



Ethical Palliative Family Nursing Care

A New Concept of Caring for Patients and Families

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A B S T R A C T

The practice of nursing has a duty to educate, communicate, and resource patients and families during the period in which the solution to an ethical dilemma is predetermined by evidence-based practice. Clearly, there is a gap in the quality of care provided or the interpretation of the quality of care being provided during difficult ethical situations requiring a systematic change to increase patient and family comfort and satisfaction.

Believing in miracles is something we are taught to do as children, but as we become adults, the impact of scientific evidence and research makes miracles further improbable. Caring for a family experiencing a situation that would require a miracle for survival can be a challenging and emotional task. Physicians and nurses are instructed to follow evidence-based practice and to maintain compassion with a realistic approach. Does the structure of medicine with evidence-based practice eliminate the hope for a miracle? Hope and

faith are 2 components of a miracle. According to the Pew Forum on Religion and Public Life, more than 79% of people still believe in miracles with a study group of 35,556 persons.¹ Healthcare personnel should not deny families the right to believe in miracles, yet healthcare personnel currently withhold resuscitative measures under certain circumstances that are evidence based. Are we denying the family the right to choose interventions in hopes for a miracle even if the outcome may be statistically proven?

The ethical situation presenting the miracle “against all odds” is

relevant to many current healthcare circumstances. Brain death, nonviable preterm delivery, and life-sustaining surgical interventions are ethical dilemmas requiring considerable efforts from the healthcare staff to comfort the patient and families. With the occurrence of these ethical dilemmas

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and others, the nurse's role is metamorphosed into palliative care and providing services to the patient and the family in the palliative family nursing care model this nurse has established: communication, education, interdisciplinary resources, and comfort care/time. These 4 areas work cohesively to impact the emotional response of the patient and family during a time of grief.

The implementation of the palliative family nursing care model into the art of nursing involves the skill to manage the emotions and education of family members as well as patients. Evidence-based practice has introduced new statistical evidence in the use of life-sustaining measures in healthcare many unbeknownst by patients and families. The nurse has a duty to educate, communicate, and resource patients and families during the period in which the solution to an ethical dilemma is predetermined by evidence-based practice. Nurses adequately trained to handle end-of-life care ethical dilemmas can be compassionate and competent in the healing process as compared with the statistically proven 47% of patients and families feeling the end-of-life care they were receiving was uncompassionate.² The completion of research within peer-reviewed journals, government regulation, and theoretical works of nursing presents a gap in the quality of care provided or the interpretation of the quality of care being provided during difficult ethical situations requiring a systematic change to increase patient and family comfort and satisfaction during end-of-life care.

Literature Review

Quality End-of-Life Care

The concept of end-of-life care is more relevant now than ever before with the aging population and economic considerations. The World Health Organization deems palliative care a necessity with the rise of demand for these services universally.³ The efforts to improve the quality of ethical compassionate end-of-life care are restrained by finances and resources as well as in debate regarding the universal approach for the optimal outcome.⁴ Historically, nurses performed clinical assessment of obligations and a moral and cognitive comprehension of the person, as well as the emotional components driving the nurse to act, defining caring with the perception of the situation.⁵ The present-day nurse caring assessment valuably includes the full aspect of the patient regarding family and spirituality. While motivating nurses to recognize all aspects of the patient's needs for patient satisfaction, the accommodating of all requests and the meeting of all medical needs become overwhelming in prioritization. Shiber and Larson⁶ claimed that literature had deemed caring as an outcome versus the means to a better outcome, and focus should move from defining caring to defining the outcomes from the process of caring; the elements of structure and process in caring present outcomes allowing the patient to cope, get personal needs met, and give the perception of being cared for. Shiber and Larson's thoughts are theoretically compatible with the palliative family nursing care model this nurse defines.

