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The Effect of the Timing of a Hospice Referral and the Perceived Quality of Care by the Family

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The Effect of the Timing of a Hospice Referral
and the Perceived Quality of Care by the Family

by

Melinda Reep

A thesis submitted to the faculty of
Gardner-Webb University School of Nursing
in partial fulfillment of the requirements for the
Master of Science in Nursing Degree

Boiling Springs

2012

Submitted by:

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Abstract

Late referrals to hospice can result in less time for the hospice team to perform assessments, establish relationships, and initiate goals. This secondary analysis addresses the effects of the length of stay of a hospice patient and the level of satisfaction reported by their caregivers after the passing of their loved one. The hypothesis of the study is that there is a direct relationship between a family's perception of the value of hospice and the length of stay of their terminally ill loved one. The setting for this secondary analysis was a non-profit hospice in the piedmont of North Carolina. Results from a family evaluation of hospice care survey were obtained from a six month period and were grouped based on length of stay. Two groups were utilized to separate length of stay: less than 30 days were considered short term and greater than 30 days were considered timely. Overall, satisfaction percentage levels offered no statistical significance for either group. Therefore, it is concluded that more data needs to be collected from longer periods of time in order to determine effects of length of stay on family satisfaction with hospice care.

Keywords: timely referral, family satisfaction, hospice

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To my husband Adam Reep and children, Aiden and Katelyn; thank you for your support, love, and encouragement as I pursued my dream of becoming a nurse educator.

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Chapter I

Introduction

Hospice services are in place to provide end of life care to the terminally ill person during the final stages of a life-limiting condition. Hospice provides an opportunity for the client and family to handle this difficult stage in life with dignity and increased comfort knowing that someone is there to offer support and symptom management. In addition, the hospice team strives to allow the client to maintain a satisfactory lifestyle through the final stages of life.

Nevertheless, despite the benefits of the multidisciplinary hospice team approach, many hospice referrals are only made within the last days or weeks of life (Casarett & Quill, 2007). According to Casarett and Quill (2007), the median length of hospice services is approximately three weeks, with around 10% of hospice referrals coming within the last 24 hours of life. With such little time, these individuals and their families are likely not to be able to obtain the maximum benefit of hospice services. With only hours to days available to perform, the hospice team has limited time to assess, build trust, or set and reach goals.

There have been several studies examining family satisfaction with hospice care in which higher levels of satisfaction were closely associated with longer lengths of care (Casarett & Quill, 2007; Rickerson, Harold, Kapo, Carroll, & Casarett, 2005; Teno et al., 2007). It is hypothesized by the researcher that longer lengths of hospice care results in higher levels of satisfaction by the bereaved family, and that the level of satisfaction is higher for clients who were able to be in the home setting rather than the facility setting.

Research Problem

By gaining access to hospice care, families and their terminally ill loved one are provided services including; nursing care, medication coverage and maintenance, medical equipment, assistance with personal care, spiritual support, social service support and counseling, volunteer and bereavement counseling. As patients approach death, many have severe pain, anxiety, and other manageable symptoms that could be more controlled with trained end of life personnel present. Also, this care could allow patients and their families to remain together in the comfort of their own home or facility, giving the family a chance to take an active role in providing or supplementing care (Hospice Association of America, 2006). However, with the knowledge that terminally ill persons and their families are not accessing these services in a timely manner, it is a concern that they are also not receiving the full benefit of hospice care.

This secondary analysis seeks to determine if the length of hospice services affects that family's satisfaction with hospice care. The length of services will be compared to satisfactory levels in the areas of pain and symptom management and emotional and spiritual support. These areas have been identified as the most helpful areas of support in end of life care (Teno et al., 2007).

Significance

Based on statistics from 2010, 41.9% of deaths in the United States included patients who were under hospice services (National Hospice and Palliative Care Organization [NHPCO], 2012). Of these deaths, 35.3% died or were discharged within seven days of admission and 49.4% died or were discharged within 14 days of admission (NHPCO, 2012). With referrals being later in the disease process, families have been

documented as reporting “unmet needs, concerns, and greater overall dissatisfaction with the quality of end-of-life care” (Teno, Casarett, Spence, & Connor, 2012). On the other hand, referrals too soon also may cause dissatisfaction for hospice families.

Unfortunately, not much research is available regarding the later topic.

Research Purpose

The purpose of this secondary analysis is to determine how a family’s perception of hospice care is influenced by the length of hospice services that are received by their terminally ill family member. The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) was the model used for this research to examine the relationship between family satisfaction and hospice services. This research was performed to provide insight into improvement of hospice care in relation to factors that families see as important in the delivery of patient-centered end-of-life care.

Conceptual Framework

The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) is the model used to examine the concept of family satisfaction with hospice care. The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) reported that the appraisal process is most heavily implicated during the outset of an event in the evaluation of its personal significance, and the evaluation of options for coping. Negative emotions such as sadness, anger, anxiety, or fear are associated with perceived harm or threat, and positive emotions such as excitement, eagerness, and confidence appear when the situation is resolved favorably (Lazarus & Folkman, 1984). The hospice team has a main goal of providing care to the patient that allows for comfort and dignity during the end-of-life. Therefore, the level of perceived satisfaction patient

centered care can be reflected in the level of resolution the family feels is reached.

Concerns presented by the patient and patient's family can be met by the nurse through performance of professional communication, therefore increasing satisfaction.

Hypothesis

A direct relationship exists between a family's perceptions of the value of hospice and the length of stay of their terminally ill loved one.

Definition of Terms

Hospice care is defined as humane and compassionate care for people in the last phases of an incurable disease, so that they may live as fully and comfortably as possible (American Cancer Society, 2011). This type of care is reserved for persons who have a prognosis of six months or less, given that the illness runs its normal course (Medicare Benefit Policy Manual, 2012).

The primary concepts, in regards to hospice care utilized in this research, will be timely referrals, communication, pain and symptom management, and emotional and spiritual support. These areas are essential in hospice care, and are considered to have a great influence on family perception of the quality of care that is provided.

Timely referrals are those referrals that are made to hospice within a month or more prior to death. Short term admission, on the other hand will be those that received less than one month of hospice services.

Satisfaction is a positive emotion that is suggested to have important adaptational significance (Folkman, 2007). These positive emotions are generated by an identifiable coping process, and it is suggested to be of utmost importance for the clinician to give

attention to positive emotions, and explore sources of these emotions, as well as how to generate them (Folkman, 2007).

Summary

Hospice care can be a beneficial service in end of life care. This secondary analysis seeks to determine how beneficial this care is for those who are referred to hospice in seven days or less from their time of death, as opposed to those who are with hospice services for longer lengths of time. Therefore, the main purpose of this secondary analysis is to determine how a family's perception of hospice care is influenced by the length of hospice services that are received by their terminally ill family member.

Chapter II

Introduction

As previously discussed, hospice care is humane and compassionate care for people in the last phases of an incurable disease so that they may live as fully and comfortably as possible (American Cancer Society, 2011). With this care, patients and their caregivers can be offered support and guidance through an extremely difficult stage in life.

The hypothesis, “A direct relationship exists between a family’s perceptions of the value of hospice and the length of stay of their terminally ill loved one,” is the focus of this inquiry. In order to do so, the concepts of hospice care, timely referrals, patient centered approach, family satisfaction, and cognitive theory of stress and coping are summarized in this paper. The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) was the model utilized to guide the investigation into current research.

