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# Oncology Nurses' Personal Understandings About Palliative Care

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**A**lthough palliative care is becoming increasingly available, many factors limit who receives palliative care and the timeliness of its receipt. Among the most important barriers are inadequate numbers of trained providers and inaccurate understanding of palliative care (Foley & Gelband, 2001). Too often, palliative care is understood as limiting options available to the patient and family, rather than as the utilization of optimal clinical knowledge and tools to improve patient care (Ferrell & Virani, 2008). Palliative care frequently is perceived as care for people who have "failed" medical treatments (Sesterhenn, Folz, Bieker, Teymoortash, & Werner, 2008) and often is equated with end-of-life care (Paice, Ferrell, Coyle, Coyne, & Callaway, 2008; Reinke et al., 2008). Of greater concern, palliative care interventions are sometimes understood as hastening death, albeit inadvertently (de Veer, Francke, & Poortvliet, 2008). These perceptions of palliative care limit opportunities for optimal care of patients and families.

Nurses spend a great deal of time with patients and are well situated to affect patients' care and outcomes (Coyne et al., 2007; Kirchoff, Beckstrand, & Anumandla, 2003). Oncology nurses, in particular, have a major role in the essential care of patients across the course of their disease (Willard & Luker, 2005). Patients with cancer often have a great symptom burden because of the nature of the disease and the consequences of treatments, despite the substantial potential for managing those symptoms (Foley & Gelband, 2001). The purpose of this study was to explore the personal understandings that oncology nurses hold about palliative care in general, including its dimensions of symptom management, decision making, and end-of-life care, and, more specifically, nurses' beliefs about when, how, and for whom palliative care should be provided.

Knowledge about palliative care has evolved rapidly over the past few decades, during which it has become a distinct specialty. "Palliative care refers to patient- and

**Purpose/Objectives:** To examine how oncology nurses define palliative care, views about who should and should not receive palliative care, and beliefs about palliative care decision making, including who should be involved and how decisions should be managed.

**Design:** Qualitative interviews and analysis.

**Setting:** Preferred location of each respondent.

**Sample:** 12 nurses representing different aspects of oncology nursing.

**Methods:** An interview guide was employed to ensure that specific topics were covered. Interviews were transcribed verbatim. Qualitative analysis consisted of independent, multiple reviews of the transcripts to share initial findings and identify, refine, and reach consensus on major themes and subthemes.

**Main Research Variables:** Nurses' definitions of palliative care, views about who should and should not receive palliative care, and beliefs about palliative care decision making.

**Findings:** Nurses' perceptions of palliative care focused on symptom management. Most did not distinguish between palliative care and hospice and believed that only patients who were near the end of life should receive palliative care. They viewed their role in decisions regarding palliative care to be limited and indirect.

**Conclusions:** Although oncology nurses should be at the cutting edge with regard to palliative care, these nurses' personal understandings could serve to limit care for many patients with cancer who could benefit from it.

**Implications for Nursing:** Education and clinical experience embedded in a continuous quality-improvement model are needed to ensure sustained change that will overcome the multiple, interwoven barriers to providing appropriate palliative care.

family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access

to information, and choice" (National Quality Forum [NQF], 2006, p. VI). Because many symptoms of cancer and other diseases can be anticipated, much of their suffering can be alleviated. Palliative care is not only about end-of-life care. Pain and other symptoms occur throughout diseases, and proactive alleviation of disease- and treatment-related symptoms should happen then as well. "Of particular importance, palliative care services are indicated across the entire trajectory of a patient's illness, and its provision should not be restricted to the end-of-life phase" (NQF, 2006, p. VI). Although palliative care can benefit people with many different diseases, this article focuses on palliative care of people with cancer.

## Goals of Cancer Treatment

According to the American Cancer Society (2009), about 1,479,350 new cases of cancer were expected to be diagnosed in the United States in 2009. Cancer-directed therapies typically should have two broad goals: (a) to cure the disease or to minimize its effects and (b) to alleviate the burdens of the disease and the negative effects of treatments (e.g., vomiting, altered blood counts). The second focus is a relatively recent addition to the practice of oncology. Until the late 20th century, treatment for cancer chiefly was tumor-directed. Treatment decisions and indicators of success generally were gauged in terms of incremental changes in tumor size, to the exclusion of more global assessments of the many effects of either the cancer or its treatments (Foley & Gelband, 2001; Joishy, 1999). Nurses have described this same early focus (Pavlish & Ceronisky, 2007).

## Palliative Care

Palliative care initially was fostered and understood in relation to end-of-life care. As providers more widely recognized that dying patients and families often had many unmet needs, palliative care arose as a distinct specialty for several reasons (Doyle, Hanks, Cherny, & Calman, 2005). Advances in treatments for many life-threatening diseases, including cancer, meant that people were living longer with diseases that previously would have been rapidly fatal. Longer life not uncommonly came with the cost of reduced quality of life; extended lifespan often meant living with one or more quality-of-life burdens, such as disabilities, pain, and mental anguish. However, advances in medical and healthcare knowledge and technology also have yielded substantial improvements in treating the symptoms of cancer (and other diseases), as well as the side effects of the life-sustaining or -prolonging treatments.