Nursing Theory and Caring

Nursing classified as a profession of caring has evolved, yet many theoretical frameworks regarding caring are historical. Theories of caring and models of caring have been introduced into the profession of nursing, only recognizing the interactions with the patient at the present time.⁷ The Humanistic Nursing Theory developed by Paterson and Zderad is analyzed in the work by Wu and Volker⁸ in regard to palliative care. The concepts within the theory develop the effort of presence and serving during palliative care as nurses work collaboratively with the patient to meet goals.⁸ Wu and Volker⁸ acknowledge that nurses play a key role in palliative care as an advocate, and families provide care on a continuous basis. Interaction theorists view nursing as a process of interactions to support patients, yet there are no theories on the social-familial interactions within nursing care.⁷

End-of-life care requires an understanding of the future and the inevitable ethical circumstances of death. Nurses who are capable of preparing the patient and family for this journey can provide a calm, comfortable environment for support and dignity. Theories of caring should be evolved to include family and future regarding the changes in societal need and preventive care. Family is to be included within the caring theory as persons rely on the opinions and comfort provided by them. Family involvement demonstrates an intimate sense of caring during a time in which modesty and integrity are compromised.

Nursing Practice

The need for quality improvement within the education of nurses regarding end-of-life care is based not only on patient satisfaction but also on the perception of care that nurses feel they provide. According to Giovanni,⁹ changes in nursing education are deemed necessary to encourage advocates and expert nurses for end-of-life care. Literature demonstrates an increased stress level by the nurse caring for the palliative care patient.¹⁰⁻¹² Peterson et al¹² provide a nurse's perspective in the background for the significance of a change in practice. Issues determined to be significantly impacting the implementation of end-of-life care in the study of Peterson et al are as follows: expectation to care for the family as well as the patient, challenges when trying to provide adequate comfort care regarding time and communication challenges, and discussion of the specific aspects of caring for a dying patient with concerns regarding mediating between the family and the patient's needs.¹² Throughout the study by Peterson et al,¹² the concepts of the palliative family nursing care model are mentioned with recommendation for communication training programs.

Palliative Care Teams

The Center to Advance Palliative Care and the End-of-Life Nursing Education Consortium are in agreement that the

team outcomes of palliative care are more productive by providing time, expertise, communication, and coordination.¹³ These organizations and others have recognized the societal need for intervention in end-of-life caregiving. The National Quality Forum developed a list of 38 preferred practices in hospice and palliative care for healthcare settings.¹⁴ The Affordable Care Act of 2010 allows aggressive treatment of illness, with palliative care services providing long-term interdisciplinary benefits.¹⁵

Although it is not mandatory to have palliative care teams within the United States, individual states may require palliative care teams as organizations are highly recommended to implement teams to improve consumer satisfaction with cost efficacy. According to the publication by the Center to Advance Palliative Care, "America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals," the District of Columbia and Vermont have 100% participation with palliative care programs.¹⁴ The average scores for America's state participation in palliative care teams are between 61% and 80% of facilities and significantly vary by geographic location.¹⁴

Palliative care teams include a medical team of doctors, nurses, interdisciplinary departments, family, and patient. This team provides comfort during the stress of serious life-threatening illness to improve the quality of life for the patient and family.¹⁴ Focus remains on individuals with chronic or complex health for palliative care consults. Personal experience indicates that a person with rapidly declining health based on urgency or trauma may not have adequate time for a consult and the benefits provided for the family. The events with no expectation of discharge or improvement of health increase the nurse's role in priority for palliative bedside care. In meeting this need, South Australia developed a Palliative Care Nursing Fellowship allowing research and evaluation of current palliative practices to be examined and amended.¹⁵ Caple¹⁶ states that nurse-led palliative care teams are more effective as the nurses spend more time with patients and families than are other healthcare professionals enabling them to ascertain situational needs.

Palliative care teams are functional with adequate awareness and effort for chronic illness.¹⁷ Nurses play a major role in the implementation and execution of palliative care referrals and care, yet all circumstances do not allow for the opportunity. Formal education is necessary to inform nursing staff of all available palliative care options.

Patient and Family Perception

According to Sherman and Cheon,¹⁸ "The burdens of family caregiving include time and logistics, physical tasks, financial costs, emotional burdens, and other health risks." This being said, the response to the stressors listed are manifested into potential anxiety and anger that can then be displaced onto nursing staff. The Family Caregiver Alliance is an advocate for legislation for caregivers as well as a valuable resource for chronic illness coping skills.¹⁹ A resource missing regarding caregiving is support for the

extended family in supporting the immediate family with grief, anger, anxiety, and feelings of helplessness. A mother who experiences the loss of a child needs not only her coping mechanisms but also those of her extended family.