Review of Literature

The literature review has been conducted in order to provide the best evidence to support the need for timely referrals in hospice care. A review of current literature was conducted utilizing Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, and EBSCO host databases. The search parameters were limited to peer reviewed journal articles and research articles that were published between the years of 2002 and 2012. The results of these database searches are discussed under each concept heading. All articles were evaluated for relevance to the main concepts prior to determining inclusion in this literature review.

Individual Concepts

A search for the concepts individually netted too many results to review that did not pertain to the topic at hand. Review of the concepts included grouping two or more concepts together to yield articles for use.

Combined Concepts

Hospice care and timely referrals. The search for hospice care and timely referrals yielded numerous results. Of these results, the articles were narrowed down for relevancy to the topic at hand. One of the major themes, covered by the chosen articles, was the barriers of timely referrals to hospice care. Some of the barriers discussed that limit hospice referrals are lack of standardized criteria for admission to hospice services (Finlay & Casarett, 2009), uncertainty of prognosis (Richards, Karagozoglu, Kilzer, 2010), discomfort in discussing prognosis by the physicians and providers (Casarett & Quill, 2007), lack of understanding of what hospice is (Matsuyama et al., 2011), and patient and family attitude toward hospice care (Casarett & Quill, 2007).

Holdsworth and King (2011) performed a study on preferences of end of life from the point of view of the patient, family, and nurse. This study identified that some patients hold a “stereotyped view of hospice as being the end, and that this fear was initially a barrier to receiving hospice support” (Holdsworth & King, 2011, p. 254). Potential patients have been reported as saying that being referred to hospice will hasten death (Holdsworth & King, 2011). Also, persons in previous studies have admitted that they were in denial about their illness, making discussing dying an inappropriate topic for them (Holdsworth & King, 2011).

Matsuyama et al. (2011) completed a study regarding how a potential

hospice patient's understanding of hospice and palliative care affects their decision to be admitted to the service. This specific study revealed that many persons have not heard of hospice care, and many of those who have, do not understand what hospice care is (Matsuyama et al., 2011). This study suggested that offering more information over the internet may offer accessibility to more individuals. Also, it was stressed that regardless if a person states that they understand what hospice is, the services still need to be explained (Matsuyama et al., 2011).

Waldrop and Rinfrette, (2007) finished a study regarding the perspectives of hospice professionals and referrals to hospice. This study identified that persons and physicians come to "the recognition that death is approaching in their own ways and often at different times" (Waldrop & Rinfrette, 2007, p. 557). To add to this there is "neither a common language for talking about nor an explicit procedure for determining if and when end-of-life care, specifically hospice admission, is appropriate" (Waldrop & Rinfrette, 2007, p. 557). Due to the uncertainty of when end-of-life will occur, limitations are put on when a physician will offer hospice as a referral.

Hospice care, timely referrals, and family satisfaction. The search for these combined concepts again yielded many results. These were narrowed down based on the actual relationship of the article to satisfaction of hospice care in relation to timing of referrals as determined by the abstract content. A total of three articles were identified to be pertinent to the study.

Teno et al. (2012) completed a study that was based on the perceptions of the timing of the hospice referral of persons who had a family member under hospice services for seven days or less. Participants were interviewed from seven different

hospice providers. Three hundred sixty-seven letters were mailed, of which 121 persons were successfully contacted by phone for follow-up. Of the 121, four were not knowledgeable about the referral process, 10 refused to be taped, there was a recording failure for five, and two narratives were eliminated because the patients were readmissions to hospice services (Teno et al., 2012). It was acknowledged in this study that persons with this short length of stay may not be subjected to the full range of services offered by hospice. Families identified a main frustration regarding a late referral as lack of communication from a physician. However, the study also uncovered that some barriers to earlier referrals likely could not have been avoided. These included the patient declining hospice services or a sudden severe acute illness that resulted in a quick death.

Rhodes, Mitchell, Miller, Connor, and Teno (2008) published an article discussing their study of perceptions of bereaved family members in regards to hospice care. The study was generated from respondents to the Family Evaluation of Hospice Care (FEHC) (Appendix A) survey. Data was compiled from 819 hospices that utilize the FEHC survey over 50 states, the District of Columbia and Puerto Rico. Of the 121,817 respondents, 116,974 answered the outcome measure.

One dimension of family perception was explored in terms of responsiveness to “attending to family needs for support” (Rhodes et al., 2008, p.367). They reported the majority of family members were more likely to have higher overall satisfaction with care if they had sufficient contact with the hospice team for spiritual and emotional support prior to the patient’s death (Rhodes et al., 2008). This suggested that entering

hospice early enough for sufficient contact between the family and the team members offering spiritual and emotional support is needed for greater satisfaction.

The response to “attending family needs for information” was determined to have an effect on overall satisfaction scores, in that family members were more likely to have positive satisfaction with hospice if they were provided adequate information on what to expect when the patient was dying (Rhodes et al., 2008, p.367-8). This included adequate information regarding how to handle pain, shortness of breath, and where in the disease process the clinician felt the patient was.

Adams, Bader, and Horn, (2009) performed research assessing the timing of hospice referral patients and satisfaction ratings. It was identified that one third of patients and/or families reported that it would have been easier if they had started hospice earlier (Adams et al., 2009). The study was a quantitative-qualitative research design in west Texas over one year. The independent variable was labeled as “would it have been easier for you if you started to receive hospice services earlier than you did” with a response of yes or no available (Adams et al., 2009, p.112). Approximately 37% of respondents reported “yes.” The study reports that there is little to no effect on place of residence on the results. Emphasis is placed on the need for specific hospice interventions that would make the patient and caregiver’s life easier to be identified on admission.

Cognitive theory of stress and coping and hospice. There were no articles to date that applied these two concepts together.

Schwarzer (1998) offers a look into Lazarus’ Stress Theory in terms of stress and coping. He reviews personal and coping resources that help to combat stressful

encounters. It is determined through Schwarzer's research that "social support can assist coping and exert beneficial effects (Schwarzer, 1998, p. 535). This support is also described as coping assistance and an exchange of resources (Schwarzer, 1998). This review offers that reader insight regarding how beneficial both emotionally and physically coping resources can be.

Strengths and Limitations of Literature

Through this literature review a great deal of information was obtained regarding late hospice referrals and barriers to hospice referrals. However, there was not any literature discovered regarding the Cognitive Theory of Stress and Coping in regards to hospice services. The literature review also failed to yield information regarding how and if satisfaction levels of hospice care are altered with patients residing in a facility, as opposed to those who receive their care in the home setting.

Summary

It is evident from reviewing literature that timing of hospice referrals is a critical factor for patients at the end of life. Patients referred to hospice less than one week prior to their date of death received less benefits of hospice in terms of symptom management, emotional and spiritual support, and nursing care (Adams et al., 2008; Rhodes et al., 2008; Teno et al., 2012). In contrast, patients referred one month or greater prior to death, who also considered the admission to hospice as timely, received the most benefits of hospice (Rickerson et al., 2005). Several studies were located that discussed the barriers to hospice referrals, which ranged from lack of standardized criteria for admission to hospice services, uncertainty of prognosis, discomfort in discussing prognosis by the physicians and providers, lack of understanding of what hospice is to the

patient and family's attitude toward hospice care (Casarett & Quill, 2007; Finlay & Casarett, 2009; Richards et al., 2010; Matsuyama et al., 2011).

