations, family situations, and housing settings. Originally, hospice existed for people dying of cancer, who had a functional family support system and a home where they could receive care (Jennings et al., 2003). Today, hospice care may take place at home, in a nursing home, or an in-patient facility.

According to the National Hospice and Palliative Care Organization’s (NHPCO) 2005 data, the number of hospice programs nationwide is increasing. Currently, there are more than 4,100 programs in the United States. Most hospices are certified by Medicare and accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCHAO) or another accrediting agency. Approximately 68% of hospice programs report
non-profit status while approximately 22% report for-profit status. Government run programs account for approximately 5% of all hospice programs. About 20% of hospice programs in the United States provide pediatric care. In the United States, over 1.2 million patients received services from hospice in 2005. Approximately one-third of all deaths in the United States in 2005 were under the care of a hospice program. In addition, 75.9% of hospice patients die in a private residence, nursing home, or other residential facility. In the general population, about 50% die in acute hospitals (NPHCO, 2005). Figures 1.2 through 1.5 display further hospice statistics and information (NPHCO, 2005). These hospice statistics support the fact that hospice is an available and appropriate intervention for dying cancer patients, which further emphasizes the importance of this master’s report and implications for the FNP role in timely hospice referrals.

Figure 1.2 Trends in Hospice Program Growth. Adapted from NHPCO Facts and Figures, 2005.
Figure 1.3 Number of Hospice Patients in 2005. Adapted from NHPCO Facts and Figures, 2005.

Figure 1.4 Average (ALOS) and Mean (MLOS) Hospice Length of Stay in 2005. Adapted from NHPCO Facts and Figures, 2005.
Admission to hospice is appropriate when the expected prognosis is 6 months or less based on the physician or medical director’s clinical judgment regarding the normal course of the individual illness (Medicare Hospice Regulations, 2005). However, in 2005, the average length of stay was 59 days (NPHCO, 2005). It is estimated that one third of patients will enroll in hospice in the last week of life (Kapo, Harrold, Carroll, Rickerson & Casarett, 2005). The mission of hospice is to increase the quality of end of life. Such untimely referral and subsequent enrollment in hospice does not allow for the patient and family to benefit fully, affecting the quality of end of life.
Problem Statement

Referral to hospice for many terminally ill cancer patients does not occur until the very end of their life. This author has observed hospice admissions as untimely as the last 24 hours of life. Admission to hospice that occurs so close to death does not allow sufficient time for hospice providers to plan for, and mobilize the resources needed, to optimize end of life care (Miller, Kinzbrunner, Petit & Williams, 2003). When patients enroll in hospice close to the time of death, there is little time for hospice providers to perform assessments, initiate interventions, and establish important patient and family relationships. Therefore, patients who are referred near the end of life do not receive the full benefits from the services that hospice offers (Miller et al., 2003; Rickerson, Harrold, Kapo, Carroll & Caserette, 2005). The likelihood of a “good death” is still evident; however, it could improve with a timelier referral to hospice.

Herein lies the problem for this Master’s Project: hospice is widely accepted and acknowledged as a valuable and appropriate intervention for dying patients, yet patients are being referred too late in their illness to benefit from all possible hospice interventions. Barriers exist that are preventing timely hospice referral. However, timely referral does exist for some patients. These patients and their families with timely referrals benefit greatly from all that hospice care has to offer (Miller et al., 2003; Schockett, Teno, Miller, & Stuart, 2005). Therefore, it is important to identify barriers that inhibit timely hospice referral. Once barriers are identified, the FNP may use interventions to remove such barriers and implement timely hospice referral.
Purpose of Project

The purpose of this Master’s Project is to identify barriers to timely referral to hospice for cancer patients of all across the lifespan through a literature synthesis and subsequent design of a survey to explore the experiences of providers in Tucson who have referred patients to hospice within the past year. Identifying and discussing barriers to timely hospice referral is important to the FNP. Information from this Master’s Project has implications for future use for the FNP; awareness of barriers to timely hospice referral existing in the literature, along with an increased understanding of local practitioners’ experiences with hospice referrals, can enlighten the FNP to individual potential barriers.

Definitions Used in Project

_Hospice_ is a public agency or private organization or subdivision of either of these that is primarily engaged in providing hospice care. _Hospice care_ means a comprehensive set of services identified and coordinated by an interdisciplinary team to provide for the physical, psychosocial, spiritual, and emotional needs of terminally ill patients and/or family members, as delineated in a specific patient plan of care. _Palliative care_ means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering (Medicare Hospice Regulations, 2005).

The definition of a _good death_ is highly individual. A literature analysis (Kehl, 2006), revealed attributes of a _good death_. Such attributes include being in control, being comfortable, and having a sense of closure. _Good death_ attributes also encompass affirmation or value of the dying person recognized, recognition of impending death,
beliefs and values honored, burden minimized, relationships optimized, and family care (Kehl, 2006). These attributes provide a tool for assessing and measuring quality of end of life and are important for providers. Bad news is any news that drastically and negatively alters the patient’s view of the future (Buckman, 1992).

Summary of Chapter 1

Over 1500 deaths from cancer occur daily in the United States. Hospice care offers interventions leading to a “good death” and is a valuable consideration for patients of all ages that are terminally ill. Recognition of the need for hospice and timely referral are crucial. Length of stay in hospice is directly related to benefit received, quality of end of life, and patient/family satisfaction (Miller et al., 2003; Rickerson et al., 2005; Schockett et al., 2005). The purpose of this Master’s Report is to identify and discuss barriers to timely hospice referral for cancer patients across the lifespan through a literature synthesis and the development of a survey to explore the experiences of providers in Tucson who have referred patients to hospice within the past year.
CHAPTER 2

Introduction

The use of theory and conceptual models allows for structure and organization to guide nursing knowledge, practice, and education (McEwen, 2007). Although theory could come from any discipline, Watson’s nursing Theory of Human Caring guides this Master’s Project. Cultural competence is crucial for the FNP caring for terminally ill patients. Therefore, Purnell’s Model for Cultural Competence is also appropriate for this project. This chapter includes a summary of Jean Watson’s Theory of Human Caring and an explanation of Purnell’s Model for Cultural Competence.

