

HOSPICE PATIENTS' COMFORT LEVEL AND FAMILY MEMBERS'
SELF-REPORTED SATISFACTION

By

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Abstract

The goal of the study was to find out whether there was a relationship between hospice patients' comfort level and family members' self-reported satisfaction. The study was conducted in a hospice care facility in the northeastern county of Maryland. Participants were family members comprised of spouses and children of the patients. All Forty-two family members who were given the survey questionnaires, completed them making the return rate 100%. Kristjason's FamCare questionnaire was used to evaluate family members' comfort level. The lowest mean was 4.44, item 4 on the questionnaire, and the highest mean was 4.95, which was item 12 on the questionnaire. The Cronbach's alpha was 0.92 which displayed high level of reliability of the FamCare scale with this sample. An acceptable Cronbach's alpha value is 0.7 (Janicak, 2017). As a result, the value of 0.92 is considerably higher than acceptable levels. The Pearson's r correlation coefficient was calculated to assess the relationship between patients' comfort level and family members' self-reported satisfaction. We used the item #1, "satisfied with the patient's pain control", as a proxy for comfort. We then took a mean of all the other items, minus item #1. The correlation between Item #1 and the mean of the other items is $r = .685$. The $p = .025$.

Chapter 1

Introduction

There are two main goals that need to be met when caring for a hospice patient and these are relief of chronic pain and provision of comfort for the patients in a manner that satisfies them and their family members. When the patient is dying, the family becomes the critical means of interaction between the hospice health care team and the patient because most patients are non-responsive and non-verbal at this stage (Coelho, Parola, Escobar-Bravo, & Apóstolo, 2016). Dealing with imminent death creates numerous concerns for both the family and the patient. The family's primary concern is the comfort of the patient. This makes it crucial for hospice health care professionals to provide holistic comfort for the patient. Research indicates that when hospice patients experience comfort through humanized care such as that of sensitive and caring health professionals and symptomatic control they tend to calm down and rest better (Worldwide Palliative Care Alliance, 2014).

Hospice care is health care that is focused on providing comfort and enhancing quality of life for individuals nearing the end of their lives. It is a unique type of care that treats pain without curing the illness (National Hospice and Palliative Care Organization, 2018). Hospice care offers hospice patients the option of remaining in the comfort of their home surrounded by family, friends, and other loved ones while providing comfort and support throughout the end-of-life process. Since this care environment is often labor intensive as well as physically and emotionally complex, supporting family caregivers in their efforts is ethically a responsibility (Guerriere, Zagorski & Coyte, 2013).

Comfortable dying is at the core of the hospice mission. Comfortable dying is an outcome measure established by the National Hospice and Palliative Care Organization

(NHPCO) as a method for assessing the quality of care provided for hospice patients (Hines, Hertz & Zanoni, 2011). Some hospices such as the Denver Hospice have adopted the NHPCO Comfortable Dying Measure protocol a standard for guiding the hospice personnel in focusing on providing comfort care for patients. The NHPCO has a variety of tools to assist hospices to compile and to submit data related to patient comfort. Hospice care is not a one-person endeavor. It is based entirely on teamwork. That team includes the family and an interdisciplinary team composed of nurses, social workers, home care professionals, and physicians. The active involvement of family members in the patient's care promotes the patient's psychological well-being. (Engström, Uusitalo, & Engström, 2011).

Satisfaction

The profit driven environment of the health care delivery system demands an assessment of the experience of family members of patients in hospice care to ensure that the care being provided is complete and meets their expectations (Clark, Milner, Beck, & Mason, 2016). Hospice patients are often unable to make decisions for themselves regarding the treatment plan suggested by the hospice professionals. The importance of including the patient's family members in hospice care to ensure delivery of quality comfort is being recognized. Family-focused care initiatives are being promoted by the Centers for Medicaid and Medicare Services, the Institute for Health Care Improvement's education and resources on family engagement, and the American Association of Critical-Care Nurses (Smith, Saunders, & Struckhardt, 2013). Engaging the family of the hospice patient in care is crucial because health care professionals cannot deliver quality care to a patient who is confused, weak, and non-verbal without engaging family members who know the patient well. Hospice provides comfort care and support for the family (National Hospice and Palliative Care Organization, 2018). The Hospice Foundation of

America (2018) asserts that hospice care offers families of hospice patients an assortment of services, which helps them spend the time they need with the patient to revisit memories and positive experiences they have had together. Because of hospice caregiving, families can say proper goodbyes to their loved ones. Hospice considers the spiritual beliefs of the family and the patients, which allow them to design customized strategies of care and communication as well as information transmission. In addition to home care hospice, there are inpatient facilities which provide pain control or acute or chronic symptom management which cannot be managed in other settings (Ong, Brennsteiner, Chow, & Herbert, 2016). Most hospices create a peaceful, nurturing, and comfortable environment. Some hospices provide services such as outdoor patios, lounges, fireplaces, pianos, personal shelving for photos and cards, and flowers to enhance the feeling of the comfort of home for the family and the patient (Horwitz-Bennet, 2014). Hospice also provides pull-out beds in patients' rooms to allow family members to spend nights with the patient and to be as comfortable as possible during this difficult time. The family can also have access to internet services connections so that outside communication is not hampered. Hospices also provide assorted refreshments and meal preparation stations for families. Furthermore, shower access and laundry facilities, in-room refrigerators, microwaves, TV sets, and coffee pots are provided to make families comfortable.