Chapter III

Methodology

This secondary analysis, *The Effect of the Timing of a Hospice Referral and the Perceived Quality of Care by the Family*, is to determine how a family's perception of hospice care is influenced by the length of hospice services that are received by their terminally ill family member. The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) was the model used for this research to examine the relationship between family satisfaction and hospice services. This research was performed to provide insight into improvement of hospice care in relation to factors that families see as important in the delivery of patient-centered end-of-life care.

Implementation

This study was a secondary analysis of a correlational descriptive study. The information from the original correlational descriptive study was obtained with written permission from a non-profit hospice organization in the piedmont of North Carolina. The original study utilized a family evaluation of hospice care survey (FEHCS, Appendix A) with the results processed through the company Deyta, LLC. Access to this company site was granted through written permission by the hospice, and an access pass code was obtained by the researcher.

Setting

The setting of this research was a non-profit hospice organization in the piedmont of North Carolina servicing approximately 700-800 hospice patients a year. The organization admits clients from within its own county, along with four surrounding counties.

Sample

The sample for this analysis included 119 respondents to the FEHCS (Appendix A) as received from January-July 2012 by the non-profit hospice in the piedmont of North Carolina. The analysis information was obtained through Deyta, LLC. Identifiable information was previously removed by this company and was not accessible to the researcher. The population of this study includes persons of all race, ethnicity, sex, and background within the local community of the non-profit hospice in the piedmont of North Carolina.

Design

This study was a secondary analysis of a correlational descriptive study. The original family FEHCS (Appendix A) was sent out to bereaved families within six weeks of their loved ones passing. The obtained survey information was from bereaved families from the months of January 2012 to July 2012. The information was stored on the company site Deyta, LLC, that is not accessible without a given ID and pass code.

Protection of Human Subjects

With this study being a secondary analysis, there was not direct contact between researcher and human subjects. The information utilized was previously obtained by mail from a non-profit hospice in the piedmont of North Carolina. Therefore, there was no risk posed to participants. Permission to complete this secondary analysis was granted by the Institutional Review Board.

Instruments

The FEHCS (Appendix A) utilized by the non-profit hospice organization in the piedmont of North Carolina, was obtained with written permission (Appendix B) as the instrument in this secondary analysis. This survey tool has limitations with regards to the comprehension of the questions by the participant, however, is utilized by hospices nationwide.

Data Collection

A FEHCS was administered to all bereaved families within the services of a not for profit hospice in the piedmont of North Carolina, by said hospice for the months of January-July of 2012. Hospice care satisfaction was assessed by the rating received by the survey. The evaluation included all areas of hospice care including nursing, symptom management, personal care, and, spiritual and emotional support. This satisfaction level was compared to the length of stay of the bereaved person and the location of death. In order to gain further awareness, the participant was asked to give reasoning to their answer. These surveys were distributed via mail and results compiled through Deyta, LLC. Documentation of consent was waived to ensure anonymity, and participants were not paid. Those who wanted to participate in the study returned the completed survey via mail to the organization with no identifiable marks.

Data Analysis

Data was compiled from the Detya, LLC company site via personal issued ID and pass code. This information was then broken down into categories of relevance to the topic, *The Effect of the Timing of a Hospice Referral and the Perceived Quality of Care by the Family*. These categories of the FEHCS included: length of stay, consistency of

hospice care with patients wishes, meeting of personal care needs, level of perceived respect, family participation, confidence, emotional support, overall care, explanations provided, timing of referral, and perceived quality of care (Appendix A). The responses were on a nominal scale. Each response was considered a component related to family satisfaction.

Summary

The design of this secondary analysis sought out to conclude if there was a relationship between lengths of stay in hospice care and increased family satisfaction with hospice care. The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) was used to examine the concept of family satisfaction in relation to hospice care. This theory determines that emotions such as sadness, anger, anxiety, or fear are associated with perceived harm or threat, and positive emotions such as excitement, eagerness, and confidence appear when the situation is resolved favorably (Lazarus & Folkman, 1984). The hospice team has a main goal of providing care to the patient that allows for comfort and dignity during the end-of-life. Therefore, the level of perceived satisfaction patient centered care can be reflected in the level of resolution the family feels is reached. There was an assumption that longer lengths of stay would allow for a greater level of resolution, resulting in higher satisfaction levels reported by bereaved families.

The responses to the FEHCS (Appendix A) measuring length of stay, consistency of hospice care with patients wishes, meeting of personal care needs, level of perceived respect, family participation, confidence, emotional support, overall care, explanations

provided, timing of referral, and perceived quality of care were used to determine the level of resolution related to family satisfaction.

Chapter IV

Results

This secondary analysis, *The Effect of the Timing of a Hospice Referral and the Perceived Quality of Care by the Family*, is to determine how a family's perception of hospice care is influenced by the length of hospice services that are received by their terminally ill family member. Included in this chapter are the results of this secondary analysis.

Sample Characteristics

A total of 314 FEHCS (Appendix A) were sent out from January 2012 through July 2012. Out of these 314 surveys, 195 were not returned, ending with a return rate of 34%. Therefore, the final sample size of this secondary analysis was 119 participants (N=119). From these statistics, 76 participants passed away in a facility and 43 in the home setting. This sample of surveys was the total amount allowed to be viewed by the non-profit hospice in the piedmont of North Carolina.

The sample of surveys was then divided into two groups by the length of stay (LOS). The FEHCS (Appendix A) has four time frames in relation to LOS ("less than 7 days", "8-14 days", "15-30 days", and "more than 30 days"). The first group was compiled from all surveys marked for "more than 30 days," and was considered the timely group. The second group included all the other time frames and was considered the short term group. (See Table 1)

Table 1

Summary of Data: Participants

Short Term < 7days	Short Term 8-14 days	Short Term 15- 30 days	Timely > 30 days
41 respondents	16 respondents	23 respondents	39 respondents

Major Findings

A total of 119 FEHCSs (Appendix A) were returned to the non-profit hospice in the piedmont of North Carolina over a six month period from January 2012 to July 2012. Of the surveys returned, all included the LOS. The surveys were divided into four groups based on LOS. These four groups were labeled timely and short term, with the short term group including “less than 7 days”, “8-14 days”, and “15-30 days”.

The FEHCS (Appendix A) includes the subtopics: Patients End of Life Wishes, Treatment of Patient Symptoms, Patient Dignity and Respect, Information for You as the Caregiver, Emotional and Spiritual Support for You, Coordination of Care, Overall Care and Services, and Patient Preferences and Special Services. For this secondary analysis the subgroups; Patient End of Life Wishes, Treatment of Patient Symptoms, Patient Dignity and Respect, and Overall Care and Services were evaluated as questions within these categories, and labeled as key indicators for satisfaction by the survey. Under the subtopic, Patients End of Life Wishes, question one and two used a nominal scale for responses (yes, no and no answer).

The results from this subtopic (Figures 1 – 2) indicated an overall high satisfaction for timely and short term groups. However, it was notable that the group “15-30 days” had the least favorable ratings overall in this category, with 9% of respondents in that group denying any discussion of patient end of life wishes, and 9% feeling that care was inconsistent with their loved ones wishes.