Theoretical Framework

Theory of Human Caring

Jean Watson’s Theory of Human Caring is one of nursing’s newest grand theories. Watson’s initial work on this theory began in 1979 and she continues to broaden and revise her work as recently as 2005 (Wills, 2007). Her theory emerged from her quest to bring new meaning and dignity to nursing and patient care (Watson, 1997). It is this concern for dignity, her value system that includes a respect for the mysteries of life, and her belief that spiritual and ethical dimensions are major factors in the human care process (Watson, 1988) that make this the appropriate theory to guide this project. This perspective provides a specific link between the Theory of Human Caring and the FNP’s efforts to provide an opportunity for death with dignity through timely hospice referral. Watson (1988) believes her views are most congruent with a “phenomenological –
existential” methodology for study and inquiry, and are most appropriate for studies that
are qualitative in design.

**Concepts of Human Caring Theory**

Watson describes nursing as the science of caring. According to Watson (1979),
balancing science with humanism is the science of caring. It is important in today’s world
to maintain human caring ideals and a caring ideology in nursing practice, especially with
the increase use of technology and aggressive treatments, often without regard to human
considerations (Watson, 2005). This is certainly fitting for the FNP working with the
terminally ill cancer patient.

The goals of Watson’s theory concepts are associated with mental-spiritual
growth for self and others. Finding meaning in one’s own existence and experiences and
discoversing inner power and control are important.

Watson defined concepts of “actual caring occasion”, “transpersonal”,
“phenomenal field”, “self”, and “time”. These concepts are essential to understand the
science of human caring. Table 2.1 lists the concepts and Watson’s definitions.

In addition, Watson devised 10 “carative factors”, which are interventions related
to the human care process that require an intention, a will, a relationship, and action. “A
commitment by the health care provider to caring as a moral ideal directed toward the
preservation of humanity and dignity is necessary” (Watson, 1988). As her ideas and
values evolved, Watson translated her original 10 carative factors into 10 “clinical caritas
processes”. Table 2.2 lists these 10 “clinical caritas processes”.

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<tr>
<th>Concept</th>
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<tr>
<td>Human being</td>
<td>A valued person to be cared for, respected, nurtured, understood, and assisted.</td>
</tr>
<tr>
<td>Health</td>
<td>Unity and harmony within the mind, body, and soul; health is associated with the degree of congruence between the self as perceived and the self as experienced.</td>
</tr>
<tr>
<td>Nursing</td>
<td>A human science of persons and human health-illness experiences that are mediated by professional, personal, scientific, esthetic, and ethical human care transactions.</td>
</tr>
<tr>
<td>Actual Caring Occasion</td>
<td>Involves actions and choices by the nurse and individual. The moment of coming together in a caring occasion presents the two persons with the opportunity to decide how to be in the relationship- what to do with the moment.</td>
</tr>
<tr>
<td>Transpersonal</td>
<td>An intersubjective human-to-human relationship in which the nurse affects and is affected by the person of the other. Both are fully present in the moment and feel a union with the other; they share a phenomenal field that becomes part of the life history of both.</td>
</tr>
<tr>
<td>Phenomenal field</td>
<td>The totality of human experience of one’s being in the world. This refers to the individual’s frame of reference that can only be known to that person.</td>
</tr>
<tr>
<td>Self</td>
<td>The organized conceptual gestalt composed of perceptions of the characteristics of the “I” or “ME” to others and to various aspects of life.</td>
</tr>
<tr>
<td>Time</td>
<td>The present is more subjectively real and the past is more objectively real. The past is prior to, or in a different mode of being than the present, but it is not clearly distinguishable. Past, present, and future incidents merge and fuse.</td>
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**10 Clinical Caritas Processes**

1. Practice of loving-kindness and equanimity within the context of caring consciousness.

2. Being authentically present, and enabling and sustaining the deep belief system and subjective life of self and one being cared for.

3. Cultivation of one’s own spiritual practices and transpersonal self, going beyond ego self.

4. Developing and sustaining a helping-trusting, authentic caring relationship.

5. Being present to, and supportive of the expression of positive and negative feelings as a connection with deeper spirit of self and the one being cared for.

6. Creative use of self and all ways of knowing as part of the caring process; to engage in artistry of caring-healing practices.

7. Engaging in genuine teaching-learning experience that attends to unity of being and meaning attempting to stay within other’s frame of reference.

8. Creating healing environment at all levels (physical as well as non-physical, subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated.

9. Assisting with basic needs, with an intentional caring consciousness, administering “human care essentials”, which potentiate alignment of mind-body-spirit, wholeness, and unity of being in all aspects of care, tending to both embodied spirit and evolving spiritual emergence.

10. Opening and attending to spiritual mysteries, and existential dimensions of one’s own life-death; soul care for self and the one being cared for.

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Table 2.2 Watson’s 10 Clinical Caritas Processes
Adapted from [http://www.uchsc.edu/son/caring/content/evolution.asp](http://www.uchsc.edu/son/caring/content/evolution.asp)
During an actual caring occasion, the nurse is able to include the mysteries of life and unknowns yet to be discovered (Watson, 1988). This is of utmost relevance to caring for dying patients and discussing the option of hospice. Dying is a unique, personal journey, full of mystery and the unknown. An actual caring occasion could occur between the nurse and family member, as well.

