Acute Care Nurses' Experiences of Basic Palliative Care

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As the population of chronically ill, older adults increases, there is a growing need for palliative care. The Institute of Medicine recommends that health care providers have a basic competency in palliative care. However, the definition of basic palliative care in practice and providers’ understanding of basic palliative care lack clarity. The purpose of this study was to describe nurses’ perceptions of basic palliative care in the acute care setting. This was accomplished by conducting focus group and individual interviews. The major themes of helping families navigate chronic illness and empowering families and subthemes of being present, giving options, and advocating emerged from the analysis. Through education and role modeling, nurses helped families navigate illness and end-of-life experiences. Study findings describe acute care nurses’ perceptions of basic palliative care and may help to identify the educational needs of nurses in order to provide basic palliative care for patients and their families in acute care settings.

KEY WORDS
acute care, basic palliative care, hospital, nursing, palliative care

EIGHTY-ONE PERCENT OF AMERICAN ADULTS OLDER THAN 65 YEARS HAVE MULTIPLE CHRONIC HEALTH CONDITIONS.1

BACKGROUND
Basic palliative care, sometimes referred to as generalist or primary palliative care, is palliative care provided by health care providers who do not have specialized training in palliative care.5 The National Consensus Project (NCP)6 has updated the guidelines for quality palliative care to include how generalist providers can meet the needs of palliative care patients. The domains within the NCP’s6 guidelines include the structure and processes of care; the physical, psychological, social, spiritual, religious, existential, cultural, ethical, and legal aspects of care; and care of the patient nearing end of life. The newest edition of these guidelines specifically encouraged all providers, including nonspecialists, to utilize the domains in “routine assessments and care of all seriously ill patients.”6 The IOM5 and NCP6 agree that generalist health care providers, including nurses, should have competency in palliative care while specialist palliative care providers be utilized in complex patient cases.

Additionally, the American Nurses Association7 has called on nurses to lead the transformation of palliative care in all areas of practice, research, education, and policy. The American Nurses Association7 recommends that every nurse practice basic or primary palliative care regardless of the setting they work in. Basic palliative care can be provided in various settings by nurses and other health care providers.

There are few studies that directly address acute care nurses' experiences of BPC in the hospital setting.8-10 The literature does address nurses' limited knowledge of palliative care11 and lack of confidence in palliative care skills12,13 as barriers to optimal care in a variety of settings. Other barriers include confusion about the definition of palliative care.

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The author has no conflicts of interest to disclose.
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DOI: 10.1097/NJH.0000000000000622

Journal of Hospice & Palliative Nursing

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care, subjective referral criteria associated with a limited life expectancy, lack of training in BPC, and a curative culture. All of these barriers impact acute care nurses’ ability to provide routine BPC.

THEORETICAL FRAMEWORK

Transformative learning theory applies experience, reflection, and dialogue as a way to understand social processes and to uncover knowledge informed by frames of reference. These components were utilized to gain knowledge about acute care nurses’ experiences of BPC in the acute care setting. Nurses shared and reflected upon their experiences of and role in providing BPC and the impact of BPC on patient and family care. In this study, nurses participated in focus group interviews, which allowed them to dialogue with other nurses with similar experiences.

METHODS

Design
The aim of the study was to describe acute care nurses’ perceptions of BPC. Therefore, a qualitative approach provided a means to gain an in-depth understanding of BPC as experienced by nurses.

Setting and Sample
Nurses were recruited from 1 health care organization that included 3 acute care hospitals in a Midwestern state. The inclusion criteria for this study were registered nurses who (a) currently worked in an acute care setting; (b) cared for adult patients; (c) could read, speak, and understand English; and (d) held any degree that allowed them to work as registered nurses. Nurses were recruited through employee emails, flyers, social media, and word of mouth.

Data Collection
Institutional review boards at the university the researcher was affiliated with and the organization from which the participants were recruited approved this study. Focus group and individual interviews were used to gather information on nurses’ experiences of BPC in the acute care setting. Nurses were invited to first participate in focus group interviews. Individual interviews were then conducted to ensure saturation and validate the data collected in the focus group interviews. All interviews lasted between 60 and 120 minutes. Participants provided written consent prior to the interviews.

A semistructured interview guide was used for both types of interviews (Table). A pilot focus group interview was utilized to refine the interview questions; this interview provided meaningful data that were included in the final data analysis.