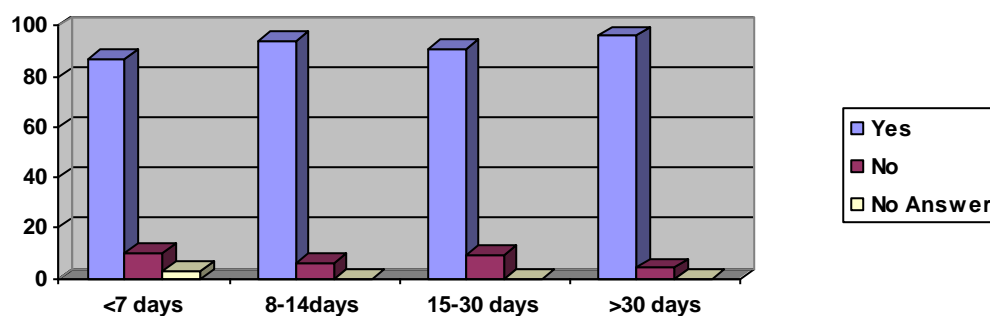


Figure 1. Did any member of the hospice team speak to the patient or family about the patient's wishes for medical treatment (in %)

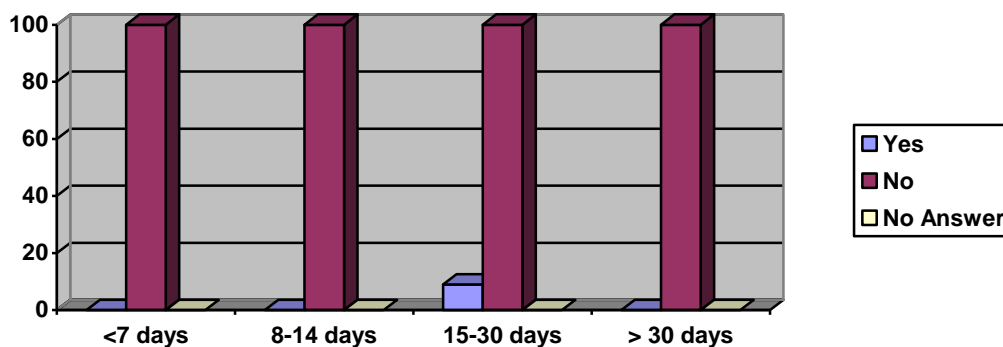


Figure 2. Was hospice care inconsistent with patient wishes (in %)

The second subgroup included questions regarding patient symptom management satisfaction. These symptoms included breathing, pain, and anxiety or sadness.

Based on the findings from the ratings of symptom management, it is noted that most of the instances of unanswered questions were due to these symptoms not occurring for many of these hospice patients. This conclusion was reached based on the answers to the following questions (See Table 2), which instruct the surveyed to skip over questions if their answer is no.

Table 2

Patient Symptom Management Satisfaction

Question	< 7 days	8-14 days	15-30 days	>30 days
3. While under the care of hospice did the patient have pain or take medicine for pain	81% answered yes 19% answered no	100% answered yes	60% answered yes 26% answered no 14% did not respond	51% answered yes 5% answered no 44% did not respond
7. While under the care of hospice did the patient have trouble breathing?	48% answered yes 50% answered no 2% did not respond	50% answered yes 50% answered no	30% answered yes 61% answered no 9% did not respond	23% answered yes 36% answered no 41% did not respond
11. While the patient was under the care of hospice, did he/she have any feelings of anxiety or sadness?	17% answered yes 76% answered no 7% did not respond	50% answered yes 50% answered no 12% did not respond	35% answered yes 0 % answered no 65% did not respond	28% responded yes 31% responded no 41% did not respond

For the topic of breathing (Figure 3), more instances of difficulty were reported for short term patients, with the only reported instances of not enough help with breathing problems occurring with the <7 day group. Anxiety and sadness (Figure 4) were reported more often in the short term group, however, 4% of the timely group reported not enough help with anxiety and sadness issues, with only 2% of the <7 day group responding this way. Pain (Figure 5) was the most reported symptom, and was overall rated as the right amount. In the timely group, 5% reported not enough pain management and in the <7 day group 1% shared the same report. In this <7 day group 1% also reported more than enough pain management, and this was the only report of this in the survey. With less overall survey respondents in the timely group, it was of greater significance that satisfaction was lower in the anxiety and pain management areas, with the Deyta analysis reporting statistical significance with 95% confidence.

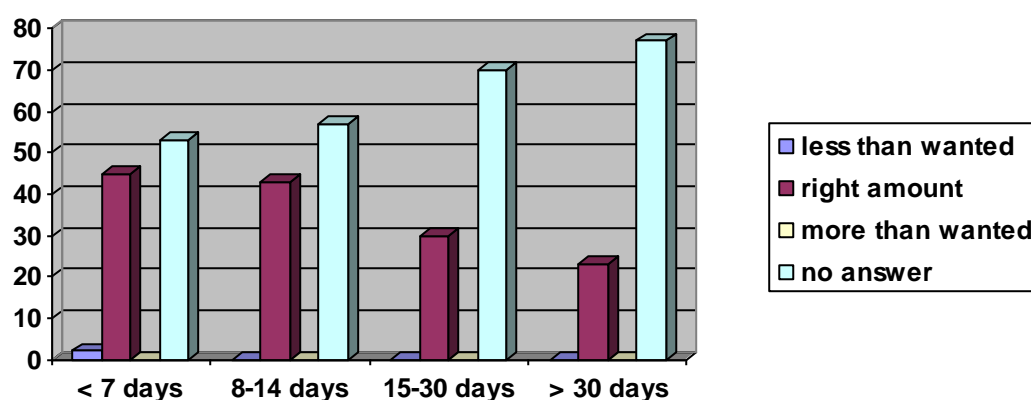


Figure 3. Help dealing with patients breathing (in %)

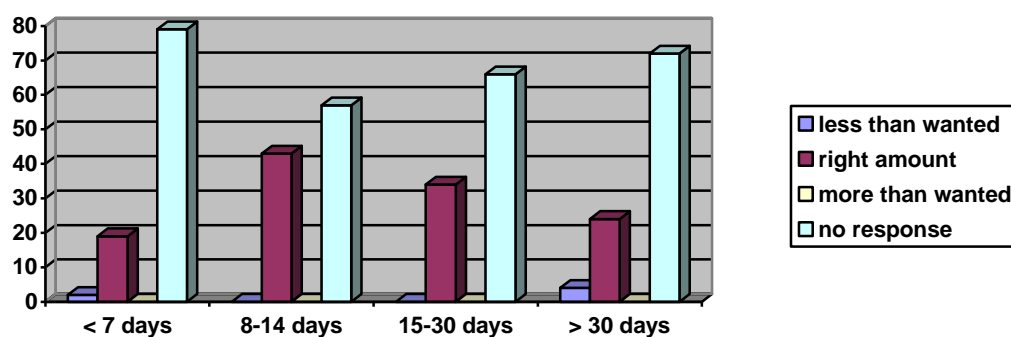


Figure 4. Help dealing with patients feelings of anxiety or sadness (in %)