The nurse being the primary caregiver is exposed to these emotional needs and concerns requiring skills in knowledge and communication. The pertinent fact is that nurses are the frontline for patient and family advocacy and should be properly trained for end-of-life ethical situations and care.

Palliative Family Nursing Care Model

Communication

According to John Costello,²⁰ senior lecturer in palliative care, University of Manchester, respectful deaths are focused on the wishes of the patient and family, with shared control over decisions with communication that is informative, truthful, and open. Open communication is essential in any aspect of nursing but most critically during end-of-life care with accommodating the patient's wishes. Assessments are completed upon admission with patients and families to ensure that the proper language, education level, and learning methods are utilized throughout hospitalization. In understanding the patients' and families' learning styles, communication can be done with ease. Nurses exemplify both verbal and nonverbal communication styles to be effective in communicating with the patient and family in times of distress.

Verbal communication allows for sharing emotion and concerns in the time of ethical stress. The patient and family may not understand the medical circumstances and the statistics influencing the outcome. The nurse should speak in a soft tone with clear articulation of words as many activities will be taking place at once. Discuss one topic at a time while facing the family to enhance the comprehensibility of the situation. Maintain eye contact and be repetitive of pertinent information. The family may be distracted by medical care, and it is best to approach the family while not completing other tasks. Listening is the most effective form of communication at this time.

Nonverbal communication is more effective in regard to demonstrating care and compassion. The nurse should use calm and smooth actions in caring for the patient. Families get intimidated and defensive with abrasive actions and will have difficulty building rapport. The nurse should maintain an open pose while listening to the patient's and family's needs without distraction. Sitting with the patient and family allows for an open approach of communication. In circumstances of death, the nurse can and should demonstrate signs of grief as applicable. Crying with the family during a loss is humane and demonstrates compassion. The nurse should maintain the duty of caring for the patient and family, yet should also go through the grief process as being a caregiver.

Education

Methods of teaching during distress are contrary to the standard methods on a routine basis. Distress increases the urgent need for clarification and triggers the autonomic nervous system, making the situation more sensitive. The nurse must maintain the priority to keep the patient and family safe if medical care is required. The nurse must gain control over the room in a respectfully assertive manner if the room is loud or chaotic. At this time, the nurse is able to collect the thoughts of the patient and family regarding the ethical dilemma they are confronting. The nurse should ask open-ended questions regarding the ethical dilemma to assess the patient's and family's awareness of the issue. Open-ended questions to the family would include the following: Can you explain to me your loved one's condition? Can you explain why your loved one is on life-sustaining measures? Listening is pertinent to educating just as in communication. The read-back-and-verify learning is most productive.²¹ The skills of communication are complementary to educating the patient and family.

Adequate assessment of the families' knowledge provides a detailed structure to their learning needs. The family may only be aware of myths and legends versus facts and statistics. The family has an emotional response to the outcomes of their loved one and may respond with disbelief and skepticism. The physician educates the families on the rationale for the lack of further medical intervention, and in practice, the nurse is continuing to educate the families as they are unable to retain the information. The physician may verbalize statistics and research, but for many families, the language is too advanced and causes confusion. The nurse is a valuable resource for the family in providing "layman's terms" to interpret statistical evidence. Nurses provide the family with pamphlets or handouts regarding these difficult medical conditions and outcomes. Pamphlets provide a reference for the family and a place to write any questions or thoughts, and in the event of a longer process, a journal may be useful for the family. After giving the information to the family, the nurse should give them time to reflect on the information and the implications for their loved one. The nurse should then return to the room to answer any questions or concerns. The education process should be intermittent and repetitive to improve retention and application. The family must understand that the intentions of the medical professionals are for beneficence.

Interdisciplinary Resources

Nurses should be aware of the available resources for ethical end-of-life care dilemmas. Medical facilities must make a priority in maintaining resources for nurses, patients, and families when an ethical dilemma has been identified. The most common interdisciplinary resources include palliative care committees, grief counselors, social workers, hospice, and religious clergy or spiritual persons. These resources are educated on medical conditions and

statistical evidence inducing these circumstances and how to properly provide care and comfort.