A transpersonal caring relationship is a special human care relationship with high regard for the whole person. Human care begins when a nurse enters the life space of another person and is able to understand the other person’s condition of spirit and soul (Watson, 1988). The nurse responds to the condition in a way that allows the recipient to release subjective feelings and thoughts he or she has longed to release. In order to be successful, the transpersonal caring relationship depends on a moral commitment to “protect and enhance human dignity” (Watson, 1988). The FNP’s commitment to protect and enhance human dignity extends along the lifespan, and through the terminal phase of an illness, with timely hospice referrals.

Purnell’s Model for Cultural Competence

Increasing one’s awareness of cultural diversity improves the ability to provide culturally competent care (Purnell, 2005). Larry Purnell’s Model for Cultural Competence offers the FNP a broad understanding of cultural diversity and the importance of cultural competence. According to Purnell, cultural competence involves the following: (1) developing an awareness of one’s own existence, thoughts, and environment without letting it have an influence on others from different backgrounds; (2) demonstrating knowledge and understanding of the other’s culture; (3) accepting and
respecting cultural differences; and (4) adapting care to be congruent with patient’s culture (Robinson & Kish, 2001).

The model (Figure 2.1) reveals four circles. The outer, first circle represents global society. The second circle represents community, the third circle represents family, and the fourth circle represents the patient. Within the four circles are 12 pie-shaped wedges representing cultural domains and associated phenomena. The concepts of the model are global society, community, family, person, and conscious competence. The center of the circle represents unknown phenomenon. The jagged line at the bottom of the diagram represents cultural consciousness as a nonlinear concept (Robinson & Kish, 2001).

Attainment of cultural competence is a progressive process beginning in a state of unconscious incompetence and progressing to a state of conscious competence. A “consciously competent” FNP learns about other cultures, verifies with patients their cultural needs, and employs culturally appropriate interventions (Robinson & Kish, 2001). Cultural competence is vital to effective communication, decision-making, and understanding when caring for terminally ill patients with diverse cultural beliefs regarding death and dying. Effective communication is also vital when discussing referral to hospice. Figure 2.1 displays the model for Purnell’s concept of cultural competence.
Summary of Chapter 2

Utilizing concepts from both Watson’s Theory of Human Caring and Purnell’s Model for Cultural Competence will improve communication with terminally ill patients considering hospice. Watson and Purnell’s ideas are congruent with the purpose of this project. Caring and communicating with patients in an intersubjective and culturally competent manner can improve quality of care and enhance the decision making process.
CHAPTER 3

Introduction

The literature synthesis is a crucial component of this project. Most literature and studies used in the synthesis are current within the past 6 years. However, a few classic studies dating back to the 1980’s were included to illustrate the historical perspective relating to the issue of timely hospice referral. This chapter includes the comprehensive literature synthesis, which is the basis for the survey.

Literature Synthesis

Databases used for the review of literature were CINAHL, Medline and Pub Med. Key words chosen for the search were “palliative care”, “hospice”, “end of life”, “timely hospice referral”, “delivering bad news”, “dying”, and “good death”. The literature search revealed multiple barriers to timely hospice referral. However, the available literature is not abundant. Barriers to timely hospice referral identified in the literature, and discussed in the literature synthesis, include race, age, increasingly aggressive treatments, knowledge deficits regarding hospice services and eligibility, and practitioner difficulty in facilitating difficult conversations and delivering bad news.

Barriers to Timely Hospice Referral

Race

Race is suggested as a barrier to timely hospice referral. There are significant differences between ethnic groups and hospice utilization. African Americans and Mexican/Mexican Americans utilize hospice services less frequently than their Caucasian counterparts (Colon & Lyke, 2003; Greiner, Perera, & Ahluwalia, 2003; Kapo,
MacMoran, & Casarett, 2005; & Rhodes, Teno, & Welch, 2006). African Americans (Greiner et al.; Kapo et al., 2005; Rhodes et al., 2006) have a 40% lower hospice use than whites do. Several explanations are posited. One explanation may be a knowledge deficit regarding hospice as an option for end of life care. Research supports that African Americans are not fully informed about the option of hospice (Cort, 2004; Rhodes, et al.).

As an ethnic group, African Americans generally perceive a long life as intrinsic and good, are less likely to have a living will, and often choose curative care as a way to avoid the reality of impending death (Cort, 2004). Likewise, African Americans are more likely to choose aggressive life-prolonging treatments (Rhodes et al., 2006; Welch, Teno, & Mor, 2005).

Cultural mistrust is another barrier to hospice care for African Americans. Cultural mistrust refers to African Americans’ mistrust of white Americans and traditional American systems, including health care systems (Cort, 2004; Rosenfeld, Dennis, Hanen, Henriquez, Schwartz, Correoso, Murtagh, & Fleishman, 2007). This cultural mistrust may be linked to a specific event in the experience of African Americans as a group. One prominent example of such an event is the Tuskegee Syphilis study of 1932-1972, which is thought to have caused mistrust even among African Americans who do not know about it (Cort). There may be an underlying fear that the patient may receive substandard care or become a guinea pig (Welch et al., 2005). Therefore, when hospice workers enter the home, they may not be welcome and viewed with suspicion (Cort). This does not allow for full benefit of hospice services.
Lack of communication or poor communication is another barrier for African Americans in end of life care. African Americans are more likely to report dissatisfaction with end of life care and communication with health care providers (Rosenfeld et al., 2007; Welch et al., 2005). In a study by Welch and colleagues (2005), end of life medical care experienced by African American and white decedents and their families was compared. Family members of African American decedents reported more dissatisfaction with communication with physicians, anticipatory guidance, and lack of support (Welch et al.). Culturally sensitive discussions regarding end of life care and hospice referrals may help alleviate some of this dissatisfaction.