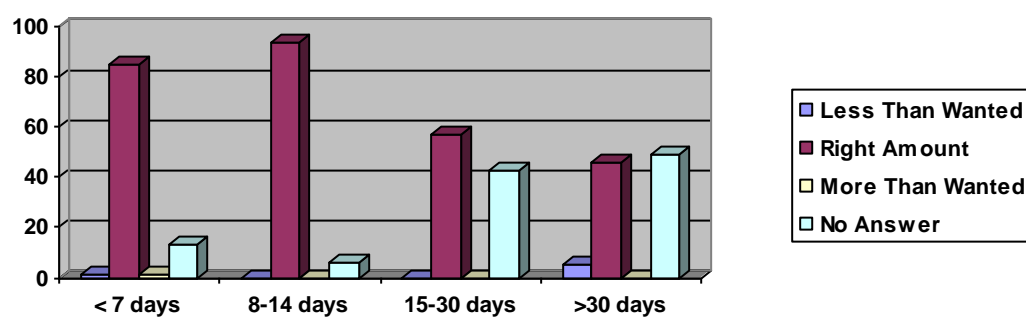


Figure 5. Medicine received for patients pain (in %)

The third subgroup covered patient dignity and respect, and yielded no significance. Overall satisfaction levels were high in this area (Figure 6). No negative responses were provided related to personal care from this surveyed group, again offering no statistical significances between the groups per the Deyta analysis.

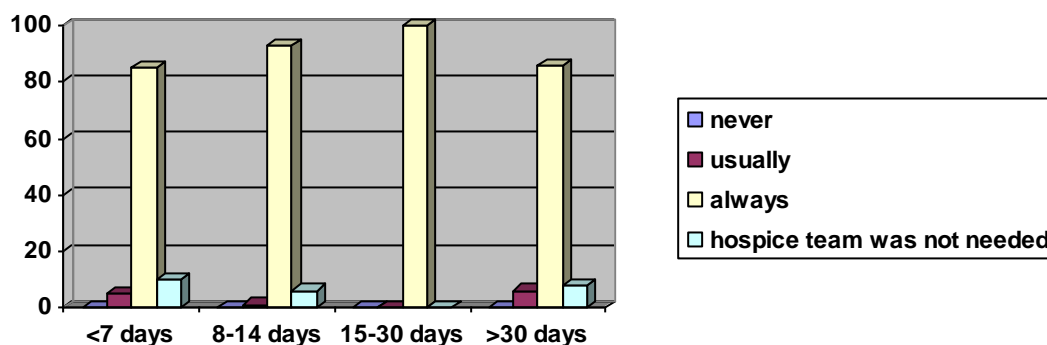


Figure 6. Patients personal needs were taken care of (in %)

The final subgroup examined was “Overall Care and Services”. This area covered most of what are considered key satisfaction drivers by the non-profit hospice in the piedmont of North Carolina. In the category overall patient care received under hospice services, a lack of response from the timely group does not allow for accurate comparison between that group and the short term groups. By the data received, no significant differences are noted per the Deyta analysis. (Figure 7)

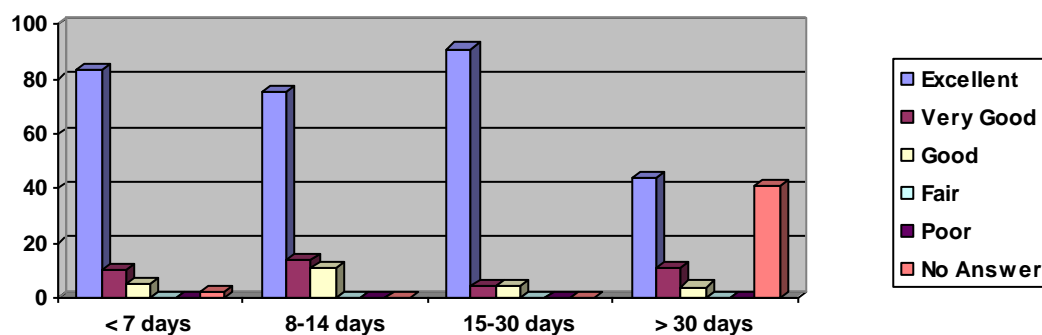


Figure 7. Overall care patient received while under care of hospice

In response to how well the hospice team responded on evenings and weekends, there was again a large lack of response in the timely group (Figure 8). However, it is noted that great satisfaction is reported in the 15-30 day area of the short term group. There is no statistical significance to report per the Deyta analysis.

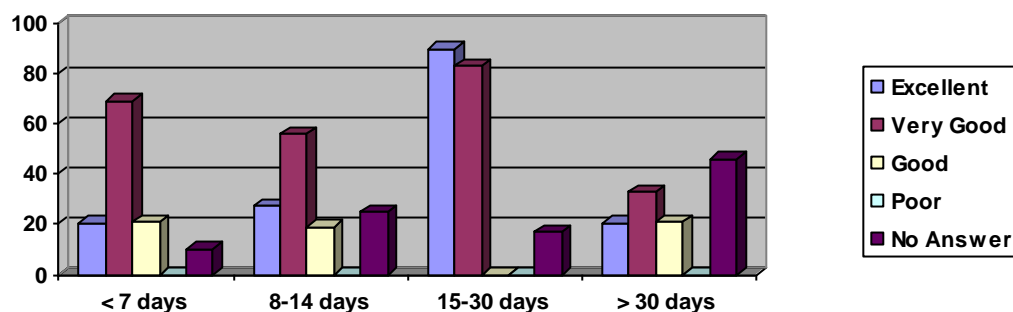


Figure 8. Hospice team response to needs in the evenings and weekends

The question “would you recommend this hospice to others?” offered a lack of response from approximately 41% of the timely group (Figure 9). It is interesting to note that the only negative responses were within this timely group. However, there is no statistical significance per the Deyta analysis.

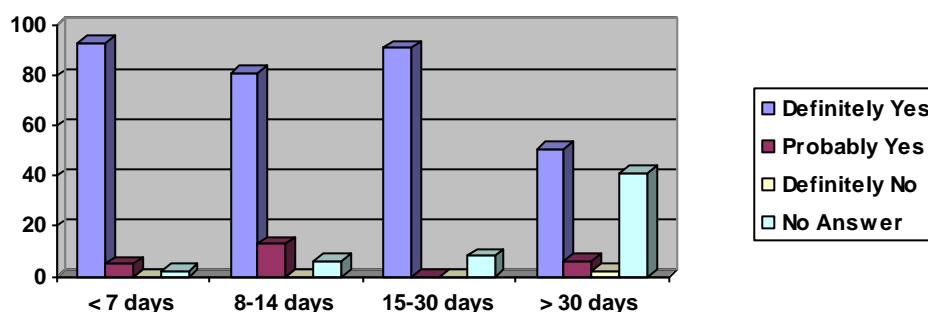


Figure 9. Would you recommend this hospice to others

The results from the family perception of the timing of hospice revealed that collectively 8% of those in the short term group felt that their loved one was referred to hospice too late (Figure 10). No such responses were found in the timely group. However, 1% of the respondents in the timely group reported their loved one being referred to hospice too early. Overall, no statistical significance was noted per Deyta analysis.