Findings from research demonstrate that involving patients' families in hospice care can produce improved outcomes, such as satisfaction for patients and their family. (Canadian Agency for Drugs and Technologies in Health, 2015). The primary reason for health care providers to develop a collaborative relationship with the patients' family is to foster an open exchange of information that is vital to assist the patient and the family to cope with distress and discomfort. When it is no longer possible to cure a serious illness, hospice is usually chosen as an option.

Both the patient and the family are aware that hospice is not designed to attempt to heal or cure the disease or to slow down the progression of the disease (National Institute on Aging, 2017).

Significance

It is hard for family members to cope with the fact that their loved one is at the end of life. Family members undergo various emotional upheavals during this time (Lysaght & Ersek, 2013). It is important for family to be involved in the care of the patient to ensure that the patient is comfortable and well-cared for and to make peace with their loss. The best way to achieve this is for the hospice to adopt a family-centric approach which includes a team of doctors, nurses, social workers, and counselors working together with the family. All medications for the patient are identified and sorted by the hospice physician who works in consultation with a hospice pharmacist (National Hospice and Palliative Care Organization, 2014). The physician determines needed medications. He is the individual responsible for ordering all medications and guiding the treatment plan. The hospice nurses administer the treatment and monitor the patient closely to ensure that they are kept as comfortable as possible. The family's role must be clearly delineated through discussions between the hospice team and the family. The comfort of the patient can be provided by the professionals as well as family members working closely with the hospice team and listening carefully to each other regarding steps that should be taken when caring for such a patient. If the patient is being taken care of in their home, family members must be advised when to contact a hospice caregiver. In case of non-verbal patients, both the hospice professionals and the family should observe carefully the patient's non-verbal cues that indicate discomfort or a need for something such as a drink of water or relief of pain. Family members are better able to identify these signs because they are the closest to the patient. As such, they can communicate the meaning of these cues to the hospice team members. As family members

continue to be involved and act as surrogate decision-makers for their loved ones, health professionals should operate with dedication and commitment in providing the necessary care and service that provides comfort for the patient and enhances their dignity and meets patients' and family members' expectation. It is vital for healthcare providers to ascertain from patients and family members their needs (Fumis, Ranzani, Faria, & Schettino, 2014). Nurses should be aware of the patient's need for pain medications and administer them on a timely basis to keep the patient comfortable. Gaining the trust and confidence of the patient's family members is necessary for the providers to provide optimum care and services. Holden (2002) reported that family members appreciate timely and honest information. They desire that providers should share with them any information about the patient's treatment, interventions, medical condition, changes in condition, and other related plans being made for them. This information is important although it may be upsetting at times.

Problem

Pain management and control is a critical approach in keeping a hospice patient comfortable. Despite the abundant availability of a broad range of effective pharmacologic pain relief medications, understanding pain is still a significant problem in hospices and other related facilities (Wilkie & Ezenwa, 2012). Hospice care is an approach that is intended to provide comfort and multifactorial support for both the patient and their family members when death is imminent. This is the reason there are federal guidelines to regulate hospice care processes and require that hospice health care professionals should ensure that the patient's pain is under control. The Federal Regulation 42 CFR Section 418.50 states that *A hospice must...make...drugs... routinely available on a 24-hour basis p. 778*; and *make...covered services available ...to the extent necessary to meet the needs of individuals for care that is*

reasonable and necessary for the palliation and management of terminal illness and related conditions (Goldstein & Glaser, 2011). State laws that govern hospices also make pain control a primary aspect of keeping patients in hospice care comfortable. Pain management is a critical issue in managing patients with chronic illnesses. It is among the most important symptoms and a major cause of distress among cancer patients and their families (Ovayolu, Ovayolu, Aytac, Serce, & Sevinc, 2015). It is essential for the hospice team to ensure that their patients receive adequate pain management since most of them are in crisis mode and many are nonverbal.

