

TIMELY REFERRALS TO HOSPICE AND FAMILY SATISFACTION

by

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DEDICATION

I dedicate this work to my husband Greg and children Ariel and Will. Your unfailing support, encouragement, and love kept me motivated throughout this journey.

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ABSTRACT

Approximately one-third of persons with a terminal illness utilize hospice care. Of those, ten percent only received hospice care during the last twenty-four hours of life. Late referrals to hospice can result in less time for the hospice team to perform assessments, establish relationships, and initiate mutually established goals requiring active interventions. Thus, the terminally ill person and their family may not receive the maximum benefits of hospice. The purpose of this study was to examine the relationship between the length of hospice care and the level of family satisfaction. King's Theory of Goal Attainment (1995) was used to guide the investigation of the personal and interpersonal concepts that may influence family satisfaction. These concepts included: pain and symptom management (personal), communication/education, and emotional/spiritual support (both personal and interpersonal). For the purpose of this investigation, high levels of satisfaction with hospice care would be considered to be reflective of goal attainment. The setting was a small hospice agency in a western state and a convenience sample of returned Family Satisfaction Surveys (Hospice A, 2000) spanning a three year period were used. The returned surveys were grouped by length of care into the Short Term group (less than a month of hospice care before death) and Timely group (one month as longer hospice care before death). A combination of Chi-square and *t*-test comparisons of means was used to test the hypothesis that longer lengths of hospice care resulted in higher levels of the family satisfaction. No significant differences existed between family satisfaction and length of care. Overall, this study found the satisfaction level with hospice care was high regardless of length of care (a mean satisfaction of 4.5 on 5 point scale).

CHAPTER 1

INTRODUCTION

Hospice services exist to serve the needs of the terminally ill person during the last stages of life-limiting or debilitating chronic conditions. Hospice care provides the terminally ill person and their family with support, symptom management, and strives to assist the person to maintain a satisfactory lifestyle through the final stages of life (McHale, 1998). In addition, the multidisciplinary team approach to hospice care offers high-quality care at end-of- life with excellent patient and family satisfaction (Casarett, Crowley, & Hirschman, 2004).

However, despite all the benefits of hospice care, the terminally ill patient is typically referred to hospice during their last days or weeks of life (Casarett & Quill, 2007). The median length of hospice services nationally is about three weeks, with approximately 10% of all hospice patients enrolling in hospice care in the last 24 hours of life (Casarett & Quill, 2007). As a result, these patients may not receive the maximum benefit of hospice services since the transition to hospice care occurs late in the life of the patient (Woods, Craig, & Dereng, 2006).

When patients enroll in hospice care within days to hours before death, the hospice team has little time to perform assessments, build trusting relationships, establish goals, and initiate effective interventions (Rickerson, Harrold, Kapo, & Casarett, 2005). Several studies, examining hospice length of care and perceived levels of family satisfaction with hospice care, found higher levels of satisfaction were associated with

longer lengths of care (Casarett & Quill, 2007; Dy, Shugarman, Lorenz, Mularski, & Lynn, 2008; Rickerson et al., 2005; Teno et al., 2007). Therefore, longer lengths of hospice services are hypothesized to result in higher levels of satisfaction experienced by the decedents' family.

Statement of the Problem and Research Question

Through hospice, the terminally ill persons and families have access to a variety of supportive services such as: nursing care, medications, medical equipment, personal care assistance, social services, spiritual support, counseling, and bereavement care. However, it is clear that terminally ill persons and families are not consistently accessing hospice care in a timely fashion (Casarett & Quill, 2007). Therefore, they may not be receiving the full complement of benefits offered through hospice care.

Earlier referrals can help to insure the terminally ill persons and families will receive the level of care and support needed, thus possibly resulting in overall high levels of satisfaction being reported by families (Weckmann, 2008). Therefore, longer lengths of hospice care in the period before death would allow patients and families access to all of the available hospice services, possibly resulting in the family's perception of high levels of satisfaction with hospice care. The question that guided this investigation was; is there a relationship between the length of care received by the hospice patient in the period before death and the level of satisfaction with hospice services as rated by the family.

This research seeks to examine if the length of hospice services influences the family's perception of satisfaction with hospice care. Additionally, it will examine if length of care (LOC) influences satisfaction levels in relation to the domains of hospice care (pain and symptom management, communication and education, emotional and spiritual support) thought to be most helpful at end-of- life (Charalambous, 2010; Raleigh, Robinson, Marold, & Jamison, 2006; Teno et al., 2007).

Purpose of this Study

This study seeks to examine the relationship of family satisfaction to the length of time hospice services are received by a terminally ill person. A retrospective review of Family Satisfaction Surveys (FSS) (Hospice A, 2000) was planned with a comparison of the responses between the group of families that received *Short Term* (less than one month) hospice care with the group designated as *Timely* (one month of hospice or greater). Further, the researcher examined the responses to identify what other factors may have influenced family satisfaction. These factors included the domains of hospice care related to pain and symptom management, communication and education, and emotional and spiritual support.

King's Theory of Goal Attainment (1992) is the model used for this research to examine the relationship between family satisfaction and hospice services. In this investigation, high levels of family satisfaction were considered to be reflective of goal attainment. This research was designed to provide direction to improve hospice care and insight into the factors families view as important in the delivery of end-of- life care.

Background and Significance

Approximately one third of persons with a terminal illness utilize hospice care, and ten percent of those individuals only received care during the last 24 hours before death (Casarett & Quill, 2007; National Hospice and Palliative Care Organization [NHPCO], 2009). Late referrals to hospice care can result in the family's perception of unmet needs and lower quality of care (Teno et al., 2007). Weckmann (2008) reported the majority of families who received hospice services for a loved one wished they had know about or had been referred to hospice care sooner.

Medicare Hospice Benefit

The Medicare Hospice Benefit (MBH), enacted by Congress in 1982, was designed for persons with a terminal illness in the last six months of life (United States Department of Health and Human Services [USDHHS] Centers for Medicare and Medicaid Services [CMS], 2010). The MHB provides comprehensive services through a team approach to manage symptoms, support, and assistance to help the person live the life they have left to the fullest (USDHHS CMS, 2010).

Hospice care focuses on the palliation of symptoms that interfere with or disrupt the terminally ill person's quality of life, utilizing a multidisciplinary team to address the physical, psychosocial, and spiritual needs of the person during the last six months of life (USDHHS CMS, 2010). The focus of hospice is comfort and care, not cure. It is a holistic approach providing for physical, emotional, social, and spiritual support through a collaborative team approach (USDHHS CMS, 2010). The MHB includes medications,

equipment, nursing care, supplies, and counseling needed to support the terminally patient and family through the dying process (USDHHS CMS, 2010).

The hospice team is comprised of a physician medical director, nurse case manager, social worker, personal physician or nurse practitioner, and other supportive staff (chaplain, hospice aide, counselors, volunteers, and therapies) (USDHHS CMS, 2010). The hospice team collaborates with the terminally ill person and family to set goals for the end-of- life symptom management and provides support to the patient and family throughout the period before death and for up to twelve months after death for the surviving family members (USDHHS CMS, 2010).

The MHB is primary source of payment for hospice services (84% of all patients), though many insurers are now covering hospice services (NHPCO, 2009). It is estimated that hospice saves Medicare an average of \$2,309 per patient over the cost of caring for patients at end-of -life without hospice (Taylor, Ostermann, Van Houtven, Tulskey, & Steinhauser, 2007). Additional savings to Medicare could be realized if seven out of ten patients, referred to hospice, were referred earlier in the period before death (Taylor et al., 2007). Researchers found the cost for care was often higher in the week before the initiation of hospice care, related to expensive hospitalizations when curative treatments failed and the patient declined (Taylor et al., 2007). However, lengths of care greater than six months on hospice care did not reflect a cost-savings over non-hospice care costs (Taylor et al., 2007). Thus, patients who are referred to hospice during the last six months of life have reduced cost of end-of-life care costs and improved quality of life over those who received traditional care (Taylor et al., 2007).

Hospice Utilization

The NHPCO estimated, in 2008, 1.45 million persons received services from hospice (NHPCO, 2009). Of those who received hospice care, 276,000 remained on hospice at the end of the year, and 212,000 were discharged alive for reasons including: 1) extended prognosis of greater than six months, 2) desire of the patient to seek curative care, and 3) other reasons (NHPCO, 2009). Nationally, 963,000 patients died while on hospice care in 2008 (approximately 38.5% of all deaths in the United States) (NHPCO, 2009). In 2003, the percentage of eligible Medicare beneficiaries that utilized hospice care was only 1.4 % for the state of Montana compared with the national average of 2.1% (American Association of Retired Persons [AARP], 2005).

Impact of Late Hospice Referrals

Approximately one third of persons with terminal illnesses utilize hospice care, and ten percent of those individuals only received hospice care in the last 24 hours of life (Casarett et al, 2007; NHPCO, 2009). Often, persons at the end-of- life do not receive the maximum benefits of hospice because of late referrals (within the last 24 hours before death) and families reported they wished they could have been introduced to hospice sooner before the death of a loved one (Weckmann, 2008; Woods et al., 2006).

Teno et al. (2007) reported that late referrals to hospice correlated with lower levels of satisfaction and decreased number of services provided to the patient and family. Lower levels of family satisfaction with hospice care are also associated with the perception of lower quality of care (Teno et al., 2007). Thus, late referrals can result in a

family having a negative perception of the quality of care provided by the hospice and a perception of the unmet needs of the patient at the end-of-life (Teno et al., 2007).

One of the barriers to hospice care cited by Casarett and Quill (2007) arose from the way that hospice care is designed as access is limited to a six months or less of life expectancy and the person must forego further curative treatments as mandated under the regulations of the MHB (USDHHS CMS, 2010). They also reported the challenges providers face when discussing goals of care and treatment options with patients, determining life expectancy, and discomfort in discussing prognosis. Referrals to hospice care are associated with imminent death in the minds of physicians and patients and this perception may delay referrals to hospice until the last days of life (Finlay & Casarett, 2009).

Even when hospice care is introduced earlier in the disease process, patients and families may not be ready to accept hospice and refuse referral to hospice care (Waldrop & Rinfrette, 2009). Casarett, Crowley, Stevenson, Xie, and Teno (2005) reported patients and families may not fully understand the scope and philosophy of hospice care and the practical support that can be provided through hospice services. This lack of knowledge can also be a barrier to the family seeking hospice care.

Increasing awareness and understanding of hospice services amongst health care providers will help to facilitate earlier (*Timely*) referrals to hospice care (Finlay & Casarett, 2009). Finlay and Casarett (2009) suggested providers' conversations with patients and families about hospice should "occur within the context of honest prognostic disclosures, discussion of patient goals, and identification of service needs" (p. 261).

Thus, providers can help insure *Timely* referrals to hospice and improve the end-of-life experiences for patients (Finlay & Casarett, 2009).

Conceptual Framework

King's Theory of Goal Attainment (1992) is the model used to examine the concept of family satisfaction with hospice care. King (1992) reported "individuals and groups interact for the purpose of attaining goals" (p. 23). In hospice care, the hospice team and patient and family interact for the purpose of achieving quality of life at end-of-life for the dying person. Goal attainment would, therefore, be reflected in high levels of satisfaction in hospice care as reported by the family. Satisfaction with care can equate to quality of care and measures of satisfaction, therefore, can be used to inform quality improvement programs (King, 1992).

King's concept of time is defined as the "duration between the occurrence of one event and the occurrence of another event" (1981, as cited in Evans, 1991; p. 43). In this investigation, the concepts of time are measured from the initiation of hospice care to the time of death.

The concept of perception in King's model "gives meaning to one's experience, represents one's image of reality, and influences one's behavior" (1981, as cited in Evans, 1991, p. 17). Evaluating the family's perception of hospice services provided insight as to whether the LOC influenced family's satisfaction.

Further, the three domains of hospice services (pain and symptom management, communication and education, and emotional and spiritual support) will be examined in

relation to the LOC to determine if the level of satisfaction in these areas differs over time. These domains of hospice services relate to King's concepts of personal (pain and symptom management) and interpersonal (communication/education and emotional/spiritual support) transactions between hospice staff and the patient and family that can result in goal attainment (King, 1992). Therefore, effective interventions in each domain of hospice care should be reflective of high levels of satisfaction and goal attainment as reported by families on the Family Satisfaction Survey (FSS) (Hospice A, 2000).

Hypothesis

Some studies reported patients received more hospice services when they received hospice for periods greater than one month (Rickerson et al., 2005; Teno et al., 2007). If the patient and family perceived benefits from the wider range of services provided with longer lengths of hospice care, the result might be reflected in higher levels of satisfaction in hospice care as reported by the family. Therefore, this research will test for the hypothesis: *Timely* referrals to hospice care will result in higher levels of satisfaction as reported by families.

Definitions

Hospice care is defined by Medicare as “a benefit designed to provide comprehensive medical care utilizing a multidisciplinary team approach to meet the needs of the terminally ill person and family” (USDHHS CMS, 2010; p. 4). Hospice care

is limited to persons who are thought to have six months of life or less if the disease progresses as expected (USDHHS CMS, 2010). It is mandated by Medicare regulations that the person and/or patient representative understands and freely elects the benefit, and is involved in the formation of the plan and goals for care (USDHHS CMS, 2010).

Hospice care is holistic as it addresses the physical, emotional, social, and spiritual needs of the patient and family (NHPCO, 2009). The main concepts related to hospice care for inquiry in this investigation will be pain and symptom management, communication and education, and emotional and spiritual support. These three domains are considered to be integral to services hospice provides and influence families perception of the quality of care provided (Teno et al., 2007).

The definition of *Timely* for this investigation were those patients who received hospice care for one month or longer in the period before death. Conversely, *Short Term* was defined as patients who received less than one month of hospice care in the period before death. These time frames were used to define the groups of hospice patients for this investigation.

The concept of satisfaction equates to the fulfillment of needs. In the scope of hospice care, satisfaction reflects the ability of hospice services to fulfill the needs of the dying patient and family. Satisfaction is an individual perception which is influenced by the person's experiences, education, and goals (King, 1981, as cited in Evans, 1991). Measuring satisfaction allows for greater understanding of the families perception of hospice services. For the purpose of this investigation, the operational definition of

satisfaction was a score greater than three on a five-point scale on the FSS (Hospice A, 2000).

Assumptions

The primary assumption for this investigation is that high levels of satisfaction, as reported by families, equates to attainment of the goals of hospice care. Goal attainment equates to quality care, thus high levels of satisfaction are also a measurement of the quality of care provided (King, 1995). The interactions between the hospice team and patient and family will result in a perception of services received. These perceptions will be reported by the family as levels of satisfaction with hospice care on the FSS (Hospice A, 2000).

The three domains of hospice care are the concepts of; 1) pain and symptom management, 2) communication and education, and 3) emotional and spiritual support. These domains correlate with the hospice's holistic scope of care that seeks to address the physical, psychosocial, and spiritual needs of the patient and family (NHCPO, 2009). The questions on the FFS (Hospice A, 2000) will be organized to examine each domain for any differences.

King's Theory of Goal Attainment (1995) was the model used to inform the personal and interpersonal concepts that influence a family's perception of satisfaction in each of the domains of hospice care. The effectiveness of interactions in each domain is reflected in the rating of satisfaction as reported by the family. These ratings will provide insight into the effectiveness of the interventions implemented by the hospice. The

outcomes of this study can help to inform quality improvement efforts if any domain is found to have low satisfaction (rating less than three on five-point scale).