At the start of the interviews, nurses were asked to define palliative care and then BPC. Following the participants’ discussion of definitions, the definition of palliative care and definition of BPC were shared with the participants to help nurses think about and share their experiences within the context of these definitions.

Data Analysis
All interviews were audio recorded and transcribed by the author. A thematic approach was used to analyze the transcripts. Transcripts were reviewed multiple times by the author to discern and revise emerging themes. Focus group interviews and individual interviews were analyzed individually before the process of indexing and sorting described by Ritchie et al was used to organize themes and subthemes. Sections from all the transcripts were sorted into a matrix, so data related to the identified theme could be further reviewed for consistency.

Credibility, transferability, confirmability, and dependability ensured trustworthiness in this study. Member checking was a strategy used for credibility. Participants volunteered to review a summary of the data analysis following the completion of the focus group interviews. Two randomly chosen volunteers confirmed the accuracy of the summary. Triangulation, using both focus group and individual interviews, also added credibility to this study. An in-depth collection of data and the data collection process, utilizing field notes, provide transferability. Confirmability was achieved through the use of audit trails and the use of direct quotes in dissemination of the results. Another qualitative researcher reviewed the design, process, transcripts, and themes throughout the course of this study to enhance dependability.

RESULTS

Sample Description
The study involved 7 focus group interviews (n = 26) and 8 individual interviews for a total of 34 nurse participants. Focus group participation ranged from 3 to 6 participants per group. Fourteen nurses (41%) in this study had 6 to 15 years of nursing experience, and 15 (44%) held a bachelor's degree in nursing. Thirty-two participants (94%) identified as female, and 26 (76%) were between the ages of 30 and 56 years. Twenty-eight participants (82%) identified their race as white and 6 (18%) as persons of color. Participants worked in a variety of specialties including oncology/hospice, orthopedic/medical-surgical, neurology/medical-surgical, float pool, and cardiac/telemetry. Half of the participants (n = 17) had not received formal education in palliative care. Seventy-one percent of the nurses (n = 24) answered yes to having a personal experience with palliative care. Nurses described “personal experience” as caring for patients or their own family or friends in an open-ended question.
Major Themes
Two major themes and 3 subthemes emerged from the participants’ description of their experience with BPC: helping families navigate chronic illness and empowering families with subthemes of being present, giving options, and advocating. Families are part of the unit of care in palliative care, and it was evident from the participants’ responses to questions about their experiences with patients that a focus on families was central to their nursing practice.

Helping Families Navigate Chronic Illness
The theme of helping families navigate chronic illness describes how nurses viewed their role in providing palliative care in an acute care setting. Nurses described helping families and patients navigate through a chronic disease process or end-of-life experience by using education and role modeling. Nurses described educating patients and families on different types of care, decision making, and how family can participate in the care of the patient.

Nurses also discussed what palliative care could be in relation to educating patients and families. One nurse described what a course of illness could look like by stating, if you're starting palliative care at the time you're getting a diagnosis and it's going to progress in a certain fashion, I feel like if you're educating the family... I feel like if you're cradling the family along with palliative care, you're telling them this is what you're going to see, and this is where it's going to go and you see those things, it's not as scary or it's expected, it's not such a big dramatic turn for the family or for the patients themselves.

This quote described the role of nurses in educating the families and patients about appropriate expectations for the trajectory of the disease, which is an important component of palliative care.

Nurses guided families as they were required to make decisions for the patient. Determining whether the patient and family had ever discussed the patient's wishes was a way of taking the burden off the family by trying to help them to execute what the patient would have wanted. One nurse felt this guidance role was necessary “because... I feel like families are facing this massive decision of I'm killing my family member.”

In end-of-life circumstances, nurses shared that “families sometimes... just do not know how to interact with the person anymore, so I think we have to lead them through that as well.” One nurse described teaching family members a relaxing hand massage technique and found that “really makes them feel good that they can do something to help him or her.” Another nurse advised families to “continue to hold their hand, talk to them, to share memories, and as a family... [share] stories, thank them... also letting them know you are going to be okay when they are gone is important.” This nurse's guidance illustrates how BPC extends to the family in end-of-life situations.