Pain control during the patient's last weeks can be a challenging patient-management issue. Although the medical community is replete with requests to improving pain control and patient comfort, there is still inadequacy in pain management (Parker, 2013). Lack of pain control for hospice patient's results in impaired function and poor quality of life for the patient. Excellence in pain control and comfort have not been the focus of many physicians and although patients do not die from pain, untreated pain can lead to discomfort and distress of both the patient and their family members. In some cases, pain is under-treated, particularly when physicians fail to order the necessary medication for pain control for the patient although pain opioid medications are available for pain control (Duenas et al., 2018). Effective management of pain is not solely reliant on prescribing and administering opioids because pain management for the terminally ill demands an understanding of pain control strategies. Although persistent pain afflicts between 49% and 83% of terminally ill patients, only 50% of them receive analgesic medications on an as-needed basis and another 25% of them do not receive analgesic medications at all (Parker, 2013). This scenario makes it imperative to study current practices in care of the terminally ill regarding pain management and comfort. According to Carson et al., (2016), family members of hospice patients experience emotional distress, which includes

anxiety, depression, and post-traumatic stress disorder, and failure to administer pain medication to the patient as it is needed only adds to the distress of the family.

Mixed results are evident in clinical trials on interventions that aim at improving communication between the hospice team and the family regarding the prognosis of the patient and the goals set to help provide care for the patient. Hospice care specialists have been trained to ensure they provide emotional support, share information about patients, and make an engagement with patients and their family members on values and goals of care. Family members play a critical role in making end-of-life decisions for the patient (Enguidanos, Housen, Penido, Mejia, & Miller, 2013).

Family Burnout

Sometimes family members can work together with the hospice team to provide a certain degree of care for the patient, particularly if they opt to receive hospice care in the home. Family members who provide care are known as family caregivers. Family caregivers usually provide their dying loved ones suffering from a variety of serious diseases such as dementia, cancer, COPD or, advanced age with multidimensional care. These family caregivers experience chronic stress unlike their formal counterparts such as physicians and nurses who function in shifts (Bevans & Sternberg, 2012). It is not uncommon for these family caregivers to experience negative psychological, physiological, and even behavioral effects of this heavy burden. Their work is not linear. It is marked by complex multiple responsibilities, tasks, and their competing priorities, which trigger unrelenting stress. Sometimes, family can develop health problems of their own due to immune dysregulation. This is where the health care provider team can intervene and stabilize the family during this difficult time. Extended stress can have adverse effects on the hypothalamic pituitary adrenal (HPA) axis, which is our central stress response

system (de Vente, van Amsterdam, Olf, Kamphuis, & Emmelkamp, 2015). When it is disturbed, the HPA axis can trigger changes in the immune system that can adversely affect the health of the individual. Often this can cause a physiological state of burnout in which the HPA axis activity is increased. This is exacerbated by changes in the psychological coping mechanisms and expectations of the caregiver. By providing the patient with appropriate and timely comfort, the hospice team can reduce or even prevent burnout in family members.

Depression

There is limited empirical evidence from research focused on assessing families with patients in hospice care. However, family members do experience high levels of physiological distress and anxiety when dealing with a terminally-ill loved one (Day, Haj-Bakri, Lubchansky, & Mehta, 2013). These physiological levels can degenerate into depression proportional to the progression of the patient's condition. Watching the progression of the disease in their loved one can trigger depressive symptoms. Family members can exhibit the levels of depression identical to that of the patient. Results of a study conducted by Oliver, Washington, Smith, Uraizee, and Demiris (2016) indicate that of the 395 family members taking care of a loved one, 23 percent were moderately or severely depressed.

Benefits of Hospice

Research has focused more on the benefits of hospice for the patients, but there is now evidence from research conducted at the Icahn School of Medicine at Mount Sinai indicating that hospice care offers benefits to family too (Ornstein et al., 2015). The findings claim that although family members experienced depression after the passing of their loved ones, these family members and spouses enrolled in a hospice support group showed improved depression after the death of a loved one than their counterparts who were not in a hospice group (Obermeyer et al.,

2014). Considerable benefits have also been seen in the patients themselves. Patients using hospice services are less likely to experience acute physical and emotional distress at the end of their life. They are also less likely to undergo invasive procedures or to be hospitalized or to be admitted to intensive care units in the last weeks of their life. This is because hospice provides support for both the patients and their families such as phone calls, letters, home visits and education material dealing with terminal illness, and grief. Hospice also provides pre-death planning, home visits, and individual as well as family therapy options.

Purpose

The purpose of this study is to determine if there is a relationship between hospice patient's comfort level and family member's self-reported satisfaction.

Research Questions/Hypothesis

For this specific important topic, the main research question is:

Is there a relationship between hospice patients' comfort level and family members' self-reported satisfaction?

The other important questions are:

1. How can family member's satisfaction be determined?
2. What role does the health professional play in ensuring family satisfaction?

Hypothesis

H₀. There is no correlation between hospice patient level of comfort and family members' levels of satisfaction.

H_a. There is a correlation between hospice patient level of comfort and family members' levels of satisfaction.

Definitions

Satisfaction level: Is measured by the rest of the FamCare scale in the study.

Comfort: The soothing and caring of another individual with the aim of making him/her feel better. Their comfort level will be assessed by item 1 on the FamCare scale, psychological, social, cultural, and spiritual needs.