Limitations

One limitation will be the FSS (Hospice A, 2000) tool. Because it was an internally developed tool, it has not been validated as an accurate measure of family satisfaction. A Cronbach's alpha test of reliability was conducted as part of this study to examine the internal consistency and reliability of the responses within the sample (Polit & Beck, 2008).

In addition, the format of the questions must be written in a language and at the level of literacy for the intended respondents (Polit & Beck, 2008). The FSS readability was examined as discussed in Polit and Beck (2008, p. 480) using the Microsoft Office software program (2007) readability statistical program to evaluate the Flesch-Kincaid (1948) grade level of the document, and any suggested wording changes were forwarded to the Hospice A's Quality Assurance and Performance Improvement (QAPI) committee for approval.

Another limitation was the sample was a convenience sample of returned surveys to a small rural hospice that serves approximately 140 patients a year. When a sample is comprised of voluntary respondents, the results may be skewed by a response bias as those with strong opinions (both negative and positive) are more likely to respond (Boslaugh & Waters, 2008).

Obtaining a large enough sample to establish significant findings was also a limitation depending on the return rate of surveys to the agency. The typical return rate for mailed surveys is around 30% (Boslaugh & Waters, 2008). As the hospice serves approximately 140 patients per year, several years worth of surveys was required to meet the sample size needed for each group (*Timely* and *Short Term*) determined by the planned power analysis.

The information on the length of care received by the patient is an optional section on the survey. Surveys without this information were excluded from the planned analysis as the length of care is the explanatory variable in the hypothesis being tested.

The scope of this study was purposefully limited to the quantitative data that is available through the current survey tool (FSS Hospice A, 2000) used by the hospice agency that has granted access to the data. The one year time frame to complete this investigation was a limitation, necessitating the exclusion of any qualitative data analysis on the comments included on the returned surveys.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

The hypothesis, “*Timely* referrals to hospice care will result in higher levels of satisfaction as reported by families,” is the focus of this inquiry. This paper summarizes the current literature available as it relates to the concepts of *hospice care*, *timely referrals*, *family satisfaction*, and *theory of goal attainment*. King’s Theory of Mutual Goal Attainment (1995) will be the model to guide the investigation in the current research, and is included now to determine if any research related to hospice care has been done using this theory.

Literature Review Process

In an effort to conduct a thorough search of all of the available literature related to the concepts of interest (*hospice care*, *timely referrals*, *family satisfaction*, and *theory of goal attainment*), a review of the current literature was conducted using the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and Medline databases. The search parameters were limited to peer reviewed journal articles, and research articles through the Montana State University Library that were published between the years of 2005 through 2010. The results of these searches are discussed under each concept heading. When the concepts became combined with the concept of

theory of goal attainment, it became necessary to expand the search to the year 2000 through 2010 in an effort to locate earlier relevant research.

To determine inclusion in this review, all articles were evaluated for relevance to the main concepts. If relevance was established, the research was then evaluated utilizing Polit and Beck's (2008) "Results Matrixes" (p. 121). This process helped to organize the research to discern themes in the findings, enabling the reviewer to determine patterns between variables and concepts (p. 121). Table 2.1 summarizes the literature review process.

Table 2.1. Literature Search Working Table.

Date Accessed	Database	Search Terms	Number of References	Comments	Number of References Used
Single Search terms					
08/25/10	CINAHL PubMed Medline	<i>hospice care</i>	487 2,686 3,493	Too many and too vague	0
08/25/10	CINAHL PubMed Medline	<i>Timely referrals</i>	58 473 173	Too many and too vague	0
08/25/2010	CINAHL PubMed Medline	<i>Family satisfaction</i>	852 15,465 14,014	Too many and too vague	0
08/25/2010	CINAHL PubMed Medline	<i>Theory of goal attainment</i>	21 2 43	Abstracts were scanned and for applicability only Whelton (2008) was relevant and included	1 Whelton, 2008

Table 2.1. Literature Search Working Table-continued.

Date Accessed	Database	Search Terms	Number of References	Comments	Number of References Used
Combined Search Terms					
08/25/10	CINAHL PubMed Medline	<i>Hospice care,</i> <i>Timely</i> <i>referrals</i>	17 18 5	Abstracts were scanned, duplicates were eliminated, the remaining articles included in review	6 Casarett & Quill, 2007; Finlay & Casarett, 2009; Melvin, 2008; Teno et al,2007; Waldrop & Rinfrette, 2007;Weckman, 2008
08/25/10	CINAHL PubMed Medline	<i>Hospice care,</i> <i>family</i> <i>satisfaction</i>	366 15,465 4,027	Too many and too vague	0
08/25/2010	CINAHL PubMed Medline	<i>Timely</i> <i>referrals,</i> <i>family</i> <i>satisfaction</i>	3 3 0	These were found also in the combination of three terms (<i>hospice care, Timely referrals, family satisfaction</i>), one excluded as not relevant.	2 Rickerson et al, 2005; Woods, Craig, & Dereng, 2006
08/25/10	CINAHL PubMed Medline	<i>Theory of</i> <i>goal</i> <i>attainment,</i> <i>hospice care</i>	1 0 0	No relevance established	0
08/25/10	CINAHL PubMed Medline	<i>Theory of</i> <i>goal</i> <i>attainment,</i> <i>Timely</i> <i>referrals</i>	0 0 0	No findings even with expanded search 2000-2010	0
08/25/10	CINAHL PubMed Medline	<i>Theory of</i> <i>goal</i> <i>attainment,</i> <i>family</i> <i>satisfaction</i>	0 0 0	No findings even with expanded search 2000-2010	0
08/25/10	CINAHL PubMed Medline	<i>Hospice care,</i> <i>Timely</i> <i>referrals,</i> <i>family</i> <i>satisfaction</i>	3 3 0	Two articles were relevant and included in the review	2 Rickerson et al, 2005; Woods, Craig, & Dereng, 2006

Literature Review

Individual Concepts

Hospice Care. A search of the concept of *hospice care*, utilizing the CINAHL database, netted 487 citations. In the PubMed and Medline databases, a search of the concept of *hospice care*, revealed 2,686 and 3,493 articles respectively. The results of these searches included far too many articles to review and, therefore, the review was limited to journal articles that combined the concept of ‘hospice care’ with the other concepts.

Timely Referrals. A search of the concept of *Timely referrals* utilizing the CINAHL database netted a total of 58 citations. In the PubMed and Medline database searches, the concept *timely referrals*, revealed 473 and 173 articles respectively. Again, this number of articles was too large to review. Therefore, the review was limited to articles that combined *timely referrals* with one or more of the other concepts.

Family Satisfaction. A search of the concept of *family satisfaction*, utilizing the CINAHL database, netted 852 citations. Using the same search parameters in the PubMed and Medline databases, the concept of *timely referrals* linked to 15,465 and 14,014 articles respectively. The abundance of articles was, again, far too great to be reviewed for this paper. Therefore, the review of this concept was limited to the journal articles that combined the concept of *family satisfaction* with the other concepts investigated.

Theory of Goal Attainment. A search of the concept *theory of goal attainment* utilizing the CINAHL database netted twenty-one citations. These citations were reviewed for applicability to the focus of this investigation. Five of the articles were rejected initially, as the focus of the articles were on the life and work of Imogene King or included only a passing reference to her work. The remaining sixteen articles were scanned for content by reading the abstracts and only the article by Whelton (2008) applied King's *theory of attainment* concept in a manner that was relevant to the focus of this paper.

Through the PubMed database, the search of the concept of *theory of goal attainment* resulted in only two articles. These articles were duplicates of the previous CINAHL search and, as previously stated, were not relevant and were not included.

A search of the Medline database for articles with the concept of *theory of goal attainment* revealed 43 articles. These were scanned by title for any possible relevance to this research and, again, only the Whelton (2008) article was deemed to be pertinent to this research.

Although the focus of the article was palliative care, it is closely related to the concept of hospice care and will be included in this review. In subsequent searches, Whelton's (2008) article was not identified, and this article was not a research article, but more of a philosophical position paper. It was included in this review as it demonstrated the application of King's theory of goal attainment as it pertained to ethical decision making at end-of-life and the nurse-patient therapeutic relationship.

Whelton (2008) discussed the nature of “being human”, and how this shared human nature deserves “moral treatment” across all stages of the lifespan from birth to death (p. 80). Whelton utilized the Aristotelian-Thomist philosophical view to establish the natural development of humans and the common human experience throughout the lifespan (pp. 79-80). The author discussed how the Aristotelian-Thomist view is integrated into the work of Imogene King’s interacting systems theory, with the emphasis on

“empowering patients to make decisions based on knowledge” [in which]”nursing seeks to empower patients and families to make decisions through education and mutual goal setting”. . . “In palliative care, emphasis on relationship and on mutual goal setting is especially important, as patient are particularly vulnerable” (pp. 84-85).

Therefore, nurses must act morally in providing support to this population. Whelton contended there are “14 guiding principles that are based on human nature and therapeutic relationships” [that will help develop nurses] “with intellectual, clinical, and moral excellence” (pp. 85-87).

This article encompassed two of the main concepts of this investigation: theory of mutual goal attainment and end-of-life care, equating to *hospice care* for the purpose of the current research. Whelton (2008) stressed “the importance of the person’s vulnerability at end-of-life, the nurse’s moral responsibility to respect the needs and perspective of the person, and through mutual goal setting the nurse promotes a sense of hope and control” (p. 85). This viewpoint supported the nurses’ role in promoting patient self-determination during the last stage of life through the process of mutual goal setting.

Combined Concepts

The next level of investigation was conducted by combining the concepts first in pairs, then in combinations of threes and, finally, using all four concepts. The summary of search results will be organized for ease of the reader into subcategories defined by the concept combinations.

Hospice Care and *Timely Referrals*. A search of the combined concepts “hospice care” and “timely referrals” through CINAHL revealed a total of 17 articles. A search of PubMed for the same time frame and concepts found 18 articles. The Medline search found five articles using the combined concepts of *hospice care* and *timely referrals*.

A review of the abstracts for appropriateness to the research was conducted. Nine of the CINAHL articles were eliminated as they were either more specific to a disease process (such as cancer) or specific to palliative care. Three of the PubMed articles (Casarett & Quill; 2007; Finlay & Casarett, 2009; Waldrop & Rinfrette, 2007) were duplicates found in the CINAHL search. Several other articles (12), eliminated through the abstract review of the CINAHL search, were duplicated by the PubMed search and were, therefore, eliminated. The remaining four articles abstracts were reviewed and eliminated because the content was either specific to the prognostication of diseases or the need to expand palliative care.

Of the five articles revealed by the Medline search, all were duplicates of the previous searches. The article by Waldrop and Rinfrette (2009) was found also in the Medline database while the other articles were duplicates of those previously eliminated.

Two of the articles (Rickerson et al., 2005; Woods et al., 2006) will be discussed later, as these articles also include the additional concept of family satisfaction. The five remaining articles were evaluated for main themes and findings.

Themes and Findings. One of the major themes covered by most of the articles was the barriers, indentified by providers and hospice professionals, for timely referrals (Casarett & Quill, 2007; Finlay & Casarett, 2009; Melvin, 2008; Waldrop & Rinfrette, 2009; Weckmann, 2008). The main barrier identified was the uncertainty of prognostication (Finlay & Casarett, 2009; Waldrop & Rinfrette, 2009). Other barriers included the: 1) lack of standardized criteria for referral to hospices (Melvin, 2008; Finlay & Casarett, 2009); 2) discomfort physicians and providers have communicating with patients and families about prognosis (Casarett & Quill, 2007, Finlay & Casarett, 2009, Melvin, 2008; Waldrop & Rinfrette, 2009); 3) patient and family attitudes toward hospice (Casarett & Quill, 2007; Melvin, 2009); and 4) lack of provider understanding of hospice care and services (Melvin, 2008; Weckmann, 2008). Melvin (2008) suggested including end-of-life education as part of the curriculum for physicians and nurses in an effort to improve comfort and understanding with hospice care, thereby possibly increasing earlier referrals.

There are also barriers that are inherent in the design of the Medicare Hospice Benefit (MHB) (United States Department of Health and Human Services [USDHHS] Centers for Medicare and Medicaid Services [CMS], 2010) that limit access to services to persons with a six month or less life expectancy and requires physicians to certify a prognosis in order to be eligible to receive care. Expanding the MHB to serve patients

during the last year of life and allowing advanced practice registered nurses (APRNs) to certify terminal prognosis are possible solutions to improve the access to, and utilization of, hospice care (Melvin, 2008).

Finlay and Casarett (2009) discussed different prognostication tools that combined functional assessments and laboratory tests to assist the provider in predicting prognosis. Casarett and Quill (2007) and Finlay and Casarett (2009) provided frameworks for providers to assist in prognostic conversations with patients, introducing hospice concepts, and helping to reframe the goals for care at end-of-life in effort to encourage patients and families to accept hospice care.

Discussion of Timeliness. The major concept of *timely referrals* to hospice care was addressed in all of the articles and several authors reported late referrals prevented patients and families from receiving the full benefits of hospice, as well as placed a burden on the agencies providing care related to the high upfront costs associated with short term referrals (Casarett & Quill 2007; Finlay & Casarett, 2009; Melvin, 2008; Waldrop & Rinfrette, 2009; Weckmann, 2008). Several articles advocated for expanding palliative care programs, and connecting patients with services early in the course of treatment for cancer and chronic illness (Finlay & Casarett, 2009; Melvin, 2008; Waldrop & Rinfrette, 2009). Two of the articles further reported transition to hospice care was eased when palliative care is introduced in timely fashion (Finlay & Casarett, 2009; Waldrop & Rinfrette, 2009).

Teno et al. (2007) examined family perception of the timing of the hospice referrals at a national level using data from collected by NHPKO using the Family

Evaluation of Hospice Care (FEHC) survey developed by Teno and colleagues (n. d.). The surveys were available to NHPCO member hospices and the data collected is submitted to the NHPCO repository. The study sought to examine perception of the timeliness of hospice referrals that were measured as “too late” or “at the right time” (p. 122). The researchers found the perception of being referred “too late” varied from 0% to 28% among participating hospices submitting 30 or more surveys in 2005 (p. 124). The results for hospices in one western state were “11-12% of families felt their loved ones were referred ‘too late’ to hospice services.” The researchers found the perception of being referred “too late”, not the length of hospice care was associated with increased “unmet needs, more concerns and lower satisfaction” (p. 124).

All the articles were supportive of timely referrals to hospice care and agreed timely referrals were of benefit to patients and families. The concept of *Timely referrals* was only specifically defined by Melvin (2008) as referrals made when the prognosis is more than 60 days and by Weckmann (2008) as referrals to hospice with more than 30 days prognosis. The discrepancy of definitions of *timeliness* in this literature review reinforces the need for more research in this area.

The types of articles reviewed only included one qualitative study (Waldrop & Rinfrette, 2009) and one quantitative study (Teno et al., 2007). The remainder of the articles were educationally focused papers that either provided frameworks for identifying and discussing hospice care with patients (Casarett & Quill, 2007; Finlay & Casarett, 2009), or focused on an overview of hospice care and patients’ eligibility (Melvin, 2008; Weckmann 2008).