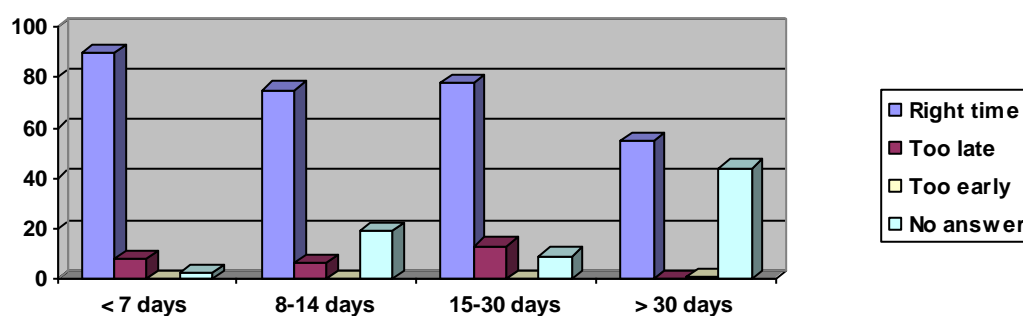


Figure 10. Timing of referral to hospice

Summary

A total of 119 FEHCS (Appendix C) were returned to non-profit hospice in the piedmont of North Carolina for the dates of January through July of 2012. Of the surveys returned, all were utilized for this secondary analysis. The surveys were divided into groups based on length of stay. For this study the subgroups, Patient End of Life Wishes, Treatment of Patient Symptoms, Patient Dignity and Respect, and Overall Care and Services were evaluated as indicators for satisfaction. Through the results collected from there were no statistical differences noted between key satisfaction indicators and length of stay.

Chapter V

Discussion

Hospice care is humane and compassionate care for people in the last phases of an incurable disease, so that they may live as fully and comfortably as possible (American Cancer Society, 2011). With this care, patients and their caregivers can be offered support and guidance through an extremely difficult stage in life.

The hypothesis, “A direct relationship exists between a family’s perceptions of the value of hospice and the length of stay of their terminally ill loved one,” was the focus of this inquiry. In order to do so, the concepts of hospice care, timely referrals, patient centered approach, family satisfaction, and cognitive theory of stress and coping were summarized in this paper. The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) was the model utilized to guide the investigation into current research.

Implication of Findings

The convenience sample of FEHCS (Appendix C) used in this study was comprised of surveys that were voluntarily returned to the agency during a seven month period. The sample may have not been a true representation of the satisfaction of the population of the families who received hospice care, as it is possible that those returning the surveys did so due to strong opinions about care received, both positively and negatively. There is a non-response bias of 66% of the total sample. Non-responders are likely to have different opinions than those who returned surveys (Holdsworth & King, 2011). Therefore, the low return rate does not likely represent the opinion of the population of the recipients of hospice services.

The short term group comprised 68% of the total sample, which is similar to the findings reported by Waldrop and Rinfrette (2009), who reported that nearly two thirds of patients receiving hospice care expire in the first month of service. The higher rate of short term and timely hospice patients is also proportional to reports of national lengths of stay (Hospice Association of America, 2006).

There were four subtopics utilized from the FEHCS in this secondary analysis, which included questions deemed by the non-profit hospice in the piedmont of North Carolina as satisfaction indicators. The first was Patients End of Life Wishes, which included two questions that used a nominal scale for responses (yes, no and no answer). The results from this subtopic indicated an overall high satisfaction for timely and short term groups. However, it was notable that the group “15-30 days” had the least favorable ratings overall in this category, with 9% of respondents in that group denying any discussion of patient end of life wishes, and 9% feeling that care was inconsistent with their loved ones wishes. There was not any statistical significance noted, however, with the slightly more unfavorable rating, it is suggested that some participants in the 15-30 day group perceived unmet needs. It is discussed by Teno et al. (2007) that good communication between hospice staff, patients, and families can calm fears, build trust, and improve the ability to take care of the dying patient. Teno et al. (2007) also mentions that late referrals may result in unmet needs. Therefore, it is not surprising that with longer lengths of stay, more time for communication is offered for discussion of end of life wishes, and those with shorter lengths of stay may feel unfulfilled in this area.

The second subgroup included questions regarding patient symptom management satisfaction. These symptoms included breathing, pain, and anxiety or sadness. Based on

the findings from the ratings of symptom management, it is noted that most of the instances of unanswered questions were due to these symptoms not occurring for many of these hospice patients. No significance was noted between the short term and timely groups when compared under this concept. However, more instances of difficulty breathing were reported for short term patients, with the only reported instances of not enough help with breathing problems occurring with the <7 day group. Anxiety and sadness were reported more often in the short term group, however, 4% of the timely group reported not enough help with anxiety and sadness issues, with only 2% of the <7 day group responding this way. Pain was the most reported symptom, and was overall rated as the right amount. In the timely group, 5% reported not enough pain management, and in the <7 day group 1% shared the same report. In this <7 day group, 1% also reported more than enough pain management, and this was the only report of this in the survey. With less overall survey respondents in the timely group, it was of greater significance that satisfaction was lower in the anxiety and pain management areas, with the Deyta analysis reporting statistical significance with 95% confidence. The greater instances of symptom management dissatisfaction in the short term group may again be related to feelings of “unmet needs” (Teno et al., 2007, p.122) due to admissions in the last hours or days before death. Based on a study of bereaved family members, Rhodes et.al. (2008) discovered respondents were more likely to have higher overall ratings of satisfaction with hospice services if they felt the patient received the right amount of pain control. The finding that 5% of the timely group reported not enough pain management was surprising. No research was found regarding long lengths of stay and negative effects of hospice. This topic is one that needs further inquiring.

The third subgroup covered patient dignity and respect, and yielded no significance. Dignity is an important aspect of the patient experience and is central to the philosophy of hospice care (Gerry, 2011). Overall satisfaction levels were high in this area. No negative responses were provided related to personal care from this surveyed group, again offering no statistical significances between the groups per the Deyta analysis.

The final subgroup examined “Overall Care and Services”. This area covered most of what are considered key satisfaction drivers by the non-profit hospice in the piedmont of North Carolina. In the category of overall patient care received under hospice services, a lack of response from the timely group does not allow for accurate comparison between that group and the short term groups. By the data received, no significant differences are noted per the Deyta analysis. This same issue is present for all four questions in this category.

Application to Theoretical/Conceptual Framework

The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) was the model used to examine the concept of family satisfaction with hospice care. The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) reported that the appraisal process is most heavily implicated during the outset of an event in the evaluation of its personal significance and the evaluation of options for coping. Negative emotions such as sadness, anger, anxiety, or fear are associated with perceived harm or threat, and positive emotions such as excitement, eagerness and confidence appear when the situation is resolved favorably (Lazarus & Folkman, 1984). The hospice team has a main goal of providing care to the patient that

allows for comfort and dignity during the end-of-life. Therefore, the level of perceived satisfaction patient centered care can be reflected in the level of resolution the family feels is reached. Concerns presented by the patient and patient's family can be met by the nurse through performance of professional communication, therefore increasing satisfaction. No significant findings were discovered in this study, so overall each group (short term and timely) was able to reach a level of resolution supported by an overwhelming positive response by bereaved families.

Limitations

The first limitation is the application of The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984). The FEHCS (Appendix A) does not specifically assess the emotions and level of resolution felt by the caregiver. The level of satisfaction in hospice care was high, but one cannot assume that this was due to positive assistance with coping and resolution. To more specifically assess the level of resolution, a change in survey tool or methodology, such as qualitative design, may be helpful.