Theoretical Framework

The theoretical framework within which the study will be conducted is Comfort Theory developed by Kathrine Kolcaba in the 1990s (1994). The theory promulgates that there are four contexts within which comfort can occur. These are physical, environmental, psycho-spiritual, and socio-cultural contexts. The physical context of the theory includes bodily sensations, homeostasis, skin care, pain relief with medication, and healing touch. The environmental context is associated with monitoring the temperature of the patient, monitoring light, sound, odor, color, and furniture in the room where the patient is. The psychosocial context focuses on the meaning of life and spirituality and coaching. The fourth context is the sociocultural in which it is imperative to promote interpersonal, family, and social relationships. It also entails customs, rituals, connection with friends, financial support, meals, and chaplain referral. The Comfort Theory places comfort in the front of healthcare. It is an immediate desirable outcome of the nursing services in health care and hospice care. Kolcaba claimed that comfort exists in three forms, namely relief, ease, and transcendence. Relief can occur if the needs of the patient are met. This can include giving the patient pain medication as in post-operative care. Ease is related to comfort occurring in a state of contentment such as reducing anxiety. The transcendence aspect is a state of comfort in which the patient can rise above their immediate challenges. The Comfort Theory can help both health care professionals in palliative and hospice settings and

researchers to identify and address the many symptoms and concerns associated with the end-of-life care for the patient and their family members. Since comfort is the main goal for a terminal patient, the Comfort Theory is appropriate for this study. Knowledge of the experiences of comfort and discomfort can be a guide for patient care in the hospice and elsewhere. The Comfort Theory provides a holistic approach to care. Both patients and family become an integral part of care for the patient. The Comfort Theory is integrated into practice by including aspects that include asking patients' families what to do to make the patient more comfortable, to teach families about comfort, to foster interdisciplinary communication, respect the patient, to coordinate care, and provide timely and relevant information to the family. The theory can also help nurses relieve the patient of fear and provide comfort and pain relief working together with the family of the patient.

Summary

Family satisfaction is as vital in hospice care as it is in other areas of healthcare delivery. It has increasingly become an essential dimension of quality measurement in care (Hopkins, 2015). It can be successfully employed to show service quality, and to discover areas where families would like to see improvement in hospice care. Recent studies have shown ongoing need to develop effective interventions to ameliorate family satisfaction in communication skills and detailed protocols to schedule meetings with individual families (Huffines et al, 213). The need for the family's support during hospice care and after the death of a loved one is important. As such, educating care providers to communicate and help families after the death is crucial to assist a family to feel comfortable and not forsaken.

Chapter 2

Literature Review

Family members functioning as informal caregivers play an important role in end-of-life care for a loved one. They can be a pivotal source of well-being and can enhance the quality of life in terminally ill patients. These family members also experience chronic stress that is associated with caring for the patient and this could trigger remarkable physical, psychosocial, and financial problems (Ullrich et al., 2017). The intervention of the hospice team of health professionals is critical in alleviating and mitigating the burden of caring for a terminally ill patient for the family and providing comfort for the patient. Clear communication between the hospice care team and the family can play an important role in ensuring that both sides receive the information they need to provide an appropriate plan of care for the patient. Many family members might not understand information about their loved one's illness and treatment plan, and providers run the risk of missing the opportunity to address issue with the families they work with (Awdish et al., 2017). The family, functioning as spokesmen for a loved one with a serious illness need answers, relief, expertise, and support. The hospice healthcare team of physicians, nurses, social workers, spiritual counselors, dieticians, and pharmacists is an interdisciplinary team that provides care that is uniquely suited for the needs of the patient and their family.

A phenomenological descriptive study was conducted as an attempt to describe the comfort and discomfort experienced by patients in palliative units including hospices. A total of 17 terminally ill patients were recruited for the study from predominantly Spanish and Portuguese units. Data for the study were collected using individual interviews of patients who were still responsive. The descriptive approach was chosen so as to explore the phenomenon of human experience in palliative care units as it is associated with comfort and discomfort

(Coelho, Parola, Escobar-Bravo, & Apóstolo, 2015). Follow-up questions were asked during the interview for the purpose of deepening understanding of the experiences of the participants. The study was conducted in line with Kolcaba's Comfort Theory (1994) which asserts that comfort is the immediate experience of being strengthened by having the needs for relief, ease, and transcendence within the theory's four contexts of physical, environmental, psychosocial, and socio-cultural. Understanding the experiences of both comfort and discomfort of patients is critical for the plan and practice of care for them and maximizing their comfort to the satisfaction of their families. The findings of this study revealed that although previous research states that comfort often appears to be associated with the physical aspect of the patient, there are other factors that promote experiences of significant comfort and discomfort that health providers should consider. These include competence and human comfort. The participants in this study also drew a contrast between their assessment of the care they received in palliative units with the care from non-palliative units which they had already been admitted to with reference to the Comfort Theory context of environmental comfort associated with lighting, temperature, and noise. This study indicated that palliative care units can be a place of comfort where the patients' therapeutic needs are met to promote both their comfort and their families' needs. The units can also be places of discomfort where the patients can face vulnerability and the families experience dissatisfaction. It is up to the hospice administration to find strategies to maximize comfort.