Hispanics are the largest minority population in the United States (Adams, Horn, & Bader, 2005). However, in the Mexican community, there is limited use of hospice and information about hospice services is lacking (Adams et al., 2005; Gelfand, Balcazar, Parzuchowski, & Lenox, 2001; Gelfand et al., 2004). Lack of knowledge regarding hospice may be due to the inability of some Mexican and Mexican Americans to speak or read English. Hospice agencies and healthcare providers often translate the word “hospice” into the Spanish word “hospicio”. In Mexico, “hospicio” is an inpatient setting similar to a nursing home. Typically, Mexican families react negatively to any suggestion about putting loved ones in nursing homes. The use of the word hospicio may be confusing to Mexicans and cause an immediate refusal to discuss the option of hospice (Adams et al.; Gelfand et al., 2001).

Mexican and Mexican Americans are an underserved population in United States healthcare. Reasons for this include poverty, undocumented citizen status, and
underinsurance. Without the benefit of a primary care physician, Mexicans and Mexican Americans are less likely to receive an early cancer diagnosis, and may present with very advanced disease. Therefore, if a patient presents at the very end stages of disease, and near death, a timely referral to hospice is unlikely (Gelfand et al., 2004). In addition, a culturally fatalistic view towards illness and passive acceptance of terminal illness may reduce the interest in hospice programs (Gelfand et al., 2004; Adams et al., 2006).

For Mexicans and Mexican Americans, family is highly valued. It is a common belief that it is the family’s responsibility to care for the ill family member and ensure a death with dignity (Adams, et al., 2006). Myths about hospice in the Mexican community include beliefs that hospice care can only take place inpatient, and that there is no role for family caregivers (Gelfand et al., 2004; Gelfand et al., 2001; Adams et al., 2006). Mexican Americans may be embarrassed to use hospice because it indicates family members are unable to carry out their care-giving role (Adams et al., 2006). In a culture where family care giving is valued, this can be a barrier to hospice acceptance.

Immigration status is another barrier to hospice care for Mexicans. Fear of investigations into immigration status keeps some Mexicans from considering hospice, and, such concerns of investigation keep many Mexicans from willingness to provide information (Gelfand et al., 2004).

An important finding in the research regarding end of life care in the Arab population revealed that both Arab Muslims and Arab Christians prefer not to tell the family member bad news (Duffy, Jackson, Schim, Ronis, & Fowler, 2006). The words “cancer” and “death” are to be avoided (Duffy et al., 2006). Arab Christian women
specifically feel that one should not talk about death in advance (Duffy et al.). This is definitely a barrier to timely hospice referral.

Avoiding a nursing home is important to many within the Arab culture. Family usually cares for a member who is dying (Duffy et al., 2006). Because many Arabs believe that life should not be extended artificially, hospice may be an acceptable option. However, many Arabs are unfamiliar with the concept of hospice (Duffy et al.).

Age

Cancer is the leading cause of nontraumatic death in American children (Beale, Baile, & Aaron, 2005; Jemal, et al., 2007). A home death may be optimal for a terminally ill child. The home environment offers presence of friends and family members, beloved pets, and toys. All of these improve quality of end of life for the child. A home death is preferred for most children and their parents (Grinyer & Thomas, 2004; Tadmor, Postovsky, Elhasid, Barak, & Arush, 2003). Hospice care allows children to die at home. Unfortunately, age is a barrier to timely hospice referral for children. Only 20 percent of hospices in the United States provide pediatric care (NHPCO, 2005). Staff that is competent in pediatric hospice care is critical for success of a pediatric hospice program. Parents of dying children have reported dissatisfaction with hospice staff that is not prepared to care for children (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Himmelstein, 2006). Of utmost importance is the skill of recognizing and assessing pediatric pain (Himmelstein).

Ineffective communication is also a barrier to pediatric hospice referral. Children and families need clear, honest and complete information in order to make end of life
decisions (Jones, 2006; Meyer, Ritholz, Burns, & Troug, 2006). While parents of terminally ill children recommend giving difficult news directly and honestly, hope is still valued and should never be taken away (Contro et al.; Hinds, Schum, Baker, & Wolfe, 2005; Tadmor et al., 2003). This is a difficult balance. Hope does not have to mean hope for a cure. Hope may imply that the child will die with dignity, surrounded by loved ones at home (Tadmor et al.). However, unrealistic hope for a cure is an inhibitor to timely hospice referral. Hospice care has been untimely for some due to a delay in parent recognition that there is no chance of a cure for the child (Kane & Primomo, 2001; Tan, Totapally, Torbati, & Wolfsdorf, 2006). Unfortunately, many practitioners do not receive training to learn effective communication skills when dealing with end of life issues within pediatrics (Hinds et al.).

The actual type of cancer that the child has may be a barrier to earlier hospice referral. Results of a study performed by Bradshaw and colleagues (2005) suggest that there is a relation between diagnosis and place of death. Children with a solid tumor who are dying of progressive diseases have more time for end of life decision making than children dying of leukemia or treatment related toxicity (Bradshaw, Hinda, Lensing, Gattuso, & Razzouk, 2005). It is this author’s experience that pediatric patients undergoing bone marrow transplant for leukemia continue with aggressive therapy until very close to death. There are challenges with both providers and parents to know when to adjust goals of care from a curative to comfort emphasis.
**Aggressive Treatment Options**

The increasing number of treatments for systemic solid tumors and hematologic malignancies is one cause of delayed hospice referrals. In the past two decades, treatment options have grown exponentially to include new cytotoxic chemotherapies, monoclonal antibodies, and molecularly targeted therapies (Earle, Neville, Landrum, Ayanian, Block, & Weeks, 2004; Mintzer & Zagrabbe, 2007). While physicians may be focusing on a “cure,” there can be a reluctance to admit that death is imminent. In qualitative studies, physicians have reported that active treatment (chemotherapy, radiation) was a barrier to earlier hospice referral (Freidman, Harwood, & Shields, 2002; Johnson & Slaninka, 1999; Sanders, Burkett, Dickenson, & Tournier, 2004).