Notwithstanding its origins, palliative care now is understood to be distinct from hospice; it should be available to patients independent of diagnosis and

prognosis and across disease trajectories (NQF, 2006; Oncology Nursing Society [ONS] & Association of Oncology Social Work [AOSW], 2007). Palliative care is family focused and has three primary foci: (a) aggressive symptom management, (b) supported decision making, and (c) end-of-life care, when and if needed (Mahon & Sorrell, 2008). Palliative care involves neither prolonging dying nor hastening death. Therefore, all hospice care is palliative, but not all palliative care is hospice.

Patients with cancer often live with significant symptom burdens. Many patients with cancer and their families are confronted with complex decisions that they do not feel prepared to make. The goal of care for many patients is cure or a long life lived well with the disease or its sequelae. Multiple, complicated symptoms of cancer and its treatments are expected for many patients, and because complex decisions are common, palliative care should be part of the usual care available to all patients with cancer. All providers should have basic palliative care skills (von Gunten, 2002; von Gunten, Ferris, Portenoy, & Glajchen, 2001; Watson, Lucas, Hoy, & Back, 2005) so that palliative care specialists can focus on the care of patients with more complex, difficult-to-treat needs. As a result, palliative care has become the standard of care for patients with cancer and other serious illnesses (Foley & Gelband, 2001; National Consensus Project for Quality Palliative Care [NCPQPC], 2009; NQF, 2006; World Health Organization, 2007). Many resources have been developed to facilitate the integration of palliative care into the care provided by oncology nurses (Coyné et al., 2007; Ferrell, Grant, & Virani, 2001; Ferrell & Virani, 2008; Ferrell, Virani, Smith, & Juarez, 2003).

ONS, in collaboration with AOSW, developed a position paper on the necessity of palliative care in oncology (2007). Among the components were symptom management, decision making, and end-of-life care, all in the context of family involvement in patient care. Importantly, the authors recommended the integration of palliative care as an element of the care of all people with cancer.

At least in part because palliative care is not widely implemented, the quality of care of many people with cancer is poor; substantial barriers remain to the use of palliative care. Because it is still often equated with end-of-life care, one might expect at least that dimension of palliative care to be widely available, but deficits remain. The palliative care conundrum within oncology was well expressed by Foley and Gelband (2001): "Even thoroughly tested, effective measures to improve the quality of life of dying patients have not been widely adopted; in contrast, the most marginal improvements in chemotherapy to extend life—often at reduced quality—diffuse remarkably quickly" (p. 28).

Two trends may influence the perceptions that oncology nurses currently hold about palliative care. Because of its roots in end-of-life care for people with cancer, oncology nurses could find it difficult to distinguish

between hospice care and palliative care. Conversely, because virtually all people with cancer are good candidates for palliative care, oncology nurses may be trendsetters in mastering the concepts of palliative care.

## Research Questions

The authors completed in-depth interviews with oncology nurses to comprehend their personal understandings about palliative care. Much prior research in which barriers to palliative care were explored used survey methodology (Hodgson & Lehning, 2008). A qualitative approach adds breadth to extant knowledge. The authors explored three major factors that are important to appropriate and timely delivery of palliative care. The authors were interested in how oncology nurses defined palliative care and, especially, the degree to which the elements of palliative care (symptom management, assistance with decision making, and end-of-life care) were incorporated into their personal descriptions of palliative care. The authors also were interested in nurses' views about who should and should not receive palliative care. In addition, the authors examined oncology nurses' beliefs about decision making in palliative care, including who should be involved and how decisions should be managed.

## Methods

Approval for the study was obtained from the human subject review board of George Mason University. A preliminary interview guide was drafted based on the authors' prior clinical and research experience with palliative care. The preliminary interview guide was pilot tested with four nurses, and minor modifications were made. Interviews with the four nurses were not included in this analysis. Because the initial interviews suggested that it was difficult for respondents to remember all of the areas addressed by palliative care (pain, suffering, anxiety, spirituality, activity, quality of life, comfort, coping, and family support), the research respondents were given a sheet displaying these areas. Interviews were audio recorded. After obtaining informed consent, interviews began with the question, "How often do you encounter patients who have issues with pain, suffering, anxiety, spirituality, activity, quality of life, comfort, coping, or family support?" The dimensions were chosen because they represent situations commonly encountered by patients and their families and can be addressed through palliative care. Because of the authors' goal of understanding the nurses' personal experiences with and views about palliative care, the guide was not meant to be used as a survey instrument. Instead, questions were modified when appropriate, probes and reflective statements were used, and an informal conversational approach (Rubin & Rubin, 1995) was encouraged to establish an environment

for in-depth discussions of the nurses' perspectives and experiences.