A cross-sectional research study was conducted by Stajduhar et al. (2017) to try and understand the perception and satisfaction of family members by comparing the family's level of satisfaction with the end-of-life in four different settings that included extended care units, intensive care units, medical care units, and palliative care units. The authors screened 1,254 death records and 558 bereaved families indicated willingness to participate in the study. But

only 388 families returned the questionnaire, a 69% return rate that was sent out regarding the quality of care and comfort their loved ones had received in these institutions prior to death. The findings of the study revealed that family members experienced low satisfaction in all units, but particularly in medical units compared to the other settings. These findings suggest that there is need for improvement in all settings regarding care and comfort of the terminally ill to the satisfaction of their families.

Another study was conducted by Wachterman et al. (2016) in which the authors sought to compare patterns of end-of-life care and family-related quality of care for patients dying of different illnesses such as end-of-life renal disease, cardiopulmonary failure, congestive heart failure, and chronic obstructive pulmonary disease (COPD). The authors adopted a retrospective cross-sectional study design conducted in 146 in-patient Veteran Affairs facilities. Sources of data were two sources from Performance Reporting and Outcomes Measurement to Improve the Standard of Care of the End-of-life Center (PROMISE). The researchers reviewed medical records for patients who died in inpatient facilities of the VA-facilities. The facilities included acute care, long-term care, and inpatient hospice units before 2012. Data were also derived from the VA's corporate Data Warehouse integrating databases that contain clinical and administrative information. The findings of the study demonstrated disparities in quality of end-of-life care depending on the diagnosis. For example, end-of-life care and comfort levels were found to be more satisfactory and favorable by family members of patients dying from cancer and dementia than by family members of patients dying from organ failure or frailty. However, these diagnosis-related variations tended to be mediated by palliative care consultation and do-not-resuscitate orders. Patients with end-organ failure and frailty had frequent episodes of uncontrolled pain and discomfort. This study highlighted the need for providing all terminal

patients with timely care and comfort to alleviate the distress of family members and to promote comfort among them, too.

A study by Serra et al. (2012) assessed the effects of guided imagery on patients undergoing radiation therapy for breast cancer. The study was conducted by the architect of the Comfort Theory, Kolcaba (1994). It was a quasi-experimental study design conducted among 60 patients suffering from depression. In this study, the experimental group of patients were required to listen to a guided imagery compact disk one time every day for 10 days. The control group did not. The authors used the Psychiatric Inpatients Comfort Scale and the Depression, Anxiety and Stress Scales (DASS-21) two times during the study, at pre-intervention and post-intervention. The authors also assessed the comfort level of the control group before and after intervention. The results of this study revealed that the treatment group had improved comfort and reduced depression levels, anxiety, and stress and their families were satisfied with the treatment of their loved ones received unlike their counterparts in the control group.

Chapter 3

Methodology

Families continue to be active members of the patient's care team and are responsible for a significant amount of direct patient care. The quality of communication and support provided to families is associated with greater satisfaction with hospice care (Ong, Brennstener, Chow, & Herbert, 2016).

Study Design

This research project was a correlational study design. In this study, the correlational design was used to investigate the relationship between hospice patients' comfort levels and their family members' self-reported satisfaction.

Participants

The participants of this project were individuals whose family members enrolled in an inpatient hospice care setting. A score for each family member representing satisfaction with the comfort level of their dying loved one in the hospice care.

Sample

The sample was a convenience sample of forty-two family members of patients admitted into a hospice inpatient facility. The participation in the study was voluntary. Refusal to participate did not affect the patient or service in any manner. The inclusion criteria were individuals who spoke and understood English. The participants were asked to participate in the study in person. The confidentiality of the participants and those who chose not to participate were assured.

Ethical Considerations.

Permission to use the survey instrument was received (Appendix C) and to distribute the survey questionnaires at the study site was obtained from the administrators of the facility (Appendix B). This researcher completed a web-based human subject research ethics-training program through Collaborative Institutional Training Initiative (CITI) and received permission from Edinboro University Institutional Review Board (Appendix A) to conduct the study.

Family members whose loved one was in a hospice setting were identified and asked to participate in the study in which they were given a rating of their satisfaction of the comfort level of the patient by completing the FamCare scale. The researcher explained to them the purpose of the study and the importance of their participation. Family members who agreed to participate were asked to sign a consent form. The consent form began with the description of the study and assured that participants understood why they were voluntarily participating in the study. The researcher explained the type of data to be collected and the procedure used to collect the data. Those who chose to participate were asked to answer the questions from a questionnaire administered by the researcher. All the information obtained in this research was strictly confidential and anonymous. No participants were compensated or coerced to participate in the study. All participants' identities and personal information were protected by coding the questionnaires rather than using names. The information gathered about the participants was locked in the researcher's private office and on the researcher's private computer.