The initiation of palliative care committees within health-care facilities reinforces the critical need for advancements within this level of caregiving and the impact on patient care. Palliative care committees reach out to families during end-of-life care with information on support and funeral preparation. Availability of this committee may be limited to weekdays during the day so the nursing staff must continue to be knowledgeable in this scope of practice. Folders with applicable information provided by the palliative care team should be available at all times.

Grief counselors are another resource in many health-care facilities. Grief counselors work within the palliative care process and are present within the palliative care committee. Progression through the stages of grief in an unforeseen experience is traumatic, and a grief counselor can assist the patient and family throughout this time. Grief counselors and social workers are resources on state law regarding postmortem care and transport.

Social workers are a resource for outpatient services and advance directives. The family should discuss code status with the physician, and advance directives should be formatted with assistance of a social worker. Nursing is also responsible to provide advance directive information in the absence of a social worker. Social workers refer families to available resources for legal information and work collaboratively with hospice for referrals of applicable patients. Clarity in the expectations of end-of-life care of the patient aids the family with anxieties regarding decision making.

Hospice provides both inpatient and outpatient services to patients and families facing mortality. Providing equipment and nursing care enables the families to have the needed environment for their loved one. Nurses must remember that hospice is not the only responsible caregiving team to provide adequate comfort care. Hospice care in the inpatient setting is not a validated reason for the hospital staff nurse to not provide bedside care. Efforts/comfort care should be provided by both care teams within the limitation of treatment.

Chaplains provide care for the spiritual needs of the patient and family during distress. Religious preferences should be assessed by the primary nurse, and the appropriate clergy/spiritual referral should be made. The patient should be presented with the decision for religious and spiritual services in order to maintain an ethical integration within end-of-life care.²² The nurse may choose within his/her comfort to also join in the clergy/spiritual practices. End-of-life religious services are respected and uninterrupted. The nurse should refrain from medical tasks to convey respect and dignity to the patient when spiritual practices are performed.

Comfort Care/Time

The primary nurse and charge nurse should be available for all needs by being an advocate in rapport and comfort. Minimize staff for comfort of the family and situational

awareness of the staff. A symbol on the door of the room notifies interdisciplinary staff of the patient's circumstances. Staffing needs are accommodated to aid the caring unit in respecting nursing hours devoted to this patient and family. Comfort care includes caring for both families and the patient potentially requiring more nursing care hours be provided.

Resources should be provided to the patient and family such as pertinent phone numbers and available food and lodging. Available waiting rooms and hospital services should also be discussed. A small task of providing tissues for crying family members is a significant sign of compassion and caring. The family dynamics can be overwhelming for a nurse, and it is important to understand limitations. Providing the families with tasks to assist and comfort their loved one helps the grieving process. Tasks such as handholding, oral care, and providing a serene environment are applicable. The nurse encourages the family to talk to the patient, and favorite memories can stimulate a response from a subdued patient.

Nursing care should continue to be provided by making the patient comfortable and maintaining their dignity. The continuation of bathing, oral care, shaving, nail trimming, and hair care demonstrate respect for the person, and the family can identify with these needs. Maintaining medication therapies for pain and anxiety is essential in the comfort of the patient and should be administered utilizing physician order and nursing judgment. Nurses should discuss their actions to the somnolent patient even if the family is not present.

Time is precious to the patient and family during these ethical situations and should not be invalidated by administration. A mother may have only minutes with her newborn previsible baby. The nurse should not feel rushed in caring for these patients and should have adequate time allotted for all tasks. Families recognize hasty actions and refrain from asking questions or asking for things they need, producing the interpretation of uncompassionate care.

Implementation

Proposed implementation is meta-analysis research by survey preimplementation and postimplementation of the palliative family nursing care model in end-of-life care. A meta-analysis approach is determined to be appropriate by survey when conducted with the sensitivity to avoid distress to the family.²³ The sample group is composed of the contact person as listed in demographics by the hospital. These individuals will be mailed a survey and choose to participate by completing and returning. One family member from each deceased patient who received end-of-life care in the facility of choice should be surveyed. The sample group risks of bias are small sample group, emotional considerations, and time in which the survey was received after loss. A psychologist should be consulted to choose an adequate time for mailing as the grief process may bias results.