Hospice Care and Family Satisfaction

A search of CINAHL, using the combined concepts of hospice care and family satisfaction, yielded 366 citations. A search of PubMed and Medline linked 15,465 and 4,027 respectively. This number of articles was too many to review for the focus of this paper. Therefore, these concepts will be combined further with other concepts.

Timely Referrals and Family Satisfaction

Three articles (Brumley et al., 2007; Rickerson et al., 2005; Woods et al., 2006) were identified from the search of the combined concepts of *timely referrals* and *family satisfaction* when searching the CINAHL and PubMed databases. An identical search conducted through Medline yielded no results. These same articles also were cited with the combination search of three concepts (*hospice care*, *timely referrals*, and *family satisfaction*) and will be discussed in that section.

Theory of Goal Attainment with Other Concepts

A thorough search of the concepts of the *theory of goal attainment* and *hospice care* yielded only one citation (Thomason, Lagowski, & Strasser, 2008) through the CINAHL database, and no articles through the PubMed and Medline databases. This article was a model comparison of different theorists' frameworks in the occupational health setting, and was not applicable to the focus of this investigation (Thomason, Lagowski, & Strasser, 2008).

A search of the combined concepts of *Timely referrals* and *theory of goal attainment* located no articles through the CINAHL, PubMed, and Medline databases.

The search parameters were expanded beyond the five year to include the years 2000 through 2010 in both data bases in efforts to determine if earlier research might be available. However, no articles were identified even with expanded search parameters.

As described above, a similar search was conducted with the combined concepts of *family satisfaction* and *theory of goal attainment* through CINAHL, PubMed, and Medline databases. Even with the expanded search parameters of the years from 2000 through 2010, no results were found.

When combining any two concepts (*hospice care, Timely referrals, and family satisfaction*) with the concept of *theory of goal attainment*, no results were found in any of the databases. The search parameters were expanded after the initial search in efforts to identify any earlier works that may have been missed by limiting the search to the past ten years. Yet, no other articles were found

Combinations of Three Concepts

Hospice Care, Timely Referrals, and Family Satisfaction

A total of three articles (Brumley et al., 2007; Rickerson et al., 2005; Woods et al., 2006) were identified when the concepts of *hospice care, timely referrals, and family satisfaction* were combined in both the CINAHL and PubMed databases. No results were found when combining these same concepts when searching the Medline database. The article by Brumley et al. (2007) was not included as the focus was on palliative care and not hospice care.

Timeliness and Family Satisfaction. The central theme evident in both studies examined the relationships of the perceptions of *family satisfaction* to *timely* enrollment in hospice care or palliative care. Rickerson et al. (2005) examined the timing of the hospice referral and the families' perception of services. Woods et al. (2006) examined the processes and barriers to transitioning to hospice care.

Rickerson et al. (2005). This article focused specifically on the three major concepts and how timely referrals to hospice care impacts the perception of family satisfaction. This qualitative study interviewed participants at the time of admission to hospice care about the “anticipated helpfulness of six hospice services” (Rickerson et al., 2005, p. 820) and a follow-up interview was done one to two months after the patient's death. The setting of this study was a single hospice in Pennsylvania. The sample (n=281) was selected from first time hospice enrollees who agreed to participate during the first hospice visit. The study spanned a period of 12 months. Of the 281 initial enrollees, six were eliminated from the study as they were discharged from hospice alive and 252 expired during the follow-up period. A total of 225 family members completed the second interview.

The researchers found that patients with “shorter lengths of stay” [on hospice]”are not benefiting fully from the services that hospice offers” (Rickerson et al., 2005; p. 821). The researchers also reported the “proportion of families who said they benefited, from the services they anticipated would be helpful, peaks at three months” (p. 822). Thus, no increased benefits were perceived by families when the LOC was greater than three months.

The services patients and families reported as being “helpful” were: pain and symptom management, telephone support, nursing visits, medications and equipment, home care/practical assistance, and emotional and spiritual support (Rickerson et al., 2005). Of these services, pain and symptom management were perceived as the most helpful in both the initial interview and at the follow-up interview (mean 2.94 patient, 2.92 family, and 2.84 family; respectively, on a three point scale).

Telephone support (TS) and nursing services (NS) had the next highest mean helpfulness ratings. However, the ranking differed by patient (mean 2.88 TS; 2.86 NS) and family perception at the first and follow-up interview (mean 2.84 and 2.72 for TS; 2.88 and 2.84 for NS respectively) (Rickerson et al., 2005). The lowest helpfulness rating was for emotional and spiritual support that had a mean of 2.47 for the patient and 2.51 for family at the first interview, and 2.59 for the family at the follow-up interview.

They found a strong association between longer lengths of hospice care and higher family satisfaction with care (Rickerson et al., 2005). It is interesting that they also found that, even with shorter lengths of care, families reported that “hospice was able to deliver the services that families needed and valued” (p. 822).

Woods et al. (2006). This research used a retrospective descriptive study to examine three dimensions of care, one of which was the timeliness of referral to hospice care. The other spheres of interest were patient-centered care and equity of care (Woods, et al., 2006). The researchers examined the admissions of patients aged 65 years and older over a 12 month period in 2003, from two not-for-profit hospices in the southeastern region of the United States. From this population, the researchers used

systematic random sampling to select a representative sample (n=161). The researchers examined the medical records of the sample to explore the three dimensions of patient-centeredness, timeliness of the referral, and accessibility of care to evaluate transitions to hospice and barriers to hospice care.

The first dimension of patient-centeredness was explored in terms of responsiveness to the “individual patient preferences, needs, and values” (Woods et al., 2006; p. 106). They reported the majority of older Americans expressed a preference for dying at home. However, most die in hospitals. The researchers reported the transition to hospice care, “enables most of the patients to remain at home for the death” (pp. 106-107). This suggested that entering hospice allows for the preferences of patient to be respected.

Woods et al. (2006) examined the transitions from various care settings to hospice care. The researchers found there was a lack of coordination with respect to needed medications and equipment that were identified as needed by hospice staff at the time of admission to hospice care. One explanation hypothesized for the poor coordination of transfers is the short time frames between the decision to refer and the actual transition to hospice care. The researchers suggested “greater anticipation, planning, and communication” [from those]”involved in care on the sending and receiving ends” [is needed to ease the transition and] “reduce stress for patients and families” (p. 107).

Woods et al. (2006) additionally examined physical and emotional support and found most patients (75%) had “multiple symptoms or problems that required the immediate attention of the hospice team” (p. 107). The researchers contended these

findings illustrated the need for improved symptom management and emotional support at end-of-life, including timely referrals to palliate symptoms.

The second dimension of timeliness of hospice referrals was also examined by the researchers (Woods et al., 2006). The researchers concluded from the functional assessment and symptom management needs of the patient at the start of care, and the length of service data, that patients are not being referred in a timely manner and, thus, do not receive the full benefits of hospice . The main barrier cited for late referrals by the researchers was the physicians' "difficulty with prognostic accuracy, erring on the side of optimism" (p. 109). The researchers proposed "interventions that minimized the barrier of 'late' referrals are expected to result in higher quality of care" (p. 109).

The third dimension examined the concept of equity of care to determine if any barriers to hospice care are related to the race of the patient (Woods et al., 2006). The races of the patients were compared to the demographics of the counties served by the hospices. The researchers found "race was not a barrier to admission" [to hospice care] "at these sites" (p. 110).

This study highlighted how "timely transfers to hospice care allowed the patient and family to receive the full benefits of hospice care" [and, thus, results in] "higher quality of care and family satisfaction" (Woods et al., 2006; pp. 108-109). The researchers also concluded hospice provides patient-centered care

"that is responsive to individual patient preferences, needs, and values [and] each patient deserves care that is customized to their values and preferences, care that is well coordinated, and timely, and care that is without discrimination" (pp. 106, 111).

Gaps in Literature

No studies were found that incorporated all the key concepts of *hospice care*, *timely referrals*, and *family satisfaction* with the *theory of goal attainment*. This gap in the literature supports further research utilizing the framework of King's Theory of Goal Attainment (1995) as it relates to the timeliness of referrals to hospice care, and perceptions of family satisfaction related to the care received. Of the research reviewed, only Whelton (2008) philosophically discussed using King's framework as a model for addressing end-of-life care issues.

Most of the studies were authored from a medical or social work standpoint (Casarett & Quill, 2007; Finlay & Casarett, 2009; Melvin; 2008; Waldrop & Rinfrette, 2008; Weckmann, 2008). This also demonstrated the need for further nursing research on these concepts. The single nursing research article (Woods et al., 2006) focused on barriers to hospice care, rather than outcomes of care.

To begin to help fill this gap in literature, a study that uses King's Theory of Goal Attainment (1995), will seek to examine the relationship between the length of hospice care and levels of family satisfaction. There is a lack of research using King's (1995) model to examine *timely* referrals to hospice care and perceived family satisfaction as evidenced by the literature review. This study adds to nursing knowledge as to how King's Theory of Goal Attainment is applicable to hospice care.

In addition, previous studies (Rickerson et al., 2005; Woods et al., 2006) focused on larger hospices in urban areas. In contrast, this study will focus on hospice care provided to patients and families in a rural setting in one Western state.

Summary

The literature review revealed a reoccurring theme in that the timeliness of referrals is a critical factor found to improve the quality of life for patients at the end-of-life (Casarett & Finlay, 2009; Rickerson et al., 2005; Weckmann, 2008; Woods et al., 2006). Patients referred to hospice care one to three months before death received the most benefits of hospice care in terms of symptom management, emotional and spiritual support, practical assistance, and nursing care; and had the highest perceived levels family satisfaction (Rickerson et al., 2005).

Patients referred to hospice care one to three months before death received the most benefits of hospice care in terms of symptom management, emotional and spiritual support, practical assistance, and nursing care (Rickerson et al., 2005). Those patients who received *timely* referrals had the highest perceived levels family satisfaction (Rickerson et al., 2005; Weckmann, 2008).

Several studies discussed the various barriers to hospice care that ranged from the provider discomfort with prognostication and communication of the prognosis to the patient (Casarett & Finlay, Melvin, 2008; 2009; Waldrop & Rinfrette, 2009; Woods et al., 2006), to the limitations of the Medicare Hospice Benefit (Casarett & Quill 2007; Melvin, 2008). Various strategies were discussed to address the identified barriers including advocating for expanded benefits for patients during the last year of life (Finlay & Casarett, 2009; Melvin, 2008).

Only the study by Whelton (2008) used King's interacting systems theory to explore the importance of promoting self determination at end-of-life through mutual

goal setting. Whelton (2008) contended nurses are morally obligated to promote a sense of control and allow the terminal person a sense of hope and control. This might translate into high levels of satisfaction with hospice care as perceived and reported by the family.

The current research could help to expand nursing knowledge about the relationship between the length of care and the perception of family satisfaction with hospice services. This increased knowledge could be used to inform efforts to promote *timely* referrals and improve hospice services.

CHAPTER 3

METHODS

Introduction

The primary goal of this study was the examination as to whether timely referrals to hospice care resulted in higher levels of family satisfaction. King's theory of goal attainment (1992) was the model that guided the design of this investigation. A simple correlational descriptive study was conducted to examine the relationship of the length of care on family satisfaction. This chapter discusses: (a) population of interest, (b) design and instrumentation, (c) procedures, and (d) planned data analysis.

Population of Interest

The population of interest for this study was the families of persons who received hospice care in the period before their death. The setting of this study was a small nonprofit hospice agency providing care to terminally ill patients, identified as Hospice A

Hospice A was located in a rural county in a western state and provided care in a variety of settings: the patients' home, nursing homes, hospitals, and an in-patient residential hospice unit (Key informant A, personal communication, November 25, 2009). The average daily census was 18 patients and the annual total patient census for 2008 was 145 patients (Key informant A, personal communication, November 25, 2009). The average daily census and the annual census of Hospice A was low in comparison to

previous studies, where hospices had average daily censuses of over 200 (Rickerson et al., 2005; Woods et al., 2006).

Sampling Process

A convenience-quota sample will be used to select family members of patients who expired while on hospice care who also returned a Hospice A survey during a three year period (2007-2010). This time frame should have allowed for a sufficient sample size to meet the group sizes need to establish significance.

Sampling Procedures

The criteria for inclusion in the study was a patient-family unit who received hospice services from Hospice A during the period preceding death and the surviving family members returned the FSS (Hospice A, 2000; see Appendix A) mailed by Hospice A to the family between two and four months after the patient's death. Patients and families were excluded if: 1) they were discharged alive or revoked hospice care; 2) families requested no further contact from the agency; or 3) surveys were not returned. These exclusions were made as a survey was not sent in these circumstances. Surveys that were returned without the length of hospice care marked were also excluded, because the LOC is integral to this research hypothesis.

The sample of surveys was divided into two groups according to the LOC as designated on the FSS (Hospice A, 2000). FSSs (Hospice A, 2000), without information on the LOC, were excluded from the sample. This stratification based on the length of

hospice care “further defined the convenience sample and this will have a greater chance of reflecting the viewpoint of the population” (Polit & Beck, 2008, p. 342).

The sample groups were designated *Timely* and *Short Term*. The *Timely* group was the participants who received hospice care for one month of care or longer in the period before death. The *Short Term* group was the participants who received hospice care for less than one month before death.

Sample Size

The statistical power analysis using the software G*Power3 (Faul et al., 2007) was performed to determine the sample sizes required to demonstrate significance. Cohen (1988, cited in Polit & Beck, 2008) stated, “In nursing research; the effect size (Cohen’s *d*) is likely to be small (.02); a medium effect (0.5) is so substantial that it can be detected by the naked eye” (p. 604). In addition, these parameters were also chosen based in previous study by Rickerson et al., (2005), as “effect size can be based on findings from earlier studies on a similar problem” (Polit & Beck, 2008, p. 603). The direction of the hypothesis (a longer length of care is related to higher family satisfaction) supported the research design and the use of a one-tailed *t*-test of means comparison between groups (Rossman & Chance, 2008). Table 3.1 is a summary of the parameters used to determine the sample size needed to establish significance for a *t*-test comparison of means and reduced risk of a Type II error.

Table 3.1. Summary of Parameters for the Power Analysis.

Test	Effect size	Power level	Alpha (α)
<i>t</i> -test comparison of means	0.35 (small-medium effect)	0.8	0.05

Surveys (FSS; Hospice A, 2000), returned to the agency from 2007 through 2010, were reviewed and categorized by length of stay. An expected limitation was the unequal size of the sample groups (*Timely* and *Short Term*). The unequal sample sizes would correlate with previous research as the median length of hospice services is less than three weeks with 10% of hospice patients dying within 24 hours of enrollment in hospice (Casarett & Quill, 2007). Therefore, the population of the *Short Term* (those patient-families who received less than one month of hospice care) was expected to be greater than the population of the *Timely* group (those patient-families with greater than one month of hospice care).

The FSS (Hospice A, 2000) also requested basic demographic information (age and sex of the patient, and diagnosis groups) and was tabulated. This information was used to stratify the groups and allowed for comparison between the groups if unequal group sizes are significant (Polit & Beck, 2008; pp. 342-3).

Rights of Human Subjects

“Protecting Human Subjects Certificate” training through the National Institute of Health was completed on October 24, 2009. This certificate is included in Appendix B.

The researcher applied for an expedited approval from the Montana State University (MSU) IRB as no direct contact between families and the researcher was planned or anticipated and the survey tool (FSS, Hospice A, 2000) data already existed. Therefore, only an examination of the existing data was conducted. Approval from the

MSU IRB was granted on November 22, 2010. A copy of this approval is included in Appendix B.