In situations where a palliative care team was consulted, a nurse noted that specialists initiate education about the disease and role of palliative care, while the role of nursing staff was to reinforce this education during the remainder of the patient's hospital stay. Other nurses felt that one way to educate and help families navigate was to “translate from doctor speak.” Nurses in this study often shared their role in answering questions after a physician had told patients and families something about the illness. When nurses were unable to answer the patient's or family members' question, they advised them to write down those questions for the physician.

### TABLE Semistructured Interview Guide

| 1. (Describe purpose of study). Tell me how you define or describe palliative care. |
| 2. How do you define basic palliative care? |
| 3. (Introduce World Health Organization [WHO] and Institute of Medicine [IOM] definitions. WHO definition: specifically highlight applicability of palliative care [PC] early in illness trajectory and that this aspect is what I’d like to talk about today. IOM definition: introduce basic PC definition, identifying that those described in the definition are all of us.) |
| 4. Thinking about the patients you care for day to day, tell me about how these definitions of palliative care can be applied to your patients and your nursing practice. |
| (Summarize key aspects of palliative care they may have mentioned in their examples.) |
| 5. Tell me about other aspects of palliative care that you feel comfortable including in your nursing practice. |
| 6. What areas do you feel you’d like more education on in order to integrate a palliative approach into your practice? |
| (Summarize education needs discussed.) |
| 7. How would you prefer to receive more education on these topics? |
Helping families navigate chronic illness entailed nurses using a variety of strategies to support the patient and family through this process. Nurses described their role and its contribution to palliative care as educating patients and families about appropriate expectations, guiding families in decision making, role-modeling interactions at the end of life, and improving communication with specialist providers. These are all important components of BPC.

**Empowering Families**
The theme of *empowering families* describes nurses' perceptions of palliative care as giving options, being present, and advocating. The first two subthemes, giving options and being present, applied to both patients and their family members, whereas advocating referred to how nurses helped advocate for the patient with families and other health care providers.

**Giving Options.** The subtheme of giving options describes how nurses help patients and families see all their choices. These options described supporting patients and families by keeping them informed not only about the options available, but also about what was happening with the patient and what could be expected in the course of illness or end-of-life experience. Nurses thought they could support patients and their families by keeping patients and families informed not only about options, but also about what was happening with the patient and what could be expected in the course of illness or the end-of-life experience. One nurse described it as “kind of giving power back to the family so they are involved, they do not feel, you know, run by their disease or something…” Another nurse described a situation where an older adult patient was deciding whether to have a feeding tube placed. The nurse knew that the patient was the main caregiver for his spouse and that this was the motivator for the feeding tube. The nurse said, “I looked at him. I said you know you can get the feeding tube, but you can decide when to stop using it. Letting him know yes you can have this option….”

One nurse felt he might be crossing a line when he informed a patient about the option of requesting a different doctor when the patient's pain was not being adequately managed. The nurse said, “I felt I was doing a disservice if I did not tell them that they have that option to make that request.” The nurses in this study thought that patients and families do not always know the extent of all their options; the nurses determined it was their job to make patients and families aware of all available options.

Finally, another nurse expressed that not offering the option of palliative care in a timely fashion was an injustice to patients. This nurse believed that patients, as well as staff, were not well educated on the difference between palliative and hospice care, and staff did not offer palliative care soon enough or provide education on the difference between palliative and hospice care. The result of this as described by this nurse was that providers were not considering the quality of life but focusing solely on the quantity of life.

**Being Present.** The second subtheme of empowering families was being present with patients and families. Nurses described being present as a way of empowering patients and families in a way that created a space for them to open up or talk about their situations if they chose to do so. At times this meant “just being quiet with them.” Being present and acknowledging the needs of another are often an emotional experience. One nurse described patients needing someone to hold their hand, and as this nurse spoke, he held another participant's hand to demonstrate this simple action. He went on to say, “Sometimes… we just hold your hands… that's just only what they needed at that particular time, you know hold your hands… they be able to pour out their mind.” Another nurse shared “just being there talking to him and understanding him, why he was feeling the way he was… when he finally opened up to me, he cried, and it made me cry too.” When relaying this story, the nurse started to cry.

Other nurses described being present for family members after a loved one had just died or was actively dying. One nurse shared an experience she had with a patient who was actively dying. She went in the room to do her charting, so she was available to the family. The patient's husband “started telling me the day that he fell in love with her, you how they'd gone to a dance… I think he was just so much at peace and felt really supported…. because we made time for them.” The nurse became tearful as she told this story. Another nurse told how just sitting with a suddenly widowed wife for an hour was central to support that family member. Nurses talked about how family members thanked them for being there and hugged them after their loss.