Instrument

There are several instruments to measure family members' satisfaction level, but in this study, the FamCare scale developed by Kristjansen (1993) was used (Appendix D). The FamCare Scale is a 20-item scale to measure family satisfaction with chronic disease care. Written permission was obtained from the originator of the instrument for the study. This tool uses a 5-point Likert scale which ranges from 1 (very dissatisfied), and 5 (very satisfied). In this study, the author measured the relationship between patients' comfort level and family members' self-reported satisfaction by using the twenty subscales. Numerical values of each answer was recorded for data analysis.

Reliability and Validity

The FamCare instrument has been in existence since 1993. Reliability and validity have been conducted on the FamCare scale (Kristjason, 1993). The FamCare Scale was utilized in a pilot test conducted by Kristjason using a convenience sample of 30 family members whose loved ones had advanced cancer. This scale demonstrated an internal consistency estimation of 0.93 at two testing times. It also yielded a test-retest correlation of 0.91. The validity of the instrument was assessed by correlating the scores of both FamCare and McCusker scales. Its estimates of criterion validity using the McCusker Scale were 0.80 and 0.77. Every instrument of research has room for improvement, but this scale has had a long history of use and is accepted as a reliable instrument for research. Research results confirm that the scale is a psychometrically sound instrument useful for measuring family satisfaction with care of the terminally ill in any similar research.

Summary

From the literature, it is evident there is a relationship between comfort level of the patient and family member satisfaction. Ensuring that a terminally-ill patient is given appropriate attention and timely medication can enhance the comfort of the patient which is important to the wellbeing of the family and support people in the patient's life (Kennedy, Brooks-Young, Gray, Larkin, Connolly..., 2014). Open communication with family members by the hospice health care team about the state of the patient and what is being done to provide maximum comfort for the patient is significant in ensuring that they are satisfied with what the healthcare professionals are doing. When family members are satisfied, they are better-able to make decisions concerning the kind of care given to their loved ones. A major source of satisfaction for family members is pain relief and comfort for hospice patient, which provides them with a sense of control and peace (Rome, Luminais, Bourgeois, & Blais, 2011).

The FamCare instrument, a reliable and valid 20-point scale, was utilized in this study to measure family satisfaction of the care rendered to a loved-one who has received hospice care.

Chapter 4

Results

Introduction

The purpose of the study was to find out if there is a relationship between hospice patients' comfort level and family members' self-reported satisfaction. This chapter details the results of the study.

Demographics of population

The participants in the study were present family members who were taking care of their loved ones in a hospice facility. They were mostly spouses and children with Medical decision-making powers for the patients. After receiving permission from the hospice administrator to conduct the study, a consent form and questionnaire were given to family members to check the answers on the Likert scale that apply to the care their loved ones were receiving. The Likert scale appraises the point of view of family members regarding the hospice care program.

Research Question

Is there a relationship between hospice patients' comfort level and family members' self-reported satisfaction?

Findings

In the study, family members' self-reported satisfaction levels were assessed by using Kristjason's 1993 FamCare instrument which consists of 20-item scale. Items on the scale were scored as very satisfied (VS) =5, Satisfied (S) = 4, Undecided (U) = 3, Dissatisfied (D) = 2, or Very dissatisfied (VD) = 1.

The score was then obtained for the overall family members' self-reported satisfaction by computing the mean of individual survey responses. The mean for the 20 questionnaires was between 4.44 and 4.95 (Appendix E). Survey question number 4 registered the lowest mean which was 4.44 (Information given about side effect). Physicians and nurse practitioners were not always there to provide medication side effects to family members and this was done by nurses, and could be one of the many reasons for the low mean. The highest mean of 4.95 corresponded to question number 12 on the FamCare scale (Availability of nurses to the family). Nurses play a significant role in health care as well as in hospice care. Apart from their traditional nursing duties of observing and recording symptoms and treatments, they also provide emotional support to terminally ill patients and their families. The mean was high probably due to the tremendous work of the nurses by providing adequate information and communicating with family members, providing emotional and spiritual support at the time they needed it most. They also prepare family caregivers for the death of the patient because family members who are prepared show positive outcomes such as perceived competence, having informational needs met, family satisfaction, and higher levels of hope than those who are not prepared (Henriksson & Arestedt, 2013).

The Cronbach's alpha was 0.92 which displayed high level of reliability of the FamCare scale with this sample. An acceptable Cronbach's alpha value is 0.7 (Janicak, 2017). As such, the value of 0.92 is considerably higher than acceptable levels. This scale has been tested by Kristjansen in 1993. The preliminary results show that the scale may be psychometrically sound to assess family satisfaction with advanced cancer.

The Pearson's r correlation coefficient was calculated to assess the relationship between patients' comfort level and family members' self-reported satisfaction.

The item #1 was used as a proxy for the variable of patient comfort. Then a mean was calculated of all the other items without item #1.

The correlation between Item #1 and the mean of the other items is $r = .685$.