After approval was received from MSU IRB, the researcher sought approval to access to the data from the returned surveys from Hospice A. Approval was granted by Hospice A's chief executive officer on December 7, 2010, as the organization does not have an IRB committee for approval. A copy of this approval is included in Appendix B.

No direct contact between the researcher and the families is anticipated. Therefore no specific patient/family consents are required (C. Sieloff, personal communication, November 25, 2009).

Study Design

The design was a correlational descriptive study, examining the relationships between the variables of the length of hospice care and family satisfaction. The goal of this study is to test the hypothesis: *Timely* referrals to hospice care will result in higher levels of satisfaction as reported by families.

Polit and Beck (2008) stated "correlation is an interrelationship or association between two variables" (p. 272). "In correlational research, the investigator does not control the independent variable; . . . only explores the association between variables or the tendency for variation of variable to related to the variation in another variable" (Polit & Beck, 2008, p. 272).

The descriptive aspect of the design is used to "describe the relationship between the variables rather than to infer cause-and-effect relationships" (Polit & Beck, 2008, pp.

274-275). Thus, the descriptive correlational design was an appropriate fit for the investigation of the relationship between the concepts of timeliness of hospice referrals and family satisfaction.

King's Theory of Goal Attainment (1996) fit the quantitative methodology as used in this inquiry. The research will examine the relationship of the length of hospice care and the levels of family satisfaction. King (1996) reported her theory could be used to "predict outcomes of events which then demonstrate effectiveness in nursing care" (p. 62). In King's theory of Goal Attainment (1996) the areas that will reflect goal attainment will be family satisfaction rating of greater than three on five-point scale on the FSS (Hospice A, 2000).

Variables

The independent variable is used to explain or predict the observed values of the response variable (Graham, Hossler, Miller, & Purdy, 2009, p. 6). The independent variable was the length of hospice services.

The variable that is to be predicted is the response (dependent) variable (Graham et al, 2009; p. 6). The response (dependent) variable in this research was the concept of family satisfaction.

Procedures

The procedure for the collection of data was already established through the policy and procedures currently in place at Hospice A (Key informant A, personal communication, November 25, 2009). A survey is sent to the surviving family member

between two and four months after the death of the patient (Key informant A, personal communication, November 25, 2009). FSSs (Hospice A, 2000), returned to the agency between January 2007 and December 2010, were used in this investigation. FSS received before January of 2007 have been compiled into annual reports that cannot be extrapolated for this study and, therefore, were not included in the sampling.

Data Collection

Agents at Hospice A blocked out any identifying information included in the surveys demographic prior to this researcher's access to protect the identity of participants. Returned FSSs (Hospice A, 2000) were reviewed and initially categorized by the length of hospice care into *Timely* and *Short Term* groups. A review of all surveys available was conducted in an effort to have enough surveys to have adequate group sizes (102 surveys/group) required to establish a small to medium effect. After all the data was retrieved from the surveys, the surveys were returned to the agency so they could be destroyed.

Sampling Process. The completed surveys were previously reviewed by Hospice A for evaluation by the Quality Assurance and Performance Improvement (QAPI) committee. The surveys are archived after review by the QAPI committee, and these were the surveys used by this researcher. Copies of the archived surveys, without any identifiable demographic information, were categorized by the length of hospice care. This researcher only accessed the FSS (Hospice A, 2000) surveys that were returned to the agency, and did not take measures to increase the return rate.

Timeline for Data Analysis. The timeframe for collection and evaluation of data was during January, 2010. The analysis took about three weeks. The results of this analysis are reported in Chapter 4.

Instrumentation

The instrument used for this investigation is the FSS (Hospice A, 2000), an unpublished internally developed tool used by the hospice in the QAPI program. The format of the FSS (Hospice A, 2000) is a combination of nominal, interval, and qualitative-type data. The FSS (Hospice A, 2000) is reviewed and revised under the direction of the QAPI committee. A copy of the FSS (Hospice A, 2000) is included in Appendix A.

For the purpose of this research, only selected nominal and all of the interval data will be analyzed and compared for differences by LOC. The open-ended responses (qualitative data) was not evaluated due to the time constraints related to the researcher's program of study.

Measurements

Nominal measurement is “the lowest level of measurement” to classify objects or events and can be used to categorize a sample (Polit & Beck, 2008; p. 556). The independent (explanatory) variable (length of hospice care) is a nominal level of measurement in this study as it only has two categories; *timely* or *short-term* lengths of care.

The dependent variable (family satisfaction with hospice care) is an interval measurement and will measure or rank family perceptions on a scale with assumed equal intervals between the numbers (Polit & Beck, 2008). Interval measurements will be used as the rating scores of the FSS are interval (Hospice A, 2000).

The FSS is a tool, developed by Hospice A (2000, see Appendix A), that includes both nominal and Likert scale formats for questions. Each question also allows for the respondent to make comments in addition to any ranking. The first nine questions use a nominal measure to select responses (Yes, No, and Not Applicable).

The questions numbered nine through 20 used a Likert scale format. These questions asked the informants to respond to a statement using a scale of varying degrees of intensity between two extremes (very dissatisfied to very satisfied). The final question (21) is an open-ended that asked the respondent to identify one area of improvement. For this study, question 21 responses and none of the comments were included in the analysis.

Planned Data Analysis

The design of this research was driven by the hypothesis: *Timely* referrals to hospice care will result in higher levels of family satisfaction. The concept of timeliness was the independent variable that defined each of the sample groups. The concept of family satisfaction was the dependent variable, and was measured in two ways (nominal and interval) using the FSS (Hospice A, 2000). This research sought to determine if there

was any relationship between the lengths of hospice care and the levels of family satisfaction.

King's Theory of Goal Attainment (1995) will be used to guide the analysis of the responses to the questions on the FSS (Hospice A, 2000). The assumption that high levels of satisfaction in each domain of hospice services (pain and symptom management, communication and education, and emotional-spiritual support) reflect goal attainment between the patient/family and the hospice provider. The concept of timeliness is thought to influence the family perception of care, with the longer lengths of hospice care allowing for more interactions and transactions between the hospice provider and patient and family.

The null hypothesis stated there is no relationship between the length of hospice care and levels of family satisfaction. The alternative hypothesis stated timely referrals will result in increased levels of family satisfaction. The direction of the alternative hypothesis dictates a one-tailed *t*-test for comparison of two means (Rossman & Chance, 2008, p. 440).

Methods

The LOC information on the FSS (Hospice A, 2000) from the demographic section was used to determine the *Timely* and *Short Term* groups. The *Timely* group was comprised of those who marked the length of hospice care as "1 month" to "Over 1 year" on the FSS (Hospice A, 2000). The *Short Term* group was comprised of the surveys marked "less than 2 wks." There was no timeframe designation for the period between "less than 2wks" and "one month" and the FSS (Hospice A, 2000, see Appendix A). The

other demographic information on gender, diagnosis, and age was analyzed to determine the group demographics and to determine if these variables are well distributed between the two groups. These demographics were also used for comparison to the national statistics on hospice demographics to determine if the groups were representative of the population of persons who receive hospice care.

The responses to questions on the FSS (Hospice A, 2000) were organized according to the type of measurement (nominal and interval). Each response was considered a component related to family satisfaction. The response to questions one through eight of the FSS (Hospice A, 2000) asked for a nominally categorized response (yes, no, and not applicable). Questions one through four did not specifically relate to the concept of family satisfaction and were not analyzed by the length of care. Questions five through eight were related to the domains of communication and education as well as emotional and spiritual support, and were analyzed by LOC using a chi-square test. This will determine if the differences of proportion between the responses are related to the LOC are statistically significant (Polit and Beck, 2008). The significance level was set at 5% ($p=0.05$).

The dependent variable responses to questions nine to twenty on the FSS (Hospice A, 2000) were interval measurements and the mean of each response was calculated for each group by LOC. A *t*-test comparison of means was conducted on the responses to these questions for each sample group. Each group's mean score was analyzed to determine if a statistically significant difference existed. The significance level was set a 5% ($p=0.05$).

The Statistical Package for the Social Sciences Statics (SSPS) 14.0 Graduate Pack (SPSS, 2005) was used to analyze the data. A chi –square test was used to examine differences in the proportions between the *Timely* and *Short Term* groups. A t- test comparison of means examined the differences between the two means of each group for questions nine through twenty. Question 21 was an opened ended question and the responses were not included in this study.

Summary

The design of this research sought to determine if there was a relationship between *Timely* referrals to hospice care and increased family satisfaction with hospice care. King’s Theory of Goal Attainment (1995) was used to examine the concept of family satisfaction as related to the length of hospice services. There was an assumption that longer lengths of care would allow more opportunities for interactions and transactions between the hospice staff and the patient and family. Through these transactions, the goals for each of the domains of hospice care could be met. Thus, goal attainment is considered to reflect high levels of satisfaction as reported by the family on the FSS (Hospice A, 2000).

It was proposed that longer lengths of hospice care would allow for increased mutual goal setting and higher satisfaction with hospice services. The responses on the FSS (Hospice A, 2000), measuring the domains of hospice care (pain and symptom management, communication and education , emotional and spiritual support; see Table 4.4 for question grouping by category) were used to determine the level of goal

attainment related to family satisfaction. The mean of each group's responses to the FSS were compared and the mean family satisfaction and length of hospice care examined to determine if any relationship existed using a *t*-test comparison of means with significance level set at 5%.

The planned analysis used chi-square and *t*-test comparison of two means to examine the differences in the ratings of the responses from the FSS (Hospice A, 2000). The analysis of the data was done using the SPSS 14.0 Graduate Pack (2005) statistical software and assistance from a statistician. The timeline for completion of this part of the research was approximately four weeks.

CHAPTER 4

RESULTS

Introduction

The purpose of this study was to examine the levels of family satisfaction of those patients who received hospice care in different time periods before death to determine if the length of care had any effect on a family's perception of care received. The mean satisfaction level for families, who had a loved one receive hospice care for a month or longer, were predicted to be greater than the satisfaction levels of those who received shorter lengths of care.

The data used in this investigation came from the Family Satisfaction Surveys (FSS) (Hospice A, 2000) returned to a small hospice agency (Hospice A) in one western state over a three year period. The surveys were categorized into two groups based on the length of hospice care the patient received in the period before death. These groups are designated as *Timely* (those with one month or longer hospice care) and *Short Term* (less than one month of hospice before death).

The questions of interest on the FSS (Hospice A, 2000) were then categorized into three domains of hospice care proposed to influence the perception of satisfaction. These domains were: 1) pain and symptom management, 2) communication and education, and 3) emotional and spiritual support.

A chi-square test for differences in responses for questions five through eight on the FSS (Hospice A, 2000) for the two groups (*Timely* and *Short Term*) was conducted.

A comparison of the means of the questions, nine through twenty from the FSS (Hospice A, 2000) using independent *t*-tests was used to determine if any significant statistical differences existed between the lengths of care and the levels of satisfaction in each of the three areas.

If the levels of satisfaction were high, King's Theory of Goal Attainment (1996) proposed the goals of the patient and family were met as a result of the transactions that occurred between the hospice staff and the patient and family. If mutual goal setting occurred during the period of hospice involvement before death, it was proposed to be reflected in high levels of satisfaction reported by families on the FSS (Hospice A, 2000).

Sample

A convenience sample of 120 FSSs (Hospice A, 2000), completed by families and returned to Hospice A, was used to explore the relationship between the length of care and the level of family satisfaction. The surveys were collected from January 2007 to December 2010. This sample of surveys was all of the available surveys from the agency, as earlier surveys were quantified into reports and discarded. Seven of the surveys were excluded because the optional demographic information on the length of care was not completed by the respondents, resulting in a final sample size of 113 (N=113)

The sample of surveys was divided into two groups by the length of care (LOC). The FSS (Hospice A, 2000) has seven time frames in relation to LOC ("less than 2 wks", "1 month", "1-3 months", "3-6 months", "6-9 months", "9-12 months", and "over 1

year”). The first group was compiled from all surveys marked as having care for “less than 2 weeks”, and this group was the *Short Term* group ($n_1=69$). The second group included all other timeframes from “one month” to “over 1 year” and was referred to as the *Timely* group ($n_2=44$). The sample size for each group was less than the required 102 surveys per group calculated by the statistical power analysis (Faul et al., 2007).

Demographics

The FSS (Hospice A, 2000) had a section for families to complete optional demographic information about the patients. The *Short Term* group was comprised of 30 (43%) males, 34 (50%) females and 5 (1%) with no gender designation. The *Timely* group had 28 (64%) males and 16 (36%) females.

There were two patients (3%) aged “41-60” years, 27 patients (40%) aged “61-80” years, 35 patients (50%) “over 80” years, and five patients (7%) without an age marked in the *Short Term* group. The *Timely* group was comprised of three patients (7%) aged “41-60” years, 21 patients (48%) aged “61-80” years, and 20 patients (45%) “Over 80” years. There were no patients with age designations as “Under 30” or “31 to 40” years in group.

The *Short Term* group had 21 patients (30%) with a diagnosis of cancer, five (7%) with a diagnosis of Alzheimer’s disease, 17 (25%) with a diagnosis of heart disease, five (7%) with a diagnosis of lung disease, 16 (23%) that indicated “other,” and five (7%) that did not mark a diagnosis. The *Timely* group had 22 patients (50%) with a diagnosis of cancer, one (2 %) with a diagnosis of Alzheimer’s disease, five (11%) with a diagnosis of heart disease, five (11%) with a diagnosis of lung disease, and 11 (25%) with “other”

marked. There were no patients with the diagnosis of AIDS. Table 4.1 is a summary of these findings.

Table 4.1 Summary of Demographics by LOC.

Gender	<i>Short Term (n₁=69)</i>	<i>Short Term%</i>	<i>Timely (n₂=44)</i>	<i>Timely %</i>	<i>Total (N=113)</i>	<i>Total %</i>
Male	30	43%	28	64%	58	51%
Female	34	50%	16	36%	50	44%
Not marked	5	7%	0	0%	5	4%
Age						
Under 30 years	0	0%	0	0%	0	0%
30-40 years	0	0%	0	0%	0	0%
41-60 years	2	3%	3	7%	5	4%
61-80 years	27	39%	21	48%	48	43%
Over 80 years	35	50%	20	45%	55	49%
Not marked	5	7%	0	0%	5	4%
Diagnosis						
Cancer	21	30%	22	50%	43	38%
Alzheimer's	5	7%	1	2%	6	5%
Heart Disease	17	25%	5	11%	22	19%
Lung Disease	5	7%	5	11%	10	9%
Aids	0	0%	0	0%	0	0%
Other	16	23%	11	25%	27	24%
Not marked	5	7%	0	0%	5	4%

Family Satisfaction Surveys

The FSS (Hospice A, 2000) was sent to families two to four months after the death of a patient. During the three year period from January 2007 to December of 2010, 418 surveys were sent and 120 surveys were returned to the agency with a return rate of 29%.

A Cronbach's alpha test of reliability was done on the answers to questions one through twenty from the FSS (Hospice A, 2000) using the Statistical Package for the

Social Sciences (SPSS) 14.0 Graduate Pack (SPSS Incorporated, 2005). The FSS reliability rating was 0.861 for all 20 questions. However, when evaluating the types of questions separately, questions 1-8 reliability decreased to 0.608 and questions 9-20 reliability increased to 0.917. This suggests the questions 9-20 have higher internal consistency that is used to estimate the internal consistency and reliability of the overall survey (Boslaugh & Watters, 2008).