Increasing numbers of patients are receiving salvage therapies at the end of life. This is resulting in more emergency room visits in the last month of life, increased admissions to, and longer stays in, the intensive care unit, and fewer days between last treatments and death (Earle et al., 2004; Mintzer et al., 2007). Results of studies support that younger practitioners and practitioners located in and around research centers are more likely to continue curative treatments beyond the point that they benefit the patient (Freidman et al., 2002; Sanders et al., 2004).

A small percentage of patients may benefit from second or third line treatment. However, most patients do not benefit, and may have progression of disease throughout treatment (Mintzer et al., 2007). Some physicians may not communicate the facts and choices clearly. Therefore, patients may perceive that there is a new drug to try, but not understand that this new drug is unlikely to prolong one’s life or quality of life (Cherlin,
Fried, Prigerson, Schulman-Green, Johnson-Hurzeler, & Bradley, 2005). With the advancement of medical science, the trend for aggressive end-stage cancer treatment is likely to continue. Although newer therapies offer hope and the possibility of tumor response for a few patients, the majority of patients will suffer worsening symptoms, toxicities (requiring emergency room visits or hospital admissions), and a delayed referral to hospice (Mintzer et al.; Earle et al., 2004).

It is not within the philosophy of hospice to accept patients undergoing aggressive, curative treatments. Aggressive, curative treatments must stop upon admission to hospice. It is the experience of this author that bone marrow transplant physicians often have difficulty switching from an aggressive, curative mindset to one of hospice care. Bone marrow patients and their families may also struggle with knowing when aggressive treatment should end. These patients often do not realize that hospice is an option. Therefore, death is likely in the intensive care unit far way from home, or a late referral to hospice occurs often just days before death.

Knowledge Deficits

A knowledge deficit on the part of the health care provider or the patient and family is a barrier to timely hospice referral. Not all physicians are fully aware of hospice services, or appropriate candidates for hospice care. Knowledge deficit has been reported by physicians as a cause of delayed or no referral to hospice (Brickner, Scannell, Marquet, & Ackerson, 2004; Friedman, Harwood, & Shields, 2002; McGorty & Bornstein, 2003). Health care providers are more likely to make timely referrals to hospice if their training and continuing education includes end of life issues (Friedman et
al., 2002). Some providers with personal hospice experience with a loved one may be more likely to recognize appropriateness of timely hospice referrals (Brickner et al., 2004; Friedman et al.; McGorty & Bornstein).

Although lay people may be aware of the concept of hospice, many are not aware of all hospice has to offer, such as spiritual and emotional support for both the patient and family (Casarett, Crowley, & Hirshman, 2004; Brickner, Scannell, Marquet, & Ackerson, 2004; Schockett, Teno, Miller, & Stuart, 2005). Patients and family members may have limited conceptions regarding hospice that may be a barrier to earlier hospice referral. Common concerns of patients and family members regarding hospice include ability of hospice to provide the degree of support the patient needs, money for payment for services, and giving up hope (Casarett et al.; Friedman et al., 2002).

**Difficulty Delivering Bad News**

Health care providers often have difficulty breaking bad news to patients, particularly when the bad news leads to a discussion of hospice (Amiel, Ungar, Alperin, Baharier, Cohen, & Reis, 2006; Baile, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000, & Casarett & Quill, 2007). How bad news is delivered may affect the patient and family’s understanding of the information, satisfaction of medical care, and future psychological development (Baile et al., 2000; Mager & Andrykowski, 2002; Rassin, Levy, Schwartz, & Silner, 2006). Difficulty or inability to effectively communicate bad news is a barrier to timely hospice discussions and referrals. Barriers to effective communication include inexperience, lack of training regarding delivering bad news, physician fear of losing control, and fear of patient or family reaction.
Initiating and maintaining a conversation dealing with bad news is very complex. Bad news is usually accompanied by distress (Baile & Beale, 2003; Ptacek & Ellison, 2000). Breaking bad news can be especially stressful for providers inexperienced in delivering bad news. Providers inexperienced in having difficult conversations may attempt to delay initiation of the conversation, therefore, delaying hospice referral (McGorty & Bornstein, 2003). Lack of skills causing reluctance to deal with the patient’s emotions has been reported as a reason for avoidance of initiating difficult conversations (Amiel et al., 2006). Many providers have never had adequate training in relaying bad news (Arnold & Koczwara, 2006; Baile & Beale; Ptacek & Ellison; Schwartz, Clive, Mazor, Ma, Reed, & Clay, 2005).

Many providers experience a fear of losing control of their emotions, or control of the situation, when delivering bad news. This fear of losing control may foster delayed initiation of difficult discussions. Provider experiences of losing control include becoming emotional during the difficult conversation, losing control of confidence, losing control associated with relationship to patient and patient’s family, and losing control of the situation (Baile & Beale, 2003; Friedrichson & Milberg, 2006). Many providers worry the patient or family will become angry and blame them for delivering the bad news or for what patients perceive as inadequate care (Friedrichsen & Milberg; Buckman).

Gaps in Literature/Summary of Chapter 3

Barriers to hospice care for African Americans are more prevalent in the literature than other racial groups. Such research may help hospices and health care providers
develop strategies to help eliminate racial barriers to hospice care, and improve cultural competence. Congruence between hospice staff and ethnic minorities would improve with increased diversity in hospice care providers.

There exists a monumental gap in the literature regarding the nurse practitioner and hospice referral. The studies reviewed in this project all used physicians. There must be substantially more research involving the nurse practitioner in hospice referral. As this project suggests, the FNP may have a significant role in the initiation of hospice discussions and subsequent timely referral. Nurse practitioners would be included in the survey, developed based on this literature review, if it were to be implemented.
CHAPTER 4

Introduction

The literature synthesis is the basis for a survey developed to describe experiences from local health care providers who have referred patients to hospice within the past year. This chapter explains the relationship of the literature synthesis to the survey. Details are included regarding constructing the survey and possible implementation of the survey. The actual survey is included at the end of this chapter.