**Advocating.** Being an advocate for patients is a basic role of nursing. Not surprisingly, nurses in this study discussed advocating for their patients as part of their role in BPC. Nurses described advocating for patients in regard to decision making, pain control, and end-of-life decisions. One nurse explained this aspect of palliative care as follows:

…trying to be more so on the patient's side when you have all those doctors and family and whatever, looking at you
going “We want you to live, we want you to do this.” And it’s just you and [the] patient on the other side going “Nope this is what she said she wants.”

The nurses indicated at times that family members did not understand the patients' wishes or were afraid of losing their loved one. In these cases, nurses considered that it was their job to stand by the patients and support their decisions despite having family and other health care members urging the patient in one way or another.

Other nurses described themselves as a buffer or go-between for the providers and patients. Nurses depicted providers who were insistent that patients should undergo surgery or procedures, putting nurses in the position of being the voice for the patient who was saying no. In some cases, they were successful; in others, they were not. One nurse described a patient who was competent and clear about her wishes to be comfortable and forego any procedures. The physician was persistent. The nurse explained how she felt “like you are the middleman a little, trying to ease the path I mean, especially for advocating for my patient's wishes that were so clear and strong and that can be really uncomfortable and hard.”

Pain control was another topic discussed when nurses talked about advocating for their patients. Nurses were very comfortable reaching out to physicians to adjust pain medication regimens to help alleviate pain for patients. Sometimes, this was an easy task, and at other times, it was not. One nurse shared, “So I kept advocating for the patient, you know, the doctor was kind of stonewalling him.”

Nurses discussed how they could more easily advocate for patients when there was a clearly written advanced directive. One nurse described an advanced directive as a way to help the family come to terms with the patient’s wishes. The nurse stated, “We were able to point to this, and the daughter said, “OK I realize now that all the treatment I’m seeking is for me and not for her.” Other nurses revealed that patients talked with nurses about family not understanding their decisions, and a patient told a nurse “tell them to let me go.” Advocating for patients is part of nursing that involves supporting patients’ wishes even when family or health care providers do not always agree or understand the wishes of the patient.

**DISCUSSION**

In this study, nurses were asked to discuss their experiences regarding BPC in their nursing practice. Palliative care can be initiated at diagnosis and continue through to end of life. Many of the nurses in this study described situations in which a patient was at or nearing the end of life. By using the techniques of transformational learning theory, nurses in this study had the opportunity to share experiences, reflect, and dialogue with other nurses in the context of BPC. Many nurses expressed a realization of their role in providing BPC and believed that they were already practicing BPC without having an official name for it.

Nurses described how they help families and patients as they navigate end of life. Nurses described how education was a key aspect of helping families and patients understand what was happening and what would happen in the future based on their nursing experiences. The results of this study are similar to another study where the nurse’s role was identified as support to the family of a dying patient and to ensure the family could be with the patient. Participants in Caswell and colleagues’ study described the nurses’ role as supporting families after the physician has delivered news about the patient’s condition and putting that information into language that was understandable for the family. Nurses in the current study described similar experiences of translating “from doctor speak” and being available to support the family once the physician left the patient’s room.

The standards of palliative care include family in the unit of care. Caswell et al identified family as an important aspect of caring for patients receiving palliative care. Factors such as uncertainty, an unfamiliar environment, limited interaction and relationships with health care providers, and inadequate communication contribute to the family’s concerns and coping ability. Nurses in this study clearly described how families were included in their nursing care of patients at end of life. They also supported families’ desire to be present with their loved one by modeling how to participate in the patient’s care.

Nurses in this study described empowering patients and families by giving options. Nurses provided options to patients and families in order to help make decisions or to help them consider options that were not communicated by physicians. The standards of palliative care state that educating patients about options and decision making is part of the health care providers’ role. Selman and colleagues’ ethnography identified that poor communication and lack of information prevented older adult patients from taking an active role in decisions about care and the future. Conversely, effective communication between health care providers and patients facilitated patients to make informed decisions about their care. Most nurses in this study felt obligated to offer and explain options to both patients and families so they were fully informed to make health care decisions.