Validity refers to the ability of a tool to measure what the tool is designed to measure. In this case, the survey is proposed to measure the level of family satisfaction with the hospice services provided in the period before death (Boslaugh & Waters, 2008).

In order to test the validity, the survey tool should have a factor analysis done to support whether the FSS (Hospice A, 2000) measures family satisfaction with hospice care as intended (Boslaugh & Waters, 2008). A factor analysis of the instrument examines “clusters of related variables or dimensions of an underlying construct” (Polit & Beck, 2008, p. 463). This analysis would allow for the grouping of questions to measure an attribute or domain of interest (Polit and Beck, 2008). This was not done due to the timeline required to complete the research.

The FSS (Hospice A, 2000) was evaluated by this researcher using Microsoft Word (Microsoft Corporation, 2007) readability statistics to assess the Flesch-Kincaid grade level and Flesch reading ease scores. It is important to assess comprehension difficulty of the document to insure it is understandable by the intended population (Polit & Beck, 2008). The Flesch-Kincaid grade reading level for the FSS (Hospice A, 2000) was assessed to be at grade 9.6. The Flesch reading ease score of 50.4 (100 point scale

with higher scores indicating greater ease of reading) is considered medium ease of reading (Polit & Beck, 2008).

Data Analysis

Demographics. The two groups (*Short Term, Timely*) were examined to determine if there were any differences in the distribution of the categories of age, gender, or diagnoses. The distribution of males was nearly equal in the *Short Term* group and the *Timely* groups (30 & 28 respectively). The distribution of females as skewed to the *Short Term* group by nearly double the *Timely* group (34 & 16 respectively). Statistical analysis of the demographic distribution was not completed due time constraints of this investigation.

There was nearly equal numbers distribution of patients aged “41-60” years (two & three respectively). The *Short Term* group had more patients aged “61-80” and “over 80” than the *Timely* group (27 to 21 & 35 to 20 respectively).

The number of patients with “Lung” disease (five) and number of patients with “Cancer” (21 and 22) were equally distributed in both the *Short Term* and *Timely* groups. The distribution of the patients with diagnoses of “Alzheimer’s,” “Heart disease,” and “Other” was skewed with the *Short Term* group having a greater number of patients in this category than the *Timely* group. Figures 4. 1, 4. 2, and 4.3 are a summary of the distributions by LOC for each group.

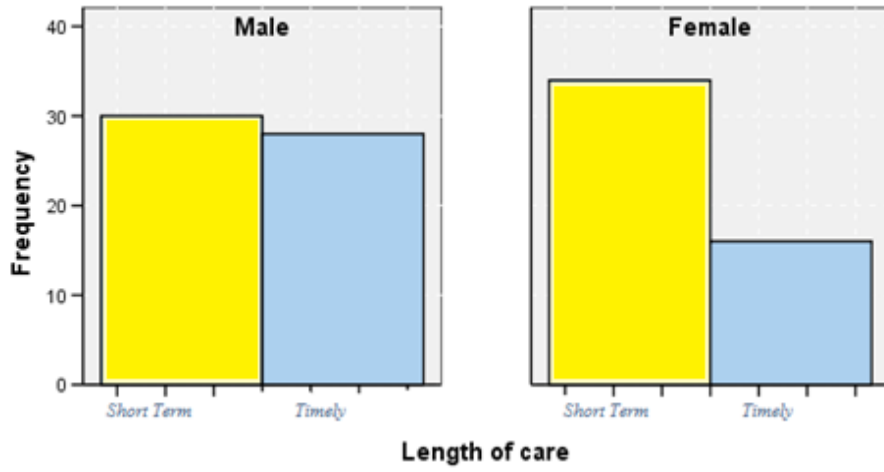


Figure 4.1. Distribution of Gender by LOC.

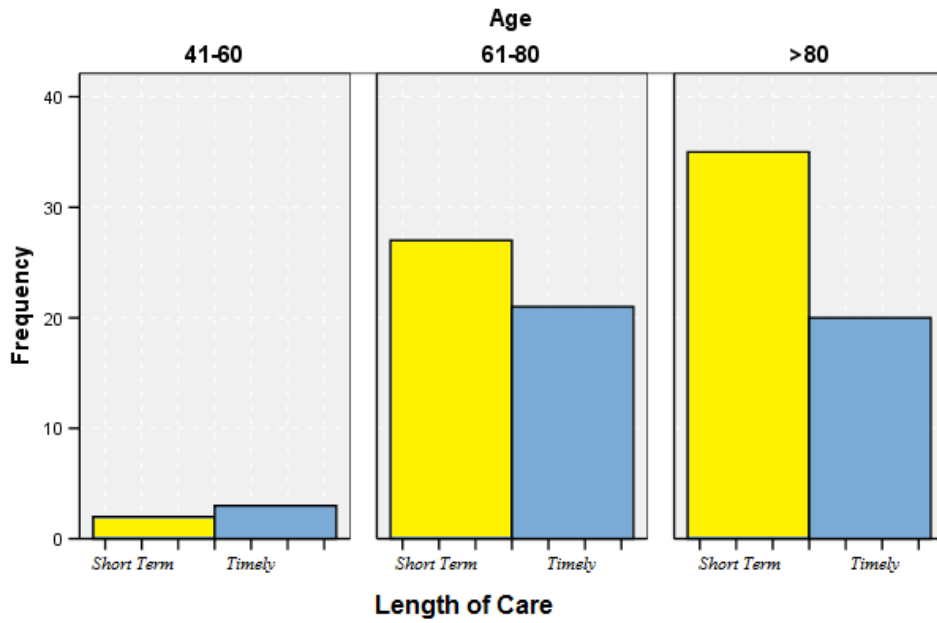


Figure 4.2. Distribution of Age by LOC.

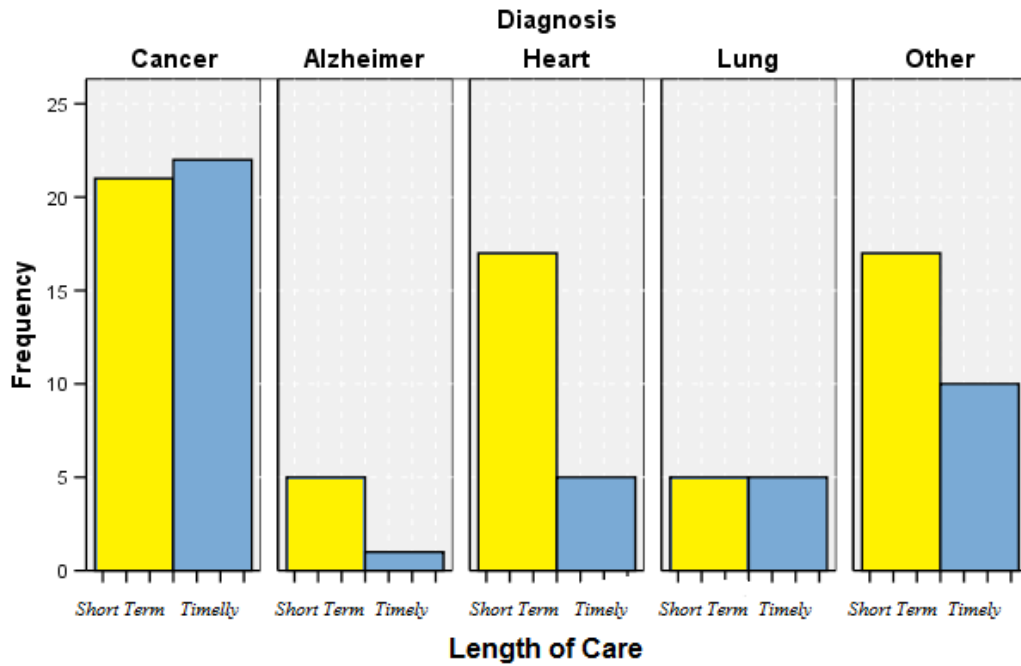


Figure 4.3. Distribution of Diagnoses by LOC.

FSS Data. The first eight questions sought to understand a family's perception of support by hospice staff with emphasis on the role of the social worker. These questions used a nominal scale for responses (yes, no, and not applicable). A summary table (see Table 4.2) of responses is included though results from questions 1-4 were not specifically related to the concept of family satisfaction and, therefore, were not analyzed by the length of care.

Table 4. 2. Summary of Responses to Question 1-8.

	Yes	No	Not Applicable
1. Based on the care your family received, would you recommend Hospice services to others?	111	1	1
2. Were you given a clear explanation of what services were available through Hospice and how to access them? (Ex: Chaplain, volunteer, Aide, Bereavement, Social Worker, Nursing)	105	5	1
3. Did your hospice provide you with adequate information about advanced directives like the living will?	98	5	9
4. Did you receive adequate information regarding your financial responsibilities related to Hospice services?	102	5	3
5. Were you offered information regarding community services? (Council in Aging, MOW, Lifeline)	65	16	28
6. If you cared for the patient at home, did hospice increase your ability to safely care for your loved ones as death approached?	63	2	41
7. Did Hospice staff provide effective emotional support for you in preparing for the death of your loved one?	94	7	7
8. Did Hospice staff offer support at the time of death?	104	6	3

Questions 5 and 6 are related to the concept of communication and education.

The results for question five were evaluated by the length care and demonstrated a slightly higher number of “yes” responses for the *Short Term* group (see Figure 4.4). A chi-square test of independence was conducted, resulting in a significance level of 5% ($p=0.05$). The probability of the chi-square test was 7.318 with a $p=0.028$ at two degrees of freedom (df), demonstrating a significant difference between the *Short Term* and *Timely* groups.

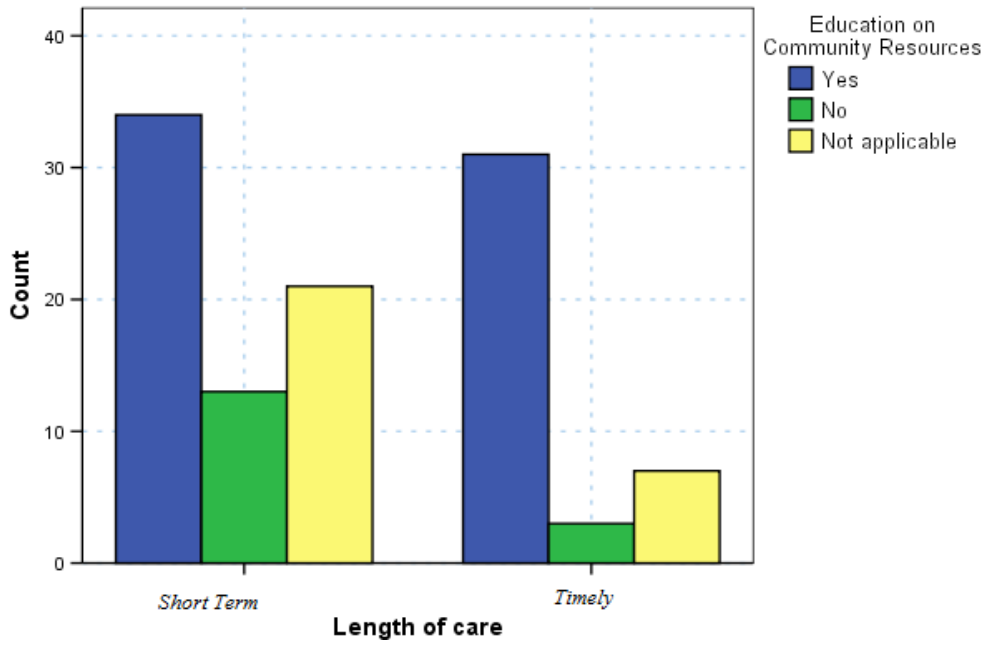


Figure 4.4. Question 5 Responses by LOC.

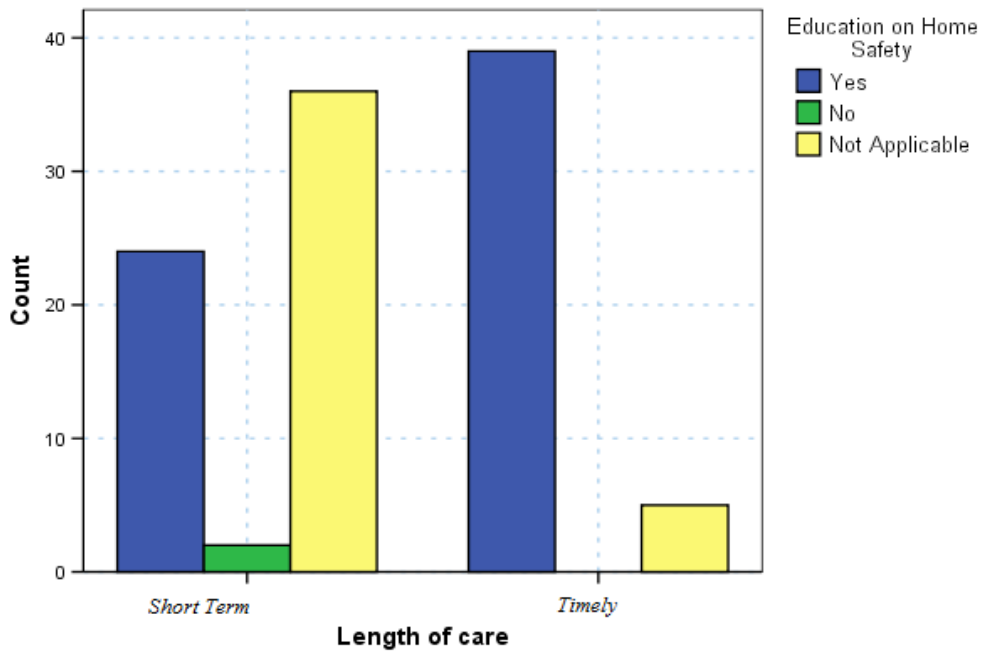


Figure 4.5. Question 6 Responses by LOC.

Question 6 was evaluated by the length of care and demonstrated higher number of “yes” responses in the *Timely* group (see Figure 4.5). The results of chi-square had a probability of 26.724 with 2 *df* with a $p < 0.000$. However, 33% of the cells had an expected count of less than five, indicating the results may not be reliable (Boslaugh & Waters, 2008).

Questions 7 and 8 were related to the concept of emotional and spiritual support. It is interesting that the *Short Term* group had a higher frequency of “yes” responses. The results of these findings are summarized in Figures 4.6 and 4.7. A chi-square test of independence for these two questions was conducted with a 5% significance level ($p=0.005$).