Constructing the Survey

The objective of this survey is to describe the experiences of local primary care providers in referring patients to hospice. Therefore, this survey is of a descriptive design utilizing concepts from the literature synthesis. The survey is in a self-administered, self-report, pencil-paper format. Benefits of utilizing a self-administered questionnaire include low cost, anonymity, and ability to ask some possibly sensitive questions (Aday, 1989). Although this survey will be mailed to providers in a paper-pencil format, participants will be offered the option to complete the survey on-line. Some participants may prefer an electronic format and this may be accomplished by providing a web address to complete the survey. Offering an alternative to paper-pencil format may increase the likelihood of participation. This survey has seven question sections. Information revealed from literature provides the basis for each section.

Section 1 and Section 3 of the survey represent personal and patient demographics. Referring primary care provider age and gender is a potential barrier to timely hospice referral (Freidman et al., 2002; Sanders et al., 2004), as is location of
patient residence (rural or urban), socioeconomic status, and race (Adams et al., 2006; Cort, 2004; Gelfand et al., 2004; Welch et al., 2005). Location of provider clinic may also influence the ability for timely hospice referrals (Friedman et al.; Sanders et al.).

Section 2 is Personal hospice beliefs. Personal experience with hospice may influence the ability to recognize the importance of timely hospice referral (Brickner et al., 2004; Friedman et al., 2002, & McGorty et al., 2003). Sections 4 and 5 deal with breaking bad news and having hospice discussions. The literature identifies difficulty breaking bad news and initiating difficult conversations as a barrier to timely hospice referral (Buckman, 1992; Friedrichson et al., 2006; Rassin et al., 2006).

Section 6 is in reference to provider experience and beliefs regarding appropriate lengths of stay for hospice patients. Longer lengths of stay in hospice allows for the patient and family to benefit from all hospice services (Miller et al., 2003; Rickerson et al., 2005). Section 7 covers personal provider’s experiences regarding barriers. Provider responses may duplicate what has been identified in the literature synthesis or uncover additional barriers previously not discussed.

Implementation of Project

It is feasible to implement this project and results of this survey will be extremely useful for the FNP. Recognizing barriers to timely hospice referral will aid the FNP in developing interventions to remove such barriers. With 1500 people dying from cancer each day nationwide (Jemal et al., 2007), the topic of timely hospice referral is of interest to the FNP and other providers. Recognizing barriers to timely hospice referral is not a novel concept; however, it is of utmost importance.
Ethical considerations are included in the possible implementation of this survey. Before distribution of this survey, approval by the institutional review board (IRB) is mandatory. Participation in this survey is voluntary. Identity of each respondent will remain unknown. Utilizing a self-administered questionnaire offers anonymity to the participant (Aday, 1989). The only identifiable information will include gender, age, and location of provider. Patient information will be protected according to the Health Insurance Portability and Accountability Act (HIPAA) guidelines.

The planned sample population to receive the survey is a cross-sectional sample of Tucson primary care providers including NPs, MDs, and PAs. Pediatric primary care providers will also be included in the sample population. The sample population will simply be picked randomly from the Tucson yellow pages. Addresses will be randomly displayed in a table format and picked. This investigator will mail surveys to 200 primary care providers with the expectation that at least 50 providers will respond. Providing a pre-addressed stamped envelope with the survey allows for ease of sending in completed survey.

Survey questions are formatted using an approach that allows for choosing the number corresponding with the best answer. This format allows for ease of interpreting the results. A comment section will be available on the survey and data may be pooled from the comment sections.
Summary of Chapter 4

The purpose of this survey is to describe experiences of Tucson primary care providers in hospice referral. The literature synthesis was the basis for developing the survey questions. Steps to implement this survey were provided in this chapter. The following pages include the completed descriptive survey for possible implementation.
Purpose

The purpose of this survey is to describe the hospice referral process among primary care provider practices in Tucson. This survey is intended for primary care providers who have referred terminally ill patients WITH CANCER to hospice in the last year. Results of this survey will be analyzed to identify barriers to timely hospice referral. Please complete this survey in a time and place that is conducive to reflective thinking. If you prefer, you may participate in this survey on line at the following website: www.keeslersurvey.com. It will take approximately 15 minutes to complete this survey. CIRCLE THE NUMBER THAT CORRESPONDS TO YOUR ANSWER.

This survey is divided into the following question sections:

1. Personal Demographics
2. Personal Hospice Beliefs
3. Patient Demographics
4. Breaking Bad News
5. Discussing Hospice
6. Hospice Referral Patterns
7. Barriers to Timely Hospice Referral
1. **Personal Demographics**

A. **What are your professional credentials?**

<table>
<thead>
<tr>
<th>Professional</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>MD</td>
<td>1</td>
</tr>
<tr>
<td>NP</td>
<td>2</td>
</tr>
<tr>
<td>PA</td>
<td>3</td>
</tr>
</tbody>
</table>

B. **What is your age range?**

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 – 30</td>
<td>1</td>
</tr>
<tr>
<td>31 – 40</td>
<td>2</td>
</tr>
<tr>
<td>41 – 50</td>
<td>3</td>
</tr>
<tr>
<td>51 – 60</td>
<td>4</td>
</tr>
<tr>
<td>&gt; 60</td>
<td>5</td>
</tr>
</tbody>
</table>

C. **What is your gender?**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
</tbody>
</table>

D. **Where is the location of your practice?**

<table>
<thead>
<tr>
<th>Location</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>1</td>
</tr>
<tr>
<td>Rural</td>
<td>2</td>
</tr>
</tbody>
</table>