The $p = .025$. These findings indicate a strong, positive, statistically significant relationship between the patient's level of comfort and family's overall satisfaction with the patient's care.

Chapter 5

Discussion

Introduction

The purpose of this study was to ascertain whether there is a relationship between patients' comfort level and family members' self-reported satisfaction. The study was done in a hospice care facility on the northeastern county of Maryland. After receiving permission from the facility to conduct the study, questionnaires and consent letters were given to family members. Forty-two questionnaires were given to family members and all of them were returned, making the return rate 100%.

While some of the literature showed family dissatisfaction with care, most of the studies indicated family satisfaction with end of life care. For example, some research findings demonstrate that involving patients' families in hospice care can produce improved outcomes such as satisfaction for patients and their family. (Canadian Agency for Drugs and Technologies in Health, 2015). Other previous studies that used the Family Evaluation of Hospice Care (FEHC) to study the predictors of family satisfaction consistently registered a positive relationship between family members' overall satisfaction with care and the quality of communication and support received from hospice staff (Holland, Keene, & Kirkendall, 2015).

The results from the study showed that information given about medication side effects had the lowest mean while availability of nurses to the family received the highest mean. Findings are consistent with previous studies which indicate that good communication and support provided to family members by nurses had strong positive relationships with overall satisfaction with hospice care. Findings from the present study reinforce the correlation between patients' comfort level and family members' self-reported satisfaction.

Limitation

The first limitation of the study was that the sample design was convenience and may not be utilized to represent all the family caregivers on the East Coast. The second limitation of the study was that the sample size was just forty-two and this small sample size is not representative of the other hospice care facilities. The third limitation was that participants were mostly Caucasians which could have affected the results. For example, African American family members of patients who received end-of-life care in hospitals, nursing homes, and home-based medical services have reported lower satisfaction than other ethnicities with the care provided (Reese, Smith, Butler, Shrestha, & Erwin, 2014). The fourth limitation was that oftentimes family members became well known to the hospice team and may have been reluctant to make statements that might have been viewed as disparaging of hospice. Another limitation was that there was a possibility some of the family members rushed to fill out the questionnaires and made some mistakes which might have altered the results. A final limitation was the use of item, “How satisfied are you with patient’s pain relief?” as a proxy measurement for the patient’s comfort. While the family member may have satisfied, a more direct measure of the patient’s comfort might have produced different results. Such a measure would be extremely difficult with patients who are nonverbal or otherwise noncommunicative, and this indicates an area for future study as well.

Applicability to Practice

Knowing the expectations and wishes of patients and family members is essential in palliative care services because such expectations have a significant effect on family satisfaction

level. Although, there are other issues in hospice services such as staff competence, visiting hours, care coordination, support, and staff level of respect for residents, availability of nurses and the quality of communication and support provided to family members is associated with greater satisfaction with hospice care (Ong et al., 2016). Another important finding is that communication appears to be correlated with family satisfaction across hospice care settings, inpatient and outpatient. Hospices should focus their efforts to ensure that their various disciplines (i.e., physicians, nurses, social workers, clergy, and personal care aides) involved in direct patient care provide patients and families with consistent information and support (Ong et al, 2016). It is observed in this study that patients' comfort level has a direct correlation with family members' self-reported satisfaction. It has also been found in various studies that involving patients' families in hospice care can produce improved outcomes, such as satisfaction for patients and their family. (Canadian Agency for Drugs and Technologies in Health, 2015).

Recommendation for future research

Repeating this study in the future with a larger and more diverse sample would be beneficial to hospice care services in the union. It would elaborate on the various determinants of family members' satisfaction with hospice services and provide information that can assist the hospice industry ameliorate both the quality of care patients and families receive at the end of life and the family member's overall satisfaction with this care. The study could be repeated by involving more hospice facilities to improve the authenticity of the study. There should be a need for measurement strategies to measure the actual comfort level of patient directly rather than by proxy measurements

Conclusion

Family members continue to play significant roles in the care of their terminally-ill loved ones. These family caregivers experience chronic stress unlike their formal counterparts such as physicians and nurses who function in shifts (Bevans et al., 2012). Their work is marked by complex multiple responsibilities, tasks, and their competing priorities, which trigger unrelenting stress. Sometimes, family can acquire health problems of their own due to immune dysregulation. Ensuring that their loved one is given the right attention and timely medication can enhance the comfort of the patient which is important to the wellbeing of the family and support people in the patient's life (Kennedy et al., 2014). Open communication with family members by the hospice health care team about the state of the patient and what is being done to provide maximum comfort for the patient is significant in ensuring that they are satisfied with what the healthcare professionals are doing. A major source of satisfaction for family members is pain relief and comfort for hospice patient, which provides them with a sense of control and peace (Rome et al., 2011).