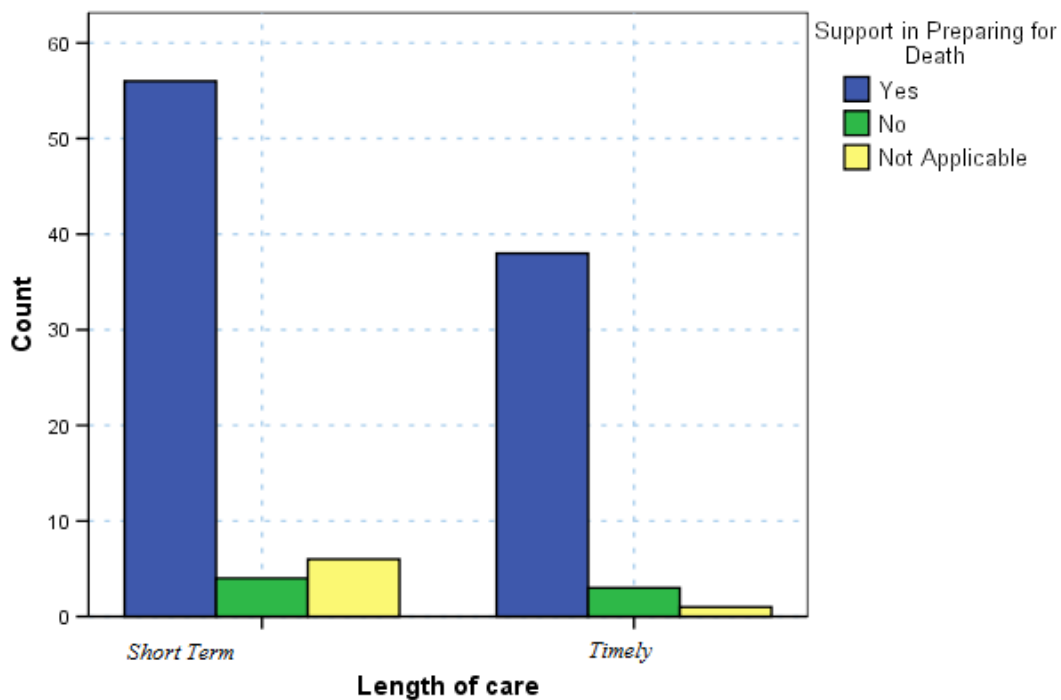


Figure 4.6. Question 7 Responses by LOC.

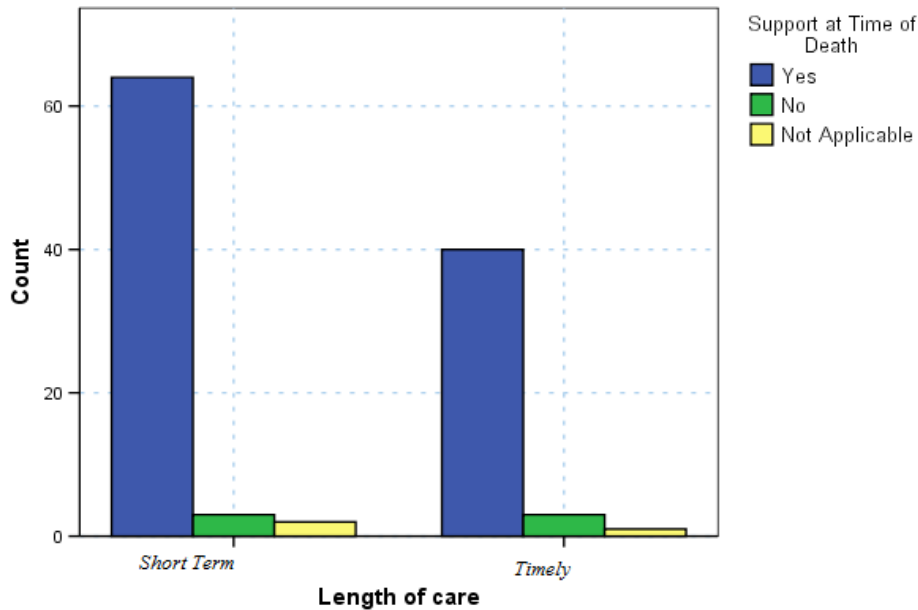


Figure 4.7. Question 8 Responses by LOC.

For question 7, the chi-square probability was 1.923 with 2 *df* and $p=3.82$, though 67% of the cells had an expected count of less than five. Thus, the sample size for the chi-square test was not satisfied.

Question 8 had a chi-square probability of 0.358 with 2 *df* and $p=0.836$ and, again, 67% of the cells had an expected count of less than five. Table 4.3 is a summary of the Pearson chi-square results for questions five, six, seven, and eight.

Table 4.3. Summary of Chi-Square Results for Questions 5, 6, 7, and 8.

Questions	Pearson Chi-square	<i>df</i>	P value	Significant
Question 5- Education on Community Resources	7.138	2	0.028	Yes
Question 6- Education on Home Safety	26.724	2	<0.001	Yes
Question 7- Support for Preparation for Death	1.923	2	0.382	No
Question 8- Support at Time of Death	0.358	2	0.836	No

The questions on the FSS (Hospice A, 2000) of concern for this research were questions nine to nineteen (question 20 was excluded as it has an open-ended response) (see Table 4.4). These questions used a Likert scale for the ranking of answers from “very dissatisfied” to “very satisfied” on a five point scale with three being “neutral” (Hospice A, 2000). These questions then were grouped into three domains; 1) pain and symptom management, 2) communication and education, and 3) emotional and spiritual support. This grouping was done to further investigate relationship between levels of family satisfaction and length of care. This was done to determine if there was a domain of hospice care that influenced the family’s perception of satisfaction more than another.

Table 4.4. Survey Questions by Category.

Pain & Symptom Management
9. How satisfied were you with the patient’s pain control after admission to Hospice?
10. How satisfied were you with the patient’s other symptoms after admission to Hospice?
Communication and Emotional Support
11. How satisfied were you with the education you received on your family members medications?
12. How satisfied were you with education and training you received on caring for your family member?
13. If you contacted the evening or weekend on-call services how satisfied were with the response?
17. Were you satisfied that the patient was referred to Hospice at the appropriate time during the course of the terminal illness?
20. Were you satisfied with the information/education given to you and your family about the dying process?
Emotional and Spiritual Support
14. How satisfied were you with Hospice’s efforts to help you manage your stress and anxiety during the illness of your family member?
15. How satisfied were you with Hospice’s efforts to assist you with your spiritual concerns?
16. Were your cultural beliefs and traditions honored and respected?
18. How satisfied were you with Hospice’s efforts to support the patient’s quality of life?
19. While on Hospice, were you or your family treated with respect and dignity?

The FSS (Hospice A, 2000) questions were averaged by category and the means of each category were compared for significant differences between the *Short Term* and *Timely* groups. The results are summarized in Table 5. A *t*-test was conducted for the three separate domains of hospice care (pain and symptom management, communication and education, and emotional and spiritual support) for each group (*Short Term* and *Timely*). The significance level was set at 5% ($p=0.05$).

A two-tailed *t*-test for the category pain and symptom management resulted in $p=0.54$. Thus, there was no significant differences between the two groups (*Short Term* and *Timely*) providing no evidence that the length of care influenced family satisfaction in this category.

A two-tailed *t*-test comparison of means for the category of communication and education resulted in $p= 0.43$. Again, there was no significant difference between the *Short Term* and *Timely* groups.

A two-tailed *t* test on the means for the domains of emotional and spiritual support resulted in a $p=0.40$. Thus, no significant difference was again demonstrated between groups (*Short Term* and *Timely*) in terms of the lengths of care.

The total mean scores for questions nine through twenty was 4.50 (SD 0.54) reflecting an overall satisfaction in hospice care. The *t*-test comparison of the means for total satisfaction scores by the length of care (*Short Term, Timely*) was not ($p=0.64$). Table 4.5 and Figure 4.8 are a summary of these findings. In summary, there is not enough evidence from questions nine through twenty to reject the null hypothesis that there is no difference in levels of family satisfaction based on the length of care.

Table 4.5. Means of Domains by LOC.

	Length of care	N	Mean	Std. Deviation	Std. Error Mean
Pain/Symptom Management	Short Term	68	4.5294	.88891	.10780
	Timely	44	4.6136	.54840	.08267
Communication/Education	Short Term	31	4.4387	.71446	.12832
	Timely	38	4.5579	.48134	.07808
Emotional/Spiritual Support	Short Term	60	4.3267	.87447	.11289
	Timely	41	4.4439	.50302	.07856
Total Satisfaction	Short Term	30	4.4667	.64905	.11850
	Timely	35	4.5333	.44012	.07439

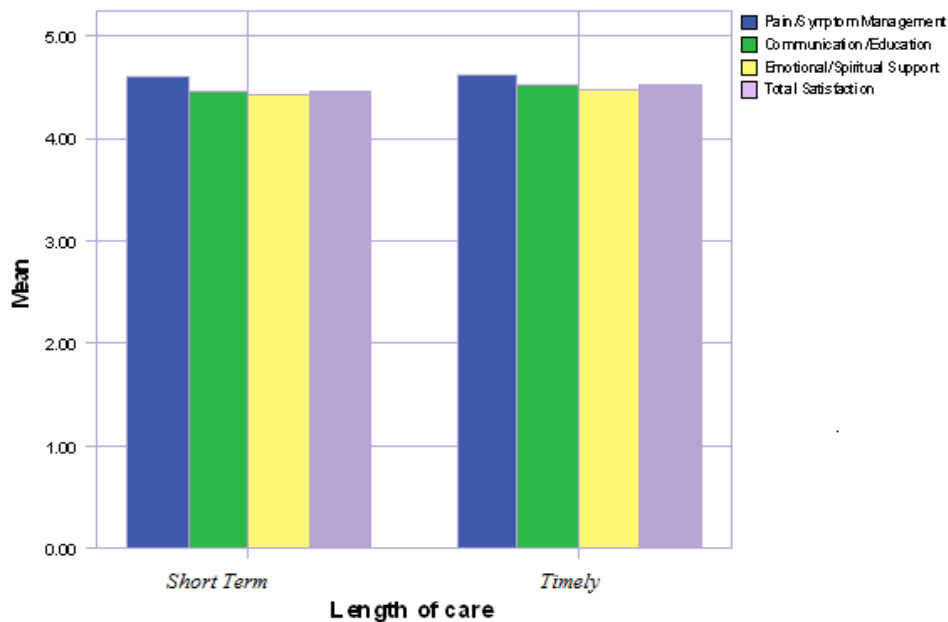


Figure 4.8. Comparison of Category means by LOC.

A scatter plot representing the values of each of the domains by *Short Term* and *Timely* lengths of care was constructed with fit lines by category added to determine if any subtle trends in the data could be identified (see Figure 4.9.). The satisfaction for the category of pain and symptom management was nearly the same for both the *Short Term*

and *Timely* groups. The domains related to communication and education and emotional and spiritual support showed a very slight increase in satisfaction levels over time. In addition, the *Short Term* group has greater variability in the range of mean scores of satisfaction than the *Timely* group suggesting shorter lengths of care may result in lower levels of satisfaction for some families.

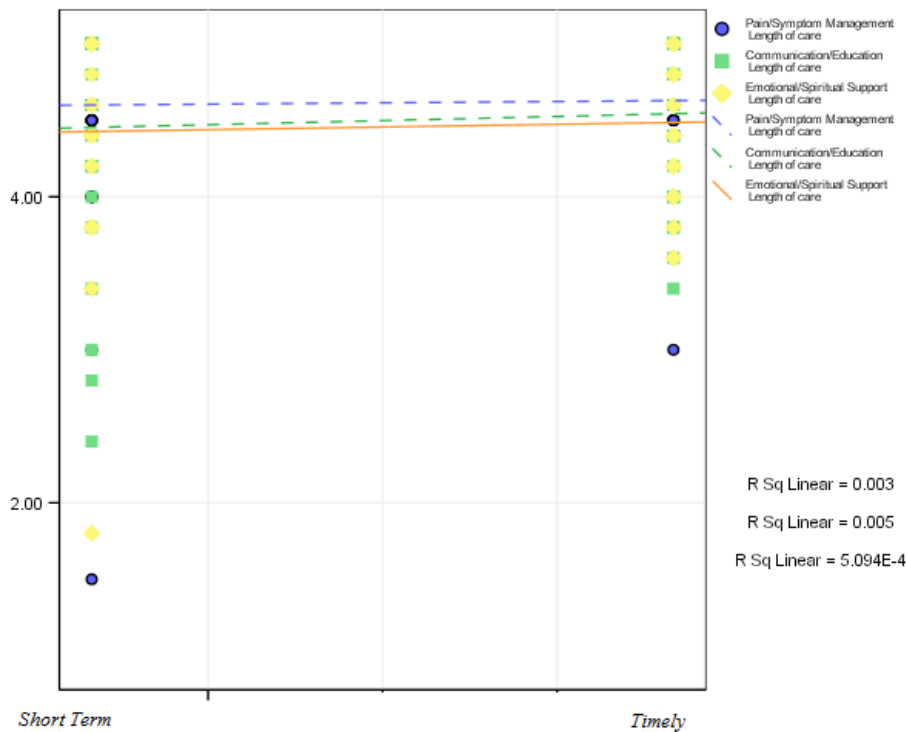


Figure 4.9. Scatter plot of Satisfaction by Domain and LOC with Fit Lines.

Summary of Findings

A total of 120 FSSs (Hospice A, 2000) were returned to the agency over a three year period from January 2009 to December 2010. Of the surveys returned, 113 were included as the length of care was marked. The surveys were divided into two groups based on the length of care.

From the first group of questions, questions five, six, seven, and eight were analyzed using a chi-square test of independence. Questions five and six demonstrated significance ($p=0.028$ and $p < 0.001$). However, only question five met the sample size requirement with no cells with expected counts less than five, satisfying the sample size requirement for chi-square test of independence.

Questions seven and eight failed to show significance ($p=0.382$ and $p=0.836$ respectively) that the lengths of care (*Short Term* and *Timely*) influenced the level of family satisfaction. However, both of the chi-squared tests had 67% of the cells with expected counts less than five, not meeting the sample size requirement for this test.

Questions nine through twenty were then categorized to help determine if any area of satisfaction showed a significant increase in the mean response by the length of care. Although there were no significant increases of mean levels of satisfaction from *Short Term* group to *Timely* group, a very slight increase over time was seen in the scatter plot for the domain of communication and education and emotional spiritual support.

Overall, the levels of satisfaction were high (mean 4.50) regardless of the length of care. This level of satisfaction suggests that the goals of hospice care for all three domains were attained by the patients as perceived by families, assuming the FSS (Hospice A, 2000) is reliable and valid. The high level of satisfaction suggests Hospice A's staff were able to meet the needs of patients and families. Thus, goal attainment could have been achieved through transactions between the hospice team and the patients and families.

CHAPTER 5

CONCLUSION

Introduction

The purpose of this study was to examine the relationship of family satisfaction to the length of hospice care a patient and family received in the period before death. The setting was a small hospice in a western state. The level of family satisfaction was measured by the FSS (Hospice A, 2000), developed by the hospice agency. The surveys were mailed to family members two to four months after the death of patient. The FSSs (Hospice A, 2000), returned to the agency over the period from January 2007 to December 2010, made up the sample (N=113) for this research.

The FSS (Hospice A, 2000) sample was divided into two groups by the length of care for the purpose of comparing the response between the two groups. The first group was comprised of the surveys with the length of care marked “less than two weeks” (*Short Term* group; $n_1=69$). The *Timely* group ($n_2=44$) included the remaining surveys where the responses ranged from “one month” to “over one year.”

The timeliness of hospice referrals is thought to have an impact on the family’s satisfaction with hospice care. Rickerson et al. (2005) found that families perceived more benefits from earlier referrals to hospice. Shorter lengths of care prevent patients and families from receiving the maximum benefit, especially if the referral is made in the days or hours before death (Woods et al., 2006).