The quantitative approach to the research questions: do family members feel the nursing staff is compassionate to their needs when a death has been predetermined by evidence-based practice; how do family members perceive end-of-life care given by nurses, and how does this impact their recommendation of the care facility, includes data and statistical evidence. The hypothesis is: The implementation of the palliative family care model during end-of-life care will significantly improve satisfaction of care as perceived by the family of those deceased. The null hypothesis states that there is no statistical correlation between the implementation of the palliative family care model during end-of-life care and the families' stated satisfaction of care.

The data collected are discrete as the sample group will be limited, and the measurement of the satisfaction of care utilizes the Likert scale numbers 1 to 5 on a scale. The independent variable is the use of the palliative family care model by nursing staff during end-of-life care, and the dependent variable is the satisfaction of comfort care as assessed by survey from the family. Ordinal data are retrieved from the survey as no numerical intervals or data are obtained. The numbers on the Likert scale indicate a perception from the individual as poor, acceptable, or excellent. The palliative family care model will be assessed with the scale from 1 to 5 in survey format with 3 chosen open-ended questions at the completion. The 3 open-ended questions for qualitative data would include the following: Please indicate specific actions you perceived as caring from the nursing staff during the end-of-life care provided. Please indicate specific actions you perceived as uncompassionate from the nursing staff during the end-of-life care provided. Would you recommend the facility and the care provided to others after your experience?

Inferential statistics are used to process the data obtained. Data collection from the survey would then be calculated into the measures of central tendency mean and mode. This data are useful in understanding the sample group and the overall interpretation of care provided. The mean provides an understanding of the average score given for end-of-life care. The mode suggests the most common score for each concept of caring. Second, statistical correlation using the Spearman rank test would enable an understanding of the palliative family care model in end-of-life care to family satisfaction. The Spearman rank test is chosen for the ability to process ordinal data with one sample group including an independent and dependent variable.²⁴

Analysis of the data includes, most importantly, the perceived satisfaction of end-of-life caring provided by nurses from families of those deceased. Literature review provided a gap in the knowledge regarding the interpretation of end-of-life care by families. Secondly, the analysis correlation of implementing the palliative family care model by nursing versus the families' satisfaction of care of determined. The correlational study would indicate either a positive or negative response to the new best practice in caring during end-of-life ethical dilemmas. The analysis of data will present indications for future research. The data may imply

the need for further study in specific aspects of caring such as the palliative care team and the relationship with nursing staff. Future studies would be indicated providing details on the palliative family care model with further development of the hypothesis.

Objectives

1. Increase awareness of ethical decisions predetermined based on evidence-based practice in nursing.
2. Identify the learning needs of nurses regarding keeping rapport and respect for the patient and family during end-of-life care in ethical dilemmas.
3. Research the interpretation of nursing care provided during end-of-life care from families of those deceased.

Quality Improvement of Patient/Family Satisfaction, Productivity

End-of-life care experiences carry with families for decades. Although negative experiences tend to be verbalized more than the positive experience, the reputation of the medical facility can be validated by excelling in this area of care. Consumers deserve respect and dignity during end-of-life care, and demonstrating these values will increase facility productivity by maintaining a positive reputation within the community. The financial reward becomes apparent with maintaining a client base, managed care, and full reimbursements from insurance companies for service excellence and patient/family satisfaction.

Summary/Conclusion

Nurses need quality improvement education within the scope of end-of-life care specifically when the outcome of the patient is predetermined by statistical evidence. Families interpret medical care as linear to statistical evidence disregarding the aspect of spirituality and faith. Verifying the family's feelings and gaining insight by survey will improve the nurse's ability to care for patients and the family's care experience. The palliative family care model is objective and generalizable including both patient and family needs recognizing not only the present but also future care by healthcare providers during a difficult ethical situation.

Theorists have evolved caring into many forms yet have neglected to include the social impact and the social expectation for satisfaction in today's society. The healthcare facilities deem end of life as discharge from the facility, yet the family continues a perception of care from their experience. A positive end-of-life care experience will allow comfort to the family and improve the reputation of the healthcare facility.

Standards of care in healthcare have changed and so should the definition and role of caring in nursing. Many

authors have discussed needing a better structure and plan for ethical end-of-life situations; however, few have developed a plan for implementation and evaluation. Palliative care teams are a resource, not a replacement for inpatient nursing care verifying a need for the palliative family care model. Patients and families rely on nurses as hope for a miracle lies within.

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