**Being present** was described by nurses as being in the here and now with patients, allowing patients the opportunity to express themselves or for families to share stories about their loved ones. These results are consistent with the findings of Robinson and colleagues’ integrative review, which demonstrated how families felt cared for...
when nurses were attentive, approachable, friendly, and regularly checked in. Many theories of hospice and palliative care include the concept of nursing presence.\textsuperscript{25} Presence was described as listening, using self, and being authentic with patients and families.\textsuperscript{26} Nurses in this study shared experiences of being quiet with patients to allow them to talk if they wanted to talk or to just be with another person in silence.

**Advocating** for patients was sometimes very difficult for nurses, and at times nurses suspected that they were stepping over the line with other providers. Yet, nurses thought it was their duty to stand by patients and support their wishes when other health care providers and family were pushing for further treatment options. Advocacy is an essential responsibility for all nurses. Studies report that nurses working in palliative care situations value their role as patient advocates.\textsuperscript{27,28} Nurses in the current study reflected advocacy by taking on the responsibility to side with patients when their wishes and preferences conflicted with that of physicians or family members. Nurses felt that when there was a conflict between the patient and the family, it was likely attributable to the family’s fear of losing their loved one.

**Limitations**

A key limitation of this study was the participants’ homogeneity. Seventy percent of the participants were from 1 of the 3 hospitals, and 47% were from an orthopedic medical-surgical unit. All nurses who participated in the interviews had experiences with caring for patients at the end of life. These experiences highlight the need for all nurses to have competence in BPC regardless of the type of setting they work in. Americans older than 65 years have multiple co-morbidities,\textsuperscript{1} which increase the complexity of care that is provided anywhere in the health care system.

Most of the participants identified as female and white. The ethnicity and gender of nurses in this study reflect nurses in the state in which the study was conducted; however, this limitation highlights that ethnic minority nurses’ perspectives and experiences are underrepresented.

Nurse managers were excluded from this study because it was the researcher’s belief that nurses might be more comfortable talking about experiences without a supervisor present. Unknown to the researcher at the time, one nurse manager did participate in a focus group interview. This deviation from the institutional review board protocol was reported to both institutions that approved the study. The inclusion of the data obtained from this focus group was discussed with other expert researchers and was determined to be valuable as it did not seem to inhibit other nurses from fully participating in the interview.

Lastly, data were not collected in a way that allowed for experiences related to how long the nurses worked in their current position or if there were differences between the levels of degrees that the nurses held to be analyzed.

**Implications for Practice**

Nurses in this study address many domains of the NCP’s\textsuperscript{6} guidelines for quality palliative care. However, there are some areas in which the nurses in this study did not feel confident in or did not discuss in the interviews, such as symptom management beyond pain, discerning differences between palliative and hospice care, and when hospice is appropriate. In addition to NCP’s\textsuperscript{6} guidelines, the American Association of Colleges of Nursing\textsuperscript{29} and End-of-Life Nursing Education Consortium\textsuperscript{30} can guide educators of nursing students and practicing nurses in ways to build competency in palliative care. Nursing assessment tools, such as the CARES tool,\textsuperscript{31} exist to aid nurses in symptom assessment for patients at end of life.

Further education on how to move families more in line with the patients’ wishes may be a better strategy for nurses to adopt rather than siding exclusively with the patient. Denham\textsuperscript{32} elaborated on the term “think family” by explaining that family-focused nurses consider the family and patient as one unit and understand that family influences patients. Considering the family as a unit and attempting to bring 2 opposing sides together rather than standing firmly to 1 side may be more beneficial for both the family and the patient.

**CONCLUSION**

Nurses in this study described their experience in caring for palliative care patients in the acute care setting. The descriptions of care fulfill many of the goals set out by the NCP.\textsuperscript{3} However, nurses in this study fall short of providing BPC to the full extent of NCP’s\textsuperscript{6} domains. Specific areas where acute care nurses could strengthen their BPC practice are in palliative assessments and care planning, symptom management beyond pain, psychological assessments and recognizing when mental health specialists are needed, family-focused care in times of conflict, and recognizing when a patient would benefit from hospice earlier in the illness trajectory. The American Association of Colleges of Nursing’s\textsuperscript{29} guide for schools of nursing can aid acute care nurses in refining symptom management that could benefit patients and their families.

**References**


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