Other limitations lie within the survey. The FEHCS (Appendix A) was developed on a national level, however the reliability and validity of the tool was unable to be offered. Further analysis of the FEHCS is recommended to determine if the items labeled as key indicators for family satisfaction, as utilized in this secondary analysis, accurately measure these attributes.

Another limitation of this study was the amount of persons able to be reached within a certain geographic location for a limited time. The returned surveys were from voluntary respondents, which may result in skewed results from individuals with stronger opinions. Many of the respondents did not provide an answer for these key questions.

Implications for Nursing

Research regarding the effects of the timing of a hospice referral within a community would contribute tremendously to nursing knowledge. The advantages of the community, including health care providers, recognizing the effects of a late referral to hospice could be life changing. By understanding what hospice is about and allowing the services to be incorporated into the plan of care, patients with life limiting illnesses can have a chance to pass with comfort and dignity in their home with their family by their side (Hospice Association of America, 2006). This particular study does not offer any significant results for nursing, but does offer ideas for further research.

Recommendations

Though this particular study offered no significant conclusions, a few areas of weakness in symptom management for the timely group were noted. The researcher recommends that future studies are completed to address issues that are faced by long term patients. Also, the creation of a standardized, validated tool, that specifically measures the key indicator concepts, could be utilized in future research as an indicator for quality care and satisfaction levels.

Conclusion

Even though this secondary analysis did not find any differences in level of satisfaction between the short term and timely groups, the results did offer an overwhelming satisfaction with the services offered by the non profit hospice in the piedmont of North Carolina. The differences in the groups may have been more defined in a larger group and for an extended period of time.

The Cognitive Theory of Stress and Coping (Lazarus, 1966; Lazarus & Folkman, 1984) was used as the basis to explore the positive feelings and levels of resolution obtained that influence family satisfaction with hospice care. Family satisfaction was categorized into four domains including: Patient End of Life Wishes, Treatment of Patient Symptoms, Patient Dignity and Respect, and Overall Care and Services. There was an assumption that the initiation of positive feelings between the hospice staff and feelings of resolution would be reflected in high levels of satisfaction reported on the FEHCS (Appendix A). Overall satisfaction levels for all four subgroups were high.

Hospice services provide end of life care to patients and families with emphasis placed on addressing physical, emotional, and spiritual needs of the patient and their loved ones. Continued research is needed on the factors that influence perceived family satisfaction with hospice care and the relation to the timing of the hospice referral.

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doi:10.1080/07481180902961187

Appendix A

Family Evaluation of Hospice Care Survey

7046651363

Hospice of Iredell

11:36:26 09-28-2012

2/6



Hospice &
Palliative Care
of Iredell County

2347 Simonson Road, Statesville, NC 28625

00000186

Evaluation of Hospice Care



2896217111

HOS-FEHC-1 (NCB)

4/25/2011

To complete
survey online:

Go to www.deyta.com/deyta and enter this code:

ACA0C417CF01

If you choose to submit the survey online, there is no need to complete or mail the paper survey.

To use this
paper survey:

Use a blue or black pen to complete the survey. Example, correct mark: ☐ ☒ ☐
Please skip if the question does not apply. Complete and mail survey using the enclosed, postage-paid envelope, as soon as possible.

Patient's End-of-Life Wishes

1. As far as you know, did any member of the hospice team speak to the patient or to a family member about the patient's wishes for medical treatment as he/she was dying? ☐ Yes ☐ No
2. At any time while the patient was under the care of hospice, did the doctor or another hospice team member do anything with respect to end-of-life care that was inconsistent with the patient's previously stated wishes? ☐ Yes ☐ No

Treatment of Patient Symptoms

3. While under the care of hospice, did the patient have pain or take medicine for pain? ☐ Yes ☐ No → If No, go to Question 7.
4. How much medicine did the patient receive for his/her pain? ☐ Less than was wanted ☐ Just the right amount ☐ More than patient wanted
5. Did you or your family receive any information from the hospice team about the medicines that were used to manage the patient's pain? ☐ Yes ☐ No ☐ Do not know
6. Did you want more information than you got about the medicines used to manage the patient's pain? ☐ Yes ☐ No
7. While under the care of hospice, did the patient have trouble breathing? ☐ Yes ☐ No → If No, go to Question 11.
8. How much help in dealing with his/her breathing did the patient receive while under the care of hospice? ☐ Less than was wanted ☐ Just the right amount ☐ More than patient wanted
9. Did you or your family receive any information from the hospice team about what was being done to manage the patient's trouble with breathing? ☐ Yes ☐ No ☐ Do not know ☐ No treatments used for breathing → Go to question 11.
10. Did you want more information than you got about what was being done for the patient's trouble with breathing? ☐ Yes ☐ No
11. While the patient was under the care of hospice, did he/she have any feelings of anxiety or sadness? ☐ Yes ☐ No → If No, Go to Question 13.
12. How much help in dealing with these feelings did the patient receive? ☐ Less than was wanted ☐ Right amount ☐ More help or attention to these feelings than patient wanted

Deyta

INTERACTION EXPERIENCE
www.deyta.com

HOS-FEHC-1 (NCB)

Adapted from a survey created by Dr. Joan Teno of Brown University, in collaboration with the National Hospice and Palliative Care Organization.

pg. 1

Patient Dignity and Respect

13. How often were the patient's personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been by the hospice team?
☐ Always ☐ Usually ☐ Sometimes ☐ Never ☐ Hospice team wasn't needed/wanted for personal care
14. How often did the hospice team treat the patient with respect?
☐ Always ☐ Usually ☐ Sometimes ☐ Never

Information for You as the Caregiver

15. While the patient was under the care of hospice, did you participate in taking care of him/her?
☐ Yes ☐ No → If No, go to Question 19.
16. Did you have enough instruction to do what was needed?
☐ Yes ☐ No
17. How confident did you feel about doing what you needed to do in taking care of the patient?
☐ Very confident ☐ Fairly confident ☐ Not confident
18. How confident were you that you knew as much as you needed to about the medicines being used to manage the patient's pain, shortness of breath, or other symptoms?
☐ Very confident ☐ Fairly confident ☐ Not confident
19. How often did the hospice team keep you or other family members informed about the patient's condition?
☐ Always ☐ Usually ☐ Sometimes ☐ Never
20. Did you or your family receive any information from the hospice team about what to expect while the patient was dying?
☐ Yes ☐ No
21. Would you have wanted more information about what to expect while the patient was dying?
☐ Yes ☐ No
22. How confident were you that you knew what to expect while the patient was dying?
☐ Very confident ☐ Fairly confident ☐ Not confident
23. How confident were you that you knew what to do at the time of death?
☐ Very confident ☐ Fairly confident ☐ Not confident

Emotional and Spiritual Support for You

24. Did any member of the hospice team talk with you about your religious or spiritual beliefs?
☐ Yes ☐ No
25. Did you have as much contact of that kind as you wanted?
☐ Yes ☐ No
26. How much emotional support did the hospice team provide to you prior to the patient's death?
☐ Less than was wanted ☐ Right amount ☐ More attention than was wanted
27. How much emotional support did the hospice team provide to you after the patient's death?
☐ Less than was wanted ☐ Right amount ☐ More attention than was wanted
28. How much help did the patient and/or you receive from volunteers while under the care of hospice?
☐ Less than was wanted ☐ Right amount ☐ More attention than was wanted
☐ Did not receive volunteer services