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Appendix A



This memo provides the notification concerning EU's Institutional Review Board (IRB) determination of the human subjects protocol:

To: Dr. Meg Larson, Principal Investigator
Stephane Sia, DNP student, Co-Investigator

From: Amy McClune, PhD, RN, Edinboro University Institutional Review Board Chair

Protocol # EU 201901

Date Approved: February 12, 2019

Title: Relationship between hospice patients' comfort level and family members' self-reported satisfaction

The EU IRB Chair has designated this committee as reviewer of the application listed above for exempt status. It has been determined that your protocol is categorized as Exempt under federal regulations 45 CFR 46.104(d), since the research design involves the following:

(d)(2) "Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:

(i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects

Exempt protocol means that as long as you continue your research as described in your protocol application, the research does not require any further review or oversight by the IRB. Should you change any procedure within your research, you are required to resubmit the protocol to the IRB for reconsideration and determination before you implement any change. All data must be retained and accessible for three (3) years after the completion of the project.

Designation as exempt signifies that the proposal adequately qualifies under 45 CFR 46.104(d) for such status.

Should you have any questions or concerns, please feel free to contact me at 814-732-2619.

Appendix B



October 31, 2018

To Whom It May Concern,

This letter is to inform you that we, at Amedisys Hospice #5015, are happy to be assisting Stephane Sia with his research to complete his project. This research will begin November 1, 2018. If you have any questions or concerns, please feel free to reach out to me at (410) 392-3750.

Sincerely,

A handwritten signature in black ink that reads "Katelyn Henley, RN". The signature is written in a cursive style with a large, sweeping initial "K".

Katelyn A. Henley, RN, BSN, CHPN, WCC

Director of Operations

Amedisys Hospice

Elkton, MD

Appendix C

RE: FarmCare Scale

Samar Aoun <dr.s.aoun@gmail.com>

Tue 9/25/2018 5:47 AM

To: Stephane Sia <S.N.Sia@eagle.clarion.edu>;

Thanks Stephane. I think you are using the tool in a research project rather than implementing it in routine service practice. I have corrected this in your form. You have permission to use it, and good luck with your study.

Kind Regards
Samar

Samar Aoun
Professor of Palliative Care | Palliative Care Unit
School of Psychology & Public Health | La Trobe University
Bundoora | Victoria | 3086 | Australia
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From: Stephane Sia <S.N.Sia@eagle.clarion.edu>
Sent: Tuesday, 25 September 2018 7:27 AM
To: dr.s.aoun@gmail.com
Subject: Re: FarmCare Scale

Appendix D



Instructions

Think about the care that your family member has received. Please answer the questions below indicating how satisfied you are with the care received: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), or very dissatisfied (VD). Not Applicable (NA) Please circle the letters below that best match your experience.

How satisfied are you with:

1	The patient's pain relief	VS	S	U	D	VD	NA
2	Information provided about the patient's prognosis	VS	S	U	D	VD	NA
3	Answers from health professionals	VS	S	U	D	VD	NA
4	Information given about side effects	VS	S	U	D	VD	NA
5	Referrals to specialists	VS	S	U	D	VD	NA
6	Availability of a hospital bed	VS	S	U	D	VD	NA
7	Family conferences held to discuss the patient's illness	VS	S	U	D	VD	NA
8	Speed with which symptoms are treated	VS	S	U	D	VD	NA
9	Doctor's attention to patient's description of symptoms	VS	S	U	D	VD	NA
10	The way tests and treatments are performed	VS	S	U	D	VD	NA
11	Availability of doctors to the family	VS	S	U	D	VD	NA
12	Availability of nurses to the family	VS	S	U	D	VD	NA
13	Coordination of care	VS	S	U	D	VD	NA
14	Time required to make a diagnosis	VS	S	U	D	VD	NA
15	The way the family is included in treatment and care decisions	VS	S	U	D	VD	NA
16	Information given about how to manage the patient's pain	VS	S	U	D	VD	NA
17	Information given about the patient's tests	VS	S	U	D	VD	NA
18	How thorough the doctor assesses the patient's symptoms	VS	S	U	D	VD	NA
19	The way tests and treatments are followed up by the doctor	VS	S	U	D	VD	NA
20	Availability of the doctor to the patient	VS	S	U	D	VD	NA

Additional comments:

Appendix E

Means

Question	N	Missing Values	Mean
Q1	42	0	4.83
Q2	42	0	4.81
Q3	42	0	4.6
Q4	41	1	4.44
Q5	40	2	4.7
Q6	42	0	4.74
Q7	42	0	4.88
Q8	42	0	4.93
Q9	41	1	4.61
Q10	40	2	4.85
Q11	41	1	4.78
Q12	42	0	4.95
Q13	41	1	4.85
Q14	42	0	4.83
Q15	42	0	4.86
Q16	42	0	4.9
Q17	42	0	4.83
Q18	42	0	4.52
Q19	41	1	4.54
Q20	40	2	4.53

Table 1 presents a summary of the items. Some of the items had missing values. The highest mean of 4.95 corresponds to question 12 whereas the lowest mean value of 4.44 corresponds to question 4.