E. **How long have you been practicing in your current role?**

<table>
<thead>
<tr>
<th>Years</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 5 years</td>
<td>1</td>
</tr>
<tr>
<td>6 – 10 years</td>
<td>2</td>
</tr>
<tr>
<td>11 – 15 years</td>
<td>3</td>
</tr>
<tr>
<td>&gt; 15 years</td>
<td>4</td>
</tr>
</tbody>
</table>

F. **Do you consider yourself adequately trained to discuss end of life concerns with your patients and patients’ families?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>I don’t know</td>
<td>3</td>
</tr>
</tbody>
</table>

Comments:
2. Personal Hospice Beliefs

A. Do you have any personal experience with a family member or close friend enrolled in hospice?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:

B. Do you consider yourself knowledgeable about hospice services and eligibility requirements?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:

C. Do you believe that hospice adds quality to a patient’s end of life?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>I don’t know</td>
<td>3</td>
</tr>
</tbody>
</table>

Comments:

D. Do you think amount of time a patient has in hospice affects the quality of end of life?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>I don’t know</td>
<td>3</td>
</tr>
</tbody>
</table>

Comments:
3. **Patient Demographics**

A. What is the age range of the patients that you have referred to hospice in the last year? Circle all that apply.

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 18 years</td>
<td>1</td>
</tr>
<tr>
<td>19 – 30 years</td>
<td>2</td>
</tr>
<tr>
<td>31 – 45 years</td>
<td>3</td>
</tr>
<tr>
<td>46 – 60 years</td>
<td>4</td>
</tr>
<tr>
<td>61 – 75 years</td>
<td>5</td>
</tr>
<tr>
<td>&gt; 75 years</td>
<td>6</td>
</tr>
</tbody>
</table>

B. What is the type of cancer of the patients that you have referred to hospice in the last year? Circle all that apply.

<table>
<thead>
<tr>
<th>Type of Cancer</th>
<th>Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Solid Tumor</td>
<td>1</td>
</tr>
<tr>
<td>Heme/Onc (Such as Leukemia)</td>
<td>2</td>
</tr>
</tbody>
</table>

C. What is the race of the patients that you have referred to hospice in the last year? Circle all that apply.

<table>
<thead>
<tr>
<th>Race</th>
<th>Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2</td>
</tr>
<tr>
<td>Black</td>
<td>3</td>
</tr>
<tr>
<td>African American</td>
<td>4</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>5</td>
</tr>
<tr>
<td>American Indian</td>
<td>6</td>
</tr>
<tr>
<td>Arab</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
</tr>
</tbody>
</table>

D. Of the patients that you have referred to hospice in the last year, were any from underserved populations?

<table>
<thead>
<tr>
<th>Response</th>
<th>Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:

E. What were the insurances of the patients that you referred to hospice in the last year?

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Circle</th>
</tr>
</thead>
<tbody>
<tr>
<td>HMO/Prepaid Plan</td>
<td>1</td>
</tr>
<tr>
<td>Medicare</td>
<td>2</td>
</tr>
<tr>
<td>Medicaid</td>
<td>3</td>
</tr>
<tr>
<td>No Insurance</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
<tr>
<td>I don’t remember</td>
<td>6</td>
</tr>
</tbody>
</table>
4. **Breaking Bad News**

A. Is breaking bad news to a patient and family difficult for you?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:

B. Do you consider it a personal failure if your patient is not cured from a potentially terminal illness?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:

C. Do you have difficulty accurately predicting life expectancy to within 6 months?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:

D. Do you ever worry about losing control when delivering bad news, such as crying or losing control of the situation?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:
5. **Discussing Hospice**

A. Do you initiate conversations about hospice?

- Yes. ................................................................. 1
- No....................................................................... 2

Comments:

B. Do you wait for patient or family to bring up hospice before conservation is initiated?

- Yes................................................................. 1
- No....................................................................... 2

Comments:

C. How do you know when it is the right time to discuss hospice?

- The patient probably has a few days to live................................. 1
- The patient probably has a few weeks to live................................. 2
- The patient probably has 6 months to live..................................... 3

Comments:

D. When discussing hospice, who is included in the discussion?

- Yourself and patient only..................................................... 1
- Yourself, patient and other staff.............................................. 2
- Yourself, patient, and family.................................................. 3
- Other............................................................................. 4

Comments:

E. When discussing hospice, what information is given regarding hospice services and eligibility?

- Written information from local hospices................................. 1
- Written information from your office..................................... 2
- No information regarding hospice services and eligibility is given.. 3
- Other............................................................................. 4

Comments:
F. Is there a hospice liaison(s) who visits your office setting?

<table>
<thead>
<tr>
<th>Yes.</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

6. Hospice Referral Patterns

A. Approximately how many cancer patients have you referred to hospice in the last year? Circle the appropriate answer.

<table>
<thead>
<tr>
<th>0 – 5</th>
<th>6 – 10</th>
<th>11 – 15</th>
<th>16 – 20</th>
<th>&gt; 20</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

B. Have you ever stayed on as “hospice doctor of record” after referral to hospice?

<table>
<thead>
<tr>
<th>Yes.</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
</tr>
</tbody>
</table>

C. In the past year, what was the average length of stay for patients you referred to hospice?

<table>
<thead>
<tr>
<th>1 - 3 days</th>
<th>4 - 14 days</th>
<th>2 - 4 weeks</th>
<th>1 month - 6 months</th>
<th>I don’t know</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

D. How much time do you believe is adequate for patients and families to benefit from hospice services?

<table>
<thead>
<tr>
<th>1 - 3 days</th>
<th>2 - 4 weeks</th>
<th>1 month – 6 months</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Comments:

E. What has family input been after death (if any), regarding timing of the hospice referral?

<table>
<thead>
<tr>
<th>Too early referral</th>
<th>Too late referral</th>
<th>Just right referral</th>
<th>No input from family</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Comments:

7. **Barriers to Timely Hospice Referral**

A. Is personal knowledge deficit ever a barrier to timely hospice referrals in your practice?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:

B. Is patient or family knowledge deficit of hospice ever a barrier to timely hospice referrals in your practice?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Comments:
C. Has patient age ever been a barrier to timely hospice referral in your practice?
   (Too young to die?)
   Yes………………………………………………………………………………..1
   No…………………………………………………………………………………2
   Comments:

D. Has continuing aggressive treatment ever been a barrier to timely hospice referral in your practice?
   Yes………………………………………………………………………………..1
   No…………………………………………………………………………………2
   Comments:

E. Has inability to assess terminality ever been a barrier to timely hospice referral in your practice?
   Yes………………………………………………………………………………..1
   No…………………………………………………………………………………2
   Comments:

F. Have you had patients in the last year refuse suggestion for hospice?
   Yes………………………………………………………………………………..1
   No…………………………………………………………………………………2
   Comments:

G. If so, what were the reasons for refusing hospice? Circle all that apply.
   Not willing to give up hope……………………………………………………1
   Not willing to stop treatment …………………………………………………2
   Not willing to admit terminal status…………………………………………3
   Patient ready, but family refuses………………………………………………4
   Family ready, but patient refuses………………………………………………5
   Other………………………………………………………………………………6
   Comments:
Please use this space to explain any further experience you have had in the past year with hospice referral. Please use HIPAA guidelines and do not provide any identifying patient information.

Thank you for completing this survey. I greatly appreciate your input. Please place your completed survey in the addressed stamped envelope provided. For any questions or if you would like a copy of the results please contact Lana Keesler FNP-S 797-7656.
CHAPTER 5

Introduction

This final chapter identifies plans for evaluation of the survey results. Identification of strengths and weaknesses of this project are also identified and discussed. Finally, this chapter includes the significance of timely hospice referral to the FNP.

Plans for Evaluation

To optimize response to this survey, reminder letters could be mailed to each provider approximately three weeks after the survey was mailed. The reminder letters would stress the importance of this survey, how it will be beneficial to practitioners, and it would thank each provider for participation. It is possible that data collection could continue for six months. This would allow adequate time for sufficient response.

Evaluation of the survey includes analysis of the descriptive data. The data that would be obtained from this survey is coded into numerical data that could be processed by a computer. Comments written in the comment sections would be written out as supplemental descriptive data. Assistance may be necessary with analysis of the data. It would be prudent to enlist such assistance from the office of nursing research at the College of Nursing. After the data is analyzed, a paper may be written and presented at various venues.
Strengths of Project

There are many strengths of this Master’s Project. The topic for this project was formulated from this author’s professional experience. The problem of untimely hospice referral in the oncology setting prompted this project. The author’s interest, passion, and professional experience allows for a complete and comprehensive perspective.

Another strength of this project is the inclusion of barriers of hospice for the Mexican/Mexican American population. Since the purpose of the survey is to explore experiences of Tucson practitioners, inclusion of the Hispanic population is important. Tucson has a large Hispanic population. Understanding barriers for this community is crucial.

The literature review is comprehensive and includes classic studies and literature. The comprehensive nature of the literature synthesis is a major strength of this project. Appropriate databases were utilized, including CINAHL, MEDLINE, and PUBMED. Literature came from nursing, medicine, psychology, and social work disciplines. Utilizing sources from different disciplines widened the scope of the problem.

Limitations of Project

After completion of this project, there are noted limitations. One limitation to this study is difficulty finding primary care nurse practitioners in Tucson. Prospective recipients of the survey will be found in the Tucson phone book. Although physicians are easily found in the phone book, many nurse practitioners are not listed. An additional step of contacting Chapter 9 of the AZNA may be needed for contact information for nurse practitioners.
An additional limit of this project is the fact that collecting data via a survey may have several disadvantages (LoBiondo-Wood & Haber, 2006). The information obtained in a survey may be limited. For example, participants in this survey may not take the time to answer questions fully or honestly. It may also be difficult for practitioners to remember details regarding patients referred to hospice a year ago. The targeted sample for this survey is health professionals. These health professionals may feel they are just too busy to participate in this survey, limiting the response rate.

Another limitation of this project is the limited scope. The survey is for practitioners in Tucson only. Results of the survey may not be applicable to practitioners of other regions. This lack of generalizability limits the project.

Significance to the FNP

With over 1500 deaths a day nationally from cancer (Jemal, et al., 2007), the FNP must be prepared to deal with terminally ill and dying patients and their families. The FNP has an advantage of caring for the whole person, not just looking at curing a disease. It is this holistic perspective that can assist the patient and family in recognizing when aggressive treatment is no longer a viable option. The FNP may utilize concepts from Watson’s Theory of Human Caring to assist in the transpersonal relationship. This may facilitate decision-making through the FNP’s commitment to “protect and enhance human dignity”.

The FNP must be knowledgeable regarding cultural competence. Purnell’s Model for Cultural Competence, explained in this project, allows the FNP to learn ways of communicating and caring for diverse patients. Literature included in this project
increases awareness of cultural differences when dealing with death, hospice, communication, and decision-making.

The FNP has the unique ability to care for patients of all ages across the lifespan. Information provided in this project regarding age as a barrier to hospice provides the FNP with awareness of issues when dealing with the dying child. Families may look to the FNP for guidance when making difficult decisions regarding end of life care for children.

One goal of this Masters Project is to decrease or eliminate any FNP knowledge deficits regarding timely hospice referral. Increasing the FNP’s awareness of the importance of timely hospice referral is crucial to quality patient end of life. Becoming aware of barriers to timely hospice referral is imperative for the FNP. The FNP has the ability to become a facilitator to timely hospice referral and improve the quality of end of life for dying patients and their families.
References