HOS-FEHC-1 (NCB)

Adapted from a survey created by Dr. Joan Teno of Brown University, in collaboration with the National Hospice and Palliative Care Organization.

pg. 2

Coordination of Care

29. How often did someone from the hospice team give confusing or contradictory information about the patient's medical treatment? ☐ Always ☐ Usually ☐ Sometimes ☐ Never
30. While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care? ☐ Yes ☐ No
31. Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care? ☐ Yes ☐ No

Overall Care and Services

32. Overall, how would you rate the care the patient received while under the care of hospice?
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor
33. How would you rate the way the hospice team responded to your needs in the evenings and weekends?
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor
☐ Never contacted evening/weekend services
34. Did the hospice team explain the plan of care to you in a way that you could understand?
☐ Yes ☐ No ☐ Hospice team did not explain plan of care to me
35. How often did you agree with changes in the plan of care?
☐ Always ☐ Usually ☐ Sometimes ☐ Never ☐ No changes were made to plan of care
36. Based on the care the patient received, would you recommend this hospice to others?
☐ Definitely No ☐ Probably No ☐ Probably Yes ☐ Definitely Yes
37. a) In your opinion, was the patient referred to hospice too early, at the right time, or too late?
☐ Too early → **Go to Question 38.** ☐ At the right time → **Go to Question 38.** ☐ Too late
- b) If you selected "Too late", would you please explain your answer?
-
38. While under the care of hospice, was the patient in a nursing home?
☐ Yes ☐ No → **If No, go to Question 40.**
39. After hospice became involved, would you say the quality of end-of-life care the patient received:
☐ Improved ☐ Stayed the same ☐ Decreased

Patient Preferences and Special Services

40. Did our hospice provide you with adequate information on "Advance Directives", such as a living will or healthcare proxy? ☐ Yes ☐ No
41. Did the patient's death occur in the setting of the patient's choice? ☐ Yes ☐ No
42. If you received support provided by a volunteer, how would you rate this support and assistance?
☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor ☐ Did not receive volunteer support
43. Did you receive enough instruction from the hospice team regarding patient safety? ☐ Yes ☐ No
44. Please rate your satisfaction with home medical equipment:
- | | | | | | |
|---|---------------------------------|---------------------------------|----------------------------|----------------------------|----------------------------|
| a. Promptness of delivery..... | <input type="radio"/> Excellent | <input type="radio"/> Very Good | <input type="radio"/> Good | <input type="radio"/> Fair | <input type="radio"/> Poor |
| b. Explanation given on how to use..... | <input type="radio"/> Excellent | <input type="radio"/> Very Good | <input type="radio"/> Good | <input type="radio"/> Fair | <input type="radio"/> Poor |
| c. Working order..... | <input type="radio"/> Excellent | <input type="radio"/> Very Good | <input type="radio"/> Good | <input type="radio"/> Fair | <input type="radio"/> Poor |
| d. Promptness of pickup..... | <input type="radio"/> Excellent | <input type="radio"/> Very Good | <input type="radio"/> Good | <input type="radio"/> Fair | <input type="radio"/> Poor |

About the Patient

45. Was the patient male or female? ☐ Male ☐ Female
46. Please choose the one disease group that best describes the primary illness that caused the patient to be referred to hospice. *(Please choose only one.)*
- | | |
|--|---|
| <input type="radio"/> Cancers - all types | <input type="radio"/> Heart & circulatory diseases |
| <input type="radio"/> Lung & breathing diseases | <input type="radio"/> Kidney diseases |
| <input type="radio"/> Liver diseases | <input type="radio"/> Stroke |
| <input type="radio"/> Dementia or Alzheimer's disease | <input type="radio"/> AIDS & other infectious diseases |
| <input type="radio"/> Frailty & decline due to old age | <input type="radio"/> Another disease (Please write in) _____ |
47. What is the highest grade or level of school that the patient completed?
- | | |
|---|--|
| <input type="radio"/> 8th grade or less | <input type="radio"/> Some high school, but did not graduate |
| <input type="radio"/> High school graduate or GED | <input type="radio"/> 1-3 years of college |
| <input type="radio"/> 4-year college graduate | <input type="radio"/> More than 4-year college degree |
48. Was the patient of Hispanic or Spanish family background? ☐ Yes ☐ No
49. Which of the following best describes the patient's race?
- | | |
|---|---|
| <input type="radio"/> American Indian or Alaskan Native | <input type="radio"/> Asian or Pacific Islander |
| <input type="radio"/> Black or African-American | <input type="radio"/> White |
| <input type="radio"/> Another race or multiracial (Please write in) _____ | |

About You

50. What is your relationship to the patient? Are you the patient's...
- | | | | | |
|--------------------------------------|-------------------------------|---|------------------------------|-------------------------------|
| <input type="radio"/> Spouse | <input type="radio"/> Partner | <input type="radio"/> Child | <input type="radio"/> Parent | <input type="radio"/> Sibling |
| <input type="radio"/> Other relative | <input type="radio"/> Friend | <input type="radio"/> Other (Please write in) _____ | | |
51. Are you male or female? ☐ Male ☐ Female
52. What is the highest grade or level of school that you have completed?
- | | |
|---|--|
| <input type="radio"/> 8th grade or less | <input type="radio"/> Some high school, but did not graduate |
| <input type="radio"/> High school graduate or GED | <input type="radio"/> 1-3 years of college |
| <input type="radio"/> 4-year college graduate | <input type="radio"/> More than 4-year college degree |
53. Are you of Hispanic or Spanish family background? ☐ Yes ☐ No
54. Which of the following best describes your race?
- | | |
|---|---|
| <input type="radio"/> American Indian or Alaskan Native | <input type="radio"/> Asian or Pacific Islander |
| <input type="radio"/> Black or African-American | <input type="radio"/> White |
| <input type="radio"/> Another race or multiracial (Please write in) _____ | |

Your Comments

Is there anything else that you would like to tell us?

Appendix B

Letter of Permission



September 19, 2012

Vickie Walker-DNP, MSN, RN
 Assistant Professor of Nursing
 School of Nursing
 Gardner-Webb University
 Boiling Springs, NC 28017

Dear Dr. Walker:

Melinda Reep, BSN RN has requested permission to do a project that involves analysis of results from Hospice of Iredell County's Family Evaluation of Hospice Care surveys. As Director of Compliance, I am happy to support Melinda and other students who have interest in end-of-life care. I have also received verification from Teresa Phillips, CEO that this project is suitable for our organization. Also, as a condition of this approval, Melinda has agreed to share her findings upon completion of her project.

As always, it is an honor to support nursing students and it is a pleasure to have them show interest in Hospice of Iredell County.

Please let me know if I can assist you in any way.

Sincerely,

A handwritten signature in cursive script, appearing to read "Rebecca Pettit".

Rebecca Pettit, MSN, RN
 Director of Quality & Compliance
 2347 Simonton Road
 Statesville, NC 28625

Cc: Melinda Reep
 Teresa Phillips

Statesville Office
 2347 Simonton Road
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www.HospiceOfIredell.org