King's Theory of Goal Attainment (1996) proposed the goals of the patient and family are met through transactions between the nurse and patient and family. Longer lengths of care allow for more time for the hospice team and patient and family to meet these mutual goals of care. If mutual goal setting occurred between the hospice team and the patient and family in the period before death, high levels of satisfaction are proposed to be reported by the family on the FSS (Hospice A, 2000).

FSS (Hospice A, 2004) consisted of twenty questions, sixteen of which were analyzed for this study. Four questions (questions 5-8) had "yes," "no," and "not applicable" responses, and these questions were analyzed with a chi-square. Twelve of the questions (questions 9-20) used a five point Likert-scale ranking of "very dissatisfied" to "very satisfied." These questions were analyzed with a two tailed *t*-test comparison of means. The results of these findings were discussed in Chapter 4. Additionally, the questions were organized around three domains of hospice care, 1) pain and symptom management, 2) communication and education, and 3) emotional and spiritual support.

Evaluation of Results

Sample

The convenience sample of FSSs (Hospice A, 2000) used in this study was comprised of surveys that were voluntarily returned to the agency during a three year period. The sample may not have been a true representation of the satisfaction of the population of families who received hospice care as an inherent sampling bias exists for

those who return surveys to the agency, and these participants might have strong opinions about the care received (both positive and negative) (Boslaugh & Waters, 2008).

There is also a non-response bias in the sample as 71% of those who received surveys did not return them to the agency. Non-responders are likely to have a different opinion than those who returned surveys (Boslaugh & Waters, 2008). Therefore, the low return rate of surveys (29%) likely does not represent the opinion of population of the families served by Hospice A and any generalizations to the greater population of those families that experienced hospice care cannot be based on this study. In addition, the number of returned eligible surveys (n=113) did not meet the 102 surveys needed per group based on a power analysis (Faul et al., 2007).

The *Short Term* group comprised 61% of the total sample. This proportion is similar to findings reported by Waldrop and Rinfrette (2009) who found nearly two thirds of patients admitted to hospice care expire within the first month.

The two sample groups (*Short Term* and *Timely*) are proportionally similar to hospice patients nationally by length of care (NHCPO, 2009). However, it is unknown if Hospice A's LOC statistics follow the national trends. Table 5.1 is a summary of comparison of demographic and LOC percentages between Hospice A and 2008 national statistics.

Table 5.1 Comparison of Hospice A and 2008 National Hospice Statistics.

	Hospice A	<i>Short Term</i>	<i>Timely</i>	2008 National Hospice Statistics (NHPCO, 2009)	
LOC	-	61%	39%	35% (7 days or less)	
Gender					
Male	51%	43%	64%		43%
Female	44%	50%	36%		57%
Not answered	5%	7%	--		--
Age					
Under 30	--	--	--		
31-40	--	--	--	<35 years	<1%
41-60	4%	3%	7%	35-64	16%
61-80	43%	39%	48%	65-84	45%
Over 80	49%	51%	45%	85+	38%
Diagnosis					
Cancer	38%	30%	50%		38%
Alzheimer's	5%	7%	2%		11%
Heart disease	19%	25%	11%		12%
Lung disease	9%	7%	11%		8%
AIDS	--	--	--		<1%
Other	24%	25%	22%		30%
Not answered	4%	7%	--		--

Demographics

The returned FSSs (Hospice A, 2000) were analyzed in terms of gender, age, and diagnosis. The FSS (Hospice A, 2000) has an optional section for respondents to complete demographic information about the hospice patient. This section was completed in all but five of the *Short Term* group and the entire *Timely* group (n=108; 95%).

Gender. The percentage of males in the *Timely* group (64%) was higher than the percentage of males in the *Short Term* group (43%). There was a higher percentage of females in the *Short Term* group (50%) than the *Timely* group (36%). Overall, there were

more males (53%) than females (46%) in the sample of returned surveys. Nationally, NHPCO (2009) reported more females use hospice services than males (57% female to 43% male in 2008). The results of Hospice A gender demographics are not representative of the national averages in terms of gender (see Table 5.1).

Age. There were five choices for the age category on the FSS (Hospice A, 2000). No respondents in either group indicated the age ranges of “under thirty” or “31 to 40.” Nationally, less than one percent of hospice patients are under the age of 35 in 2008, so it is not surprising that there were no patients in these age ranges in the sample (NHPCO, 2009).

The groups had percentages of patients aged “41-60” which were less than 10% (3% *Short Term* and 7% *Timely*). Nationally, 16% of patients were aged 35 to 64 years in 2008 (NHPCO, 2009).

The *Short Term* group had 39% aged “61-80” years and the *Timely* group had 48% age “61-80” years. Nationally, only 16% of patients were aged 65 to 74 years and 29% were aged 75 to 85 years in 2008 (NHPCO, 2009). This researcher suggests a revision of the age categories on the FSS (Hospice A, 2000) to those grouping used in the NHPCO (2009) statistics, which would allow for more direct comparisons.

NHPCO (2009) reported 38% of patients on hospice were age 85 or older in 2008. The results for this sample were also heavily weighted in the “over 80” years (51% for the *Short Term* group, 45% for the *Timely* group, and 49% total for the sample). The demographics for the sample, as compared with the national percentages, suggest the sample for this study is fairly representative of hospice patients by age. However, a

statistical analysis between Hospice As and the national percentages (NHPCO, 2009) was not done. The information is only included to allow for comparison of Hospice A demographics and those nationally.

Diagnosis. There were six options for indicating a patient's diagnosis on the FSS (Hospice A, 2000): "cancer," "Alzheimer's," "heart disease," "lung disease," "AIDS," and "other." The percentage of "cancer" patients was 30% for the Short Term group and 50% for the Timely group. Nationally, 38% of the patients on hospice have the diagnosis of "cancer" (NHPCO, 2009). See Table 5.1 for a summary of these findings.

The national percentage of hospice admissions with "Alzheimer's" (and dementia) was 11% in 2008 (NPHCO, 2009). The percentages for the *Short Term* group were 7% and 2% for the *Timely* group.

The national percentages for the primary diagnosis of "heart disease" in 2008 were 12% (NHPCO, 2009), compared to the *Timely* group's percentage of 11%. In contrast, the *Short Term* group had percentages double the national percentages (25%). The higher percentage of patients might be explained by more families of patients with heart disease responding to the survey or by more patients with heart disease being referred to Hospice A during the last month of life. However, since the researcher did not have access to the total population demographics of patients during the study period, no explanation for this anomaly is offered.

Both groups had percentages that were different than the national percentage for "lung disease" (8%) in 2008 (7% *Short Term*, 11% for *Timely*,) (NHCPO, 2008).

However, the percentage for Hospice A overall is 9% for lung disease was close to the national percentage.

Less than one percent of the patients admitted to hospice have the diagnosis of “AIDS” for 2008 (NHPCO, 2009). Therefore, it is not surprising that there were no “AIDS” among the respondents. The percentages for “other” (25% *Short Term*, 22% *Timely*, and 24% total) were less than the national percentage of “other diagnoses” which is 30% (NHCPO, 2009). Although this is lower than expected, since demographic information was not available for the population served by Hospice A, no inferences regarding these differences is offered.

Polit and Beck (2008) stated “a representative sample is one whose key characteristics closely approximate those of the population” (p. 340). Comparing the demographic characteristics of the sample from Hospice A to the nationally reported percentages was done to determine if the sample could be considered representative of the national population of hospice patients in 2008 (NHPCO, 2009). Several differences and similarities are noted between the national (2008) and those of Hospice A sample (see Table 5.1). Although there are similarities in many of the demographics (nationally and in the sample), no inference of representation is made by the researcher.

Question Analysis by Domains of Hospice Care and LOC

Pain and Symptom Management. Questions 9 and 10 were the only questions related to the domain of pain and symptom management. This domain is of critical importance to patients and families (Dy et al., 2008). Rickerson et al. (2005) also

reported pain and symptom management was anticipated by patients and families to be the most helpful aspect of hospice care at the start of hospice care.

No significant differences were found when the means of the *Short Term* and *Timely* groups were compared for this concept. However, there was greater variability in the *Short Term* group than in the *Timely* group. This suggests that some of the families of patients perceived lower satisfaction with pain and symptom management, even though the overall mean for this concept is high (mean of 4.5 on 5 point scale for the *Short Term* group).

The greater variability in the responses in *Short Term* group may be related to unrelieved symptoms before death. Studies have reported that hospice admissions in the last hours or days before death can result in “unmet needs” (Rickerson et al, 2005, Teno et al., 2007; p. 122). These unmet needs might then be reflected in the families “dissatisfaction” in the domain of pain and symptom management accounting for the greater variability.

Communication and Education. Communication and education were grouped together as a domain of hospice services because both are linked with perceptions of family satisfaction and the ability to understand and care for patients at end-of-life (Charalambous, 2010). Good communication between hospice staff and patients and families can ease the fears, build trust, and can result in education and improved ability of families to provide care to dying patient (Charalambous, 2010; Teno et al., 2007).

There were a total of seven questions that corresponded to this domain. Questions 5 and 6 were analyzed with a chi-square test of independence to determine the strength of

differences in responses for the *Short Term* and *Timely* groups. Only question five, evaluating the hospice's ability to provide education on community resources, resulted in significant findings. This suggests *Timely* referrals support greater opportunities for hospice staff to educate patients and families on community resources.

The findings for the chi-square test of independence on question six were determined to not be reliable due to lower than expected values in some of the categories. However, the *Timely* group selected more "yes" responses, suggesting an understanding of home safety may improve with longer lengths of care.

The averages of questions 11, 12, 13, 17, and 20 were grouped together within the concept of communication and education and then categorized by LOC. The results were then analyzed using a two tailed *t*-test comparison of means but no significance differences were found between groups in terms of LOC.

The mean satisfaction for communication and education was only slightly higher and there was less overall variability in responses was found for the *Timely* group. This slight upward trend in satisfaction suggests longer LOC improve might improve the families perceptions related to the concept of communication and education. Teno et al. (2007) reported families and patients being referred to hospice "too late" felt less informed about what to expect, resulting in "unmet needs" (p. 122). Therefore, it makes sense that longer lengths of care could allow for relationship and trust building and, as a result, a greater understanding of the dying process.

Emotional and Spiritual Support. The hospice domain of emotional and spiritual support broadly encompasses quality of life, holistic care, compassion, respect, and

personal belief systems. The emotional and spiritual support provided by hospice has been found to influence decisions about hospice enrollment and decisions to keep patients at home (Raleigh, Robinson, Marold, & Jamison, 2006). Rickerson et al. (2005) also found patients and families anticipated the emotional and spiritual support would be “helpful” at the time of hospice enrollment, and was still rated “helpful” at the time of the bereavement interview (p. 822).

Questions 7 and 8 examined the families’ perceptions of support in preparing for death, and support at the time of death respectively. A chi-square test of independence was done and there was no significance between the *Short Term* and *Timely* groups.

Questions 14, 16, 18, and 19 were analyzed with a two-tailed *t*-test comparison of means for any differences between the *Short Term* and *Timely* groups. No significance differences were identified between the groups for any of these questions.

The combined mean satisfaction of questions 14, 16, 18, and 19 for both groups were high (4.3 for the *Short Term* and 4.4 for the *Timely* group on a 5 point scale). There was greater variability in the *Short Term* group responses, suggesting that some families did not receive the emotional and spiritual support they needed, possibly attributed to the shorter lengths of hospice services. When hospice care is provided in the last hours or days of life, the shorter length time frames to address emotional and spiritual needs can result in the perception of “unmet needs” (Teno et al., 2007, p. 122).

The overall mean satisfaction for questions nine through twenty was analyzed for each group (*Short Term*, *Timely*) using the two tailed *t*-test. Even though no significant was found between the *Short Term* and *Timely* groups for total satisfaction, the overall

mean was high (4.5 on a 5 point scale) suggesting the goals for hospice care were attained as perceived by the families in all three of the concepts measured.

Study Limitations

The first limitation is related to the application of the King's Theory of Goal Attainment (1996). The FSS (Hospice A, 2000) does not specifically assess the process of mutual goal setting. There was an assumption that mutual goal setting between hospice staff and the patient and family would lead to transactions. Even though the overall level of satisfaction in hospice care was high, one cannot be certain this was related to mutual goal attainment or transactions. To more specifically assess goal attainment (King, 1996), a change in the survey tool or methodology such as a qualitative design could be helpful.

There are several limitations related to the FSS (Hospice A, 2000) tool. Because it was an internally developed tool, the reliability and validity of the tool has not been established. Within this study, the Cronbach's alpha completed on the questions 1-20 of the FSS (Hospice A, 2000) was 0.861. Further analysis of the validation of the FSS (Hospice A, 2000), using a factor analysis, is recommended to determine if the grouping of questions for each of the domains of interest (pain and symptom management, communication and education, and emotional and spiritual support) accurately measures these attributes (Polit & Beck, 2008).

The Flesch-Kincaid grade level assessment was grade 9.6 and Flesch ease of readability score was 50.4 which is considered a medium ease (Calderon, Morales, Liu,

& Hays, 2006; Polit & Beck, 2008). Knowing the readability of the survey tool allows researchers to “predict the validity of responses on self-administered surveys based on the respondents’ reading ability” (Calderon et al., 2006; p. 50). Calderon et al. (2006) reported the average American has a reading level between seventh and eighth grade. Therefore, surveys that are written above the level of the population may not truly reflect the views of the target population. Calderon et al. (2006) suggested that surveys be written at a fifth grade level as this reading level would allow the survey to be understandable to a larger cross-section of the population with varied levels of literacy. In the case of the FSS (Hospice A, 2000), revisions to the survey would be necessary to achieve to lower the reading level and increase the reading ease. This might be necessary as the population of hospice patients are generally over the age of 65 years (NHCPO, 2009), and Calderon et al. (2006) identified “persons over age 65” [as possibly having] “marginal or very limited reading skills” (p. 50). A summary of the recommended changes in the FSS (Hospice A, 2000) will be forwarded to the agency for consideration by the QAPI committee.

Another limitation is that all of the data was collected from a single rural hospice agency in one western state. This limitation resulted from the size of the population served. The hospice had an average daily patient census of 20 and served an average of 139 patients and families a year over the three year period from January 2007 and December 2010. This is the smallest population of any of the hospices reviewed in the literature (Casarett et al., 2005; Rickerson, et al., 2005; Woods et al., 2006).

The size of the sample was also a limitation as the sample was comprised of the FSSs (Hospice A, 2000) returned over a three year period. A statistical power analysis predicted the groups (*Short Term* and *Timely*) would need to be at least 102 each. Hospice A only had FSS (2000) going back three years. A total of 120 surveys were obtained, though only 113 surveys included the LOC information needed. This resulted in a *Short Term* group size of 69 and a *Timely* group size of 44. This is far less than the number needed to establish sufficient power to reduce the chance of Type I and Type II errors. Even though only one question (five) resulted in a significant finding, due to small sample size, the chance for a false positive (Type I error) is high (Polit & Beck, 2008). There is also a possibility of Type II errors (false negative) for the results of the remaining questions also related to small sample size.

The sample was comprised of respondents who voluntarily returned the surveys to the agency (convenience sample) and, thus, was comprised of persons who are more likely to have a strong opinion about the services (Boslaugh & Waters, 2008). These opinions may not be reflected by the larger population of families of hospice patients. To understand more accurately the opinion of the families of hospice patients, a telephone interview of all families of hospice patients after the death could provide a more representative sample.

To improve the response rate of respondents to the FSS (Hospice A, 2000), the agency could include a self addressed stamped envelope with the survey and a postcard reminder to return the surveys. Or, a telephone survey of hospice services might provide a better response rate over the mailed surveys.

Implications

Implications for Practice

In this study, the findings suggest there is an overall satisfaction with hospice as evidenced by the mean levels of satisfaction with hospice care. The increased variability in responses within the *Short Term* group in all domains of hospice care suggests families, in this group, may perceive unmet needs before death and report dissatisfaction in hospice care. *Timely* referrals allow patients and families to have full access to hospice services, whereas *Short Term* referrals in the last days of life may limit the access to the full benefits of hospice, resulting in unmet needs.

In this study, no significance was found between the LOC and family satisfaction. However, these findings are not reflective of previously findings that suggest families perceived more benefits and less unmet needs at end-of-life with longer lengths of hospice care in the period before death (Rickerson et al., 2005; Teno et al., 2007). Rickerson et al. (2005) reported the optimal LOC from the patients and family's perspective was three months.

Increasing understanding and the benefits of early referrals for the terminally ill patient and family has many potential benefits for all involved. Promoting education of health care providers on the unique needs at the end-of- life and supporting *Timely* referrals to hospice will help insure patients and families receive the specialized care that is hospice.

Implications for Management

Quality of care is an important measure for hospice agencies, and high levels of satisfaction with hospice are used to validate the effectiveness of hospice services (Dy et al., 2008). The findings of this study show a high overall level of satisfaction with Hospice A's services provided to patients and families (mean of 4.5 on 5 point scale) over the three year study.

Measurements of satisfaction can be used to evaluate the quality of hospice care and inform quality improvement programs (Teno et al., 2007; Dy et al., 2008). The Medicare conditions of participation (USDHHS CMS, 2010) for hospices emphasize a continuous quality assessment and performance improvement based on patient outcomes. Family satisfaction survey results can be used to guide staff education and patient services based on the feedback received from the surveys.

Implications for Education

In the review of literature, the timing of hospice referrals was found to be influenced by many factors such as the physicians' comfort with discussing a patient's prognosis and end-of-life issues (Casarett & Quill, 2007; Finlay & Casarett, 2009). The patient or family's understanding, acceptance, and receptiveness to hospice and previous experiences with hospice care can also influence the timing of hospice care (Dy et al., 2008, Teno et al., 2007).

Finlay and Casarett (2009) recommend the need for clinicians to recognize when are eligible for hospice care so earlier enrollments in hospice can improve the quality of life for patients dying of cancer. Using tools such as the Palliative Performance

Scale (Victoria Hospice Society, 2009, cited in Finlay & Quill, 2007), Karnofsky Performance Score (Karnofsky et al., 1948 as cited in Finlay & Casarett, 2009), and others can help clinicians recognize clinical indicators of decline as most cancer patients decline predictably over the last months of life (Finlay & Casarett, 2009). Early recognition of a patient's decline facilitates the disclosure of the prognosis to the patient, possibly resulting in *Timely* referrals to hospice (Finlay & Casarett, 2009).

Casarett and Quill (2007) advocated for clinicians to use a structured strategy to discuss hospice care with patients and family. This strategy is suggested as an approach to discussing hospice care with patient through a systematic approach, identifying the care needs of the patient and framing hospice care as an option to meet those needs (Casarett & Quill, 2007). Having a framework to discuss hospice care is hoped to decrease the clinicians' discomfort for "bad news discussions" and help patients and make informed choices based on the needs and goals for care (Casarett & Quill, 2007, p. 447).

Implications for Research

The findings of this study suggest families perceive high satisfaction in all domains of hospice care examined. Although the FSS (Hospice A, 2000) does not address the process of mutual goal setting and goal attainment, the assumption that high satisfaction is reflective of goal attainment would suggest the goals of hospice care in each domain were met through transactions within hospice.

King's Theory of Goal Attainment (1996) is well suited for application to hospice care. The patient and family are at the center of hospice care and the goals of the patient

and family determine the level of services needed to meet those goals. More exploration of the patient/family and hospice staff transactions, mutual goal setting, and goal attainment at end-of-life is needed.

A qualitative study to explore the use of goals between patients and families to establish transactions, and the family's perception of whether those goals were achieved would add to nursing knowledge and the application of King's theory to hospice care. This could involve a series of interviews of patients and families at the beginning of hospice care and with families after the death of the patient. Additionally, a sample comprised of both *Short Term* and *Timely* lengths of hospice care could provide insight into how mutual goal setting and attainment may differ between these two groups (King, 1996).

Teno et al. (2007) reported the limitations of family self administered surveys, including the possibility of inaccurate perceptions of "unmet needs for emotional support and pain management" (p. 125). The authors further reported the "reliability of information provided by proxies found they were more reliable regarding observable symptoms and quality of services than subjective features of the patient experience" (Teno et al., 2007, p. 125). Perceptions of family satisfaction about the care received by hospice patients can be influenced by many factors such grief and or anger over suffering, previous care or experiences with hospice, and or anger over the death of the patient (Dy et al., 2008). The burden of providing care to the patient and the ability to manage the patient at home can also influence the family's perception of hospice (Raliegh, Robinson, Marold, & Jamison, 2006). The FSS (Hospice A, 2000) is not able

to assess these kinds of factors. This researcher suggests future revisions in the FSS (Hospice A, 2000) include questions which assess the respondent's perception of these factors and their influence on satisfaction with hospice care.

Overall, satisfaction is a complex subjective concept. What may satisfy one may not be acceptable to another. Dy et al. (2008) suggested measures of satisfaction should account for differences in diagnoses and care settings. Using measures of satisfaction as an outcome measure of quality of care can help further understanding of the family's hospice experience. However, only the use of a standardized measurement tool would allow for comparison of hospice care between agencies.

The use of a standardized validated tool that specifically measures the concepts of pain and symptom management, communication and education, and emotional and spiritual support is needed. This instrument could help improve the understanding of the concept of satisfaction as a quality of care indicator. Also, standardization of the survey process will allow for comparison of hospice services between agencies and help to guide quality improvement efforts within agencies.

Conclusion

Even though this study did not find any differences in levels of satisfaction between the *Short Term* and *Timely* groups, the results did show an overall satisfaction with the services provided by Hospice A. The very slight differences between the two groups might be found to be significant with a larger sample. Although there is no agreement in the literature about the optimal length of hospice care, most studies

suggested that a hospice LOC of one month and longer results in patients and families reporting higher levels of satisfaction.

King's Theory of Goal Attainment (1996) was used as the basis to explore the personal and interpersonal relationships that influence family satisfaction with hospice care. Family satisfaction was categorized into three domains to determine if any one domain might have a greater association with LOC. The domains explored were pain and symptom management, communication and education, and emotional spiritual support. There was an assumption that the process of mutual goal setting would be reflected be in high levels of satisfaction as self reported on the FSS (Hospice A, 2000).

Overall satisfaction for all three domains was high (4.5 average on 5 point scale). There were slight increases in satisfaction for communication and education and in emotional and spiritual support in the *Timely* group as compared to the *Short Term* group. It would seem that a longer length of time in hospice could allow more time to meet the goals established.

Hospices provide quality end-of- life care to patients and families using a holistic approach to address the physical, emotional, and spiritual needs of the patient and family. More research is needed to explore the factors that influence the family's perception of satisfaction and the timing of the hospice referrals. Additionally, an exploration of King's Theory of Goal Attainment (1996) concepts and hospice care, using a qualitative study design, would also contribute to nursing knowledge.

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APPENDICES

APPENDIX A

FAMILY SATISFACTION SURVEY (HOSPICE A, 2000)

Family Satisfaction Survey (Hospice A, 2000)

Please take a few minutes to complete the enclosed survey and help us by evaluating the care and support you have received through Hospice staff and volunteers. The information received from this survey is very important to us and is used to improve Hospice A services. We constantly strive to provide our patients with excellent care and support, and we value the opinions and comments from the patients and families we serve.

Please indicate the response that best represents your satisfaction with the Hospice services you and your family received. Comments are welcome. Thank you.

1. Based on the care your family received, would you recommend Hospice services to others?

- Yes No NA

Comments: _____

2. Were you given a clear explanation of what services were available through Hospice and how to access them? (Example: Chaplain, Volunteer, Aide, Bereavement, Social Worker, Nursing.)

- Yes No NA Comments: _____

3. Did your hospice provide you with adequate information about advance directives like the living will?

(Example: Living Will, Comfort One, Medical Power of Attorney.)

- Yes No NA

Comments: _____

4. Did you receive adequate information regarding your financial responsibility relating to Hospice services?

- Yes No NA

Comments: _____

5. Were you offered information regarding community services? (Council on Aging, MOW, Lifeline.)

- Yes No NA

Comments: _____

6. If you cared for the patient at home, did Hospice increase your ability to safely care for your loved one as death approached?

- Yes No NA Comments: _____

7. Did Hospice staff provide effective emotional support for you in preparing for the death of your loved one?

- Yes No NA Comments: _____

8. Did you receive adequate support at the time of death?

- Yes No NA Comments: _____

9. How satisfied were you with the patient's pain control after admission to Hospice?

Not Applicable	Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied
0	1	2	3	4	5

Comments: _____

18. How satisfied were you with Hospice's efforts to support the patient's quality of life?
 Not Applicable Very Dissatisfied Dissatisfied Neutral Satisfied Very Satisfied
 0 1 2 3 4 5
 Comments: _____

19. While on Hospice, were you and your family treated with respect and dignity?
 Not Applicable Very Dissatisfied Dissatisfied Neutral Satisfied Very Satisfied
 0 1 2 3 4 5
 Comments: _____

20. Were you satisfied with information/education given to you & your family about the dying process?
 Not Applicable Very Dissatisfied Dissatisfied Neutral Satisfied Very Satisfied
 0 1 2 3 4 5
 Comments: _____

21. If there was one thing Hospice could do better, what would it be?

Additional Comments: _____

Hospice Patient Information (optional)	
Sex:	<input type="checkbox"/> Male <input type="checkbox"/> Female
Diagnosis:	<input type="checkbox"/> Cancer <input type="checkbox"/> Alzheimer's <input type="checkbox"/> Heart Disease <input type="checkbox"/> Lung Disease <input type="checkbox"/> AIDS <input type="checkbox"/> Other

Age:	<input type="checkbox"/> Under 30 <input type="checkbox"/> 31-40 <input type="checkbox"/> 41-60 <input type="checkbox"/> 61-80 <input type="checkbox"/> Over 80
How long were hospice services received:	<input type="checkbox"/> Less than 2 wks <input type="checkbox"/> 1 month <input type="checkbox"/> 1-3 months <input type="checkbox"/> 3-6 months <input type="checkbox"/> 6-9 months <input type="checkbox"/> 9-12 months <input type="checkbox"/> Over 1 year

Your name and relationship to patient (optional)

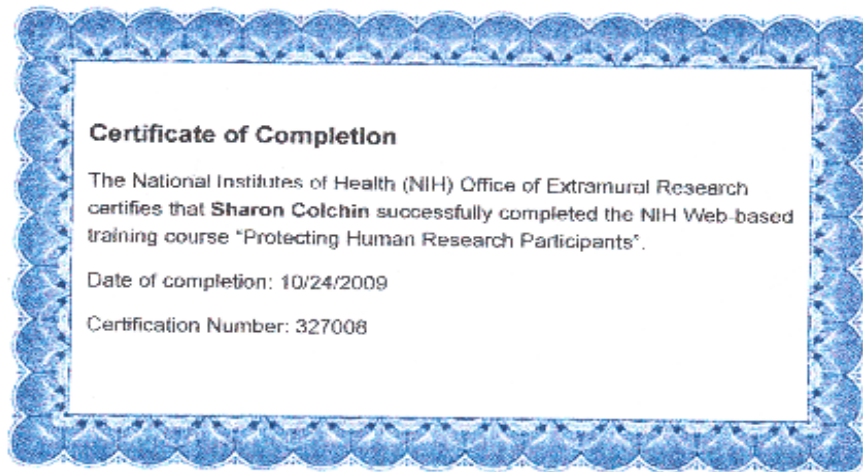
Would you like a phone call? Yes No Phone # _____

THANK YOU!

(Modified 11-25-09 to remove agency information, 2-22-11 to format for Appendix)

APPENDIX B

CONSENT DOCUMENTS



Expedited Institutional Review Board Approval



INSTITUTIONAL REVIEW BOARD For the Protection of Human Subjects FWA 00000165

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Administrator:
Cheryl Johnson
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MEMORANDUM

TO: Sharon Ann Colchin

FROM: Mark Quinn, Ph.D. Chair *mark Quinn Ch.*
Institutional Review Board for the Protection of Human Subjects

DATE: November 22, 2010

SUBJECT: "Relationship of Hospice Care to Family Satisfaction" [SC112210-EX]

The above research, described in your submission of November 22, 2010, is exempt from the requirement of review by the Institutional Review Board in accordance with the Code of Federal Regulations, Part 46, section 101. The specific paragraph which applies to your research is:

- (b)(1) Research conducted in established or commonly accepted educational settings, involving normal educational practices such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.
- (b)(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability or reputation.
- (b)(3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if: (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) federal statute(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.
- (b)(4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available, or if the information is recorded by the investigator in such a manner that the subjects cannot be identified, directly or through identifiers linked to the subjects.
- (b)(5) Research and demonstration projects, which are conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine: (i) public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; or (iv) possible changes in methods or levels of payment for benefits or services under those programs.
- (b)(6) Taste and food quality evaluation and consumer acceptance studies. (i) if wholesome foods without additives are consumed, or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA, or approved by the EPA, or the Food Safety and Inspection Service of the USDA.

Although review by the Institutional Review Board is not required for the above research, the Committee will be glad to review it. If you wish a review and committee approval, please submit 3 copies of the usual application form and it will be processed by expedited review.

Letter to Hospice A to Request Access to Data

DEC 03 2010



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 32 Campus Drive
 #7416
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 Fax: (406) 243-6746

November 24, 2010

Dear Mr. Bartos,

I am nearing the end of my graduate studies at Montana State University and have proposed a research project to examine family satisfaction as related to length of hospice care. I have received approval from my graduate committee and the MSU institutional review board to move forward with my research in this area.

I am requesting access to copies Marcus Daly Hospice Family Satisfaction Survey that is returned as part of the hospice quality improvement program. In the copy making process all identifying patient and or family information will be deleted from the forms. I intend to review the results of the family responses for levels of satisfaction related to length of care. I will also examine the validity of the current tool used by hospice as part of my research. I will provide Marcus Daly Hospice a summary of my findings as well as report these findings in my thesis. All agency information published in my thesis is anonymous.

With your permission, I would like to have access to the past three years of returned surveys. This should provide me with a large enough sample to determine if length of hospice care or other factors influence levels of family satisfaction with hospice services.

If you want to meet with me to discuss any aspect of my planned research before granting permission, please feel free to contact me at 406-546-8855 and I will be happy to discuss my research with you. I will need a written response if approval is granted to include with my thesis.

Thank you for your consideration of my research and I hope you feel this project will mutually benefit Marcus Daly Hospice and assist me with completing my research.

Sincerely,

Sharon Colchin BSN, RN
 Graduate Nursing Student
 Montana State University