The mailing list of ONS members for a three-state region was purchased, and 143 invitations to participate were sent out. Members who had opted not to receive non-ONS mailings were not included. Twenty-one members expressed interest in participating, and 12 oncology nurses, who represented different practice areas within oncology nursing, were interviewed (see Table 1).

All respondents were practicing in oncology at the time of study. They represented nine different institutions. None of the respondents had formal education in palliative care, although one had specific training in pain management. Several expressed great interest in the topic and had sought out conferences or other educational offerings on related topics. One was trying to enroll in an End-of-Life Nursing Education Consortium (ELNEC) course at the time of study.

## Interviews

As noted, at the beginning of the interview, all nurses were handed a list of areas of concern that should be addressed by palliative care. When the nurses were asked how often they experienced such circumstances in practice, all described daily encounters with all situations.

The interviews were carried out by the authors and a doctoral-level graduate research assistant who was trained by the authors. Graduate assistant training consisted of formal instruction on interview practices with the preliminary guide and a guided review and critique of the preliminary interviews completed by all participants. Interviews were completed in the location of each respondent's choice and included places of work, home, and public venues. The interviews ranged from 30–77 minutes in length ( $\bar{X}$  = 44 minutes). All interviews were transcribed

**Table 1. Sample Characteristics**

Characteristic	n
<b>Gender</b>	
Female	11
Male	1
<b>Race</b>	
Caucasian	10
African American	1
Asian American	1
<b>Practice environment</b>	
100% clinical	6
Clinical with education, research, or administration	5
100% research	1
<b>Level of education</b>	
Bachelor's degree	6
Master's degree	6

N = 12

Note. Practice environments represented a range of urban, suburban, and rural sites as well as community and teaching institutions.

verbatim by a professional transcriptionist or one of the authors. Although theoretical saturation (Strauss & Corbin, 1998) was reached after nine interviews, additional interviews were conducted to include more participants who were not advanced practice nurses.

## Analysis

Analysis of the qualitative interviews consisted of multiple reviews of the transcriptions to identify, refine, and reach consensus on major themes and subthemes. The authors began their analysis by working separately with the transcripts as they were produced to ascertain major themes and associated narrative statements. The authors then shared their initial findings in hard copy. Each researcher reviewed the other's preliminary findings and then scheduled meetings to discuss them, reflect on the basis for each, and reconcile differences, which were minor. The three themes presented in this article were identified by both authors to be among the most obvious. Following the initial analytical meetings, the authors were assigned specific themes to explore further by again reviewing all of the narratives. The goals at that point were to flesh out and refine the themes and to ascertain relevant subthemes by identifying and assessing all narrative segments related to the assigned themes. The authors used a constant-comparison strategy (Strauss & Corbin, 1998) by considering segments that supported the evolving themes and subthemes, as well as those that were related but were unsupportive or that suggested thematic variations, and by continually refining the themes and subthemes. Again, the revised themes, subthemes, and relevant narrative segments associated with them were shared initially in hard copy and followed by discussions to reach consensus. By working separately and then comparing and discussing initial findings to reach consensus, the authors were able to enhance the validity and reliability of the findings.

## Results

The authors describe nurses' understanding of three aspects of palliative care: "What is palliative care?" "Who should receive palliative care?" and "Who makes decision about palliative care?" The themes that resulted from the questions were relatively narrow and simple. They tended to focus on symptom management and exclude the other aspects of palliative care.

### What Is Palliative Care?

One striking aspect of the interviews was that even those oncology nurses who had very inclusive and supportive approaches to their everyday practice of nursing—approaches that included most of the elements of palliative care—tended to provide very basic descriptions of palliative care. One common theme was the

confusion between palliative and hospice care—a sense that palliative care is symptom management (for some, aggressive symptom management) to the exclusion of curative medicine. The following are examples.

Palliative care to me is understanding that we are not curing a disease but that you are taking care of the entire person, so that that they can reach the last stage of their life without suffering.

So palliative care to me means basically, you're not going for a cure, you're going for making you comfortable living out the best quality of life that you can while you have it, and not necessarily going for every single . . . research trial, chemo[therapy], or anything like that 'cause that could make you just as miserable. So, it is still going forward with some treatments, but treatments that will make your life better, not necessarily prolong it.

Palliative care, when you get to that stage that . . . there is no more . . . you've failed every kind of regimen or you've made a conscious decision not to get any chemotherapy or not to get any treatment. And then I think that people are entitled to be comfortable, I think that's important, and that they are able to be supported in whatever way possible.

Other oncology nurses perceived a difference between palliative care and hospice, but viewed them sequentially. They saw palliative care as a step toward hospice or a transition stage on the trajectory toward hospice.

Palliative care should be the first step before hospice . . . if we are not getting our patients into palliative care before we say they are ready for hospice, then we are not doing our job.

I think hospice, because they've been doing it for so long, they are terrific at it, and many doctors, instead of trying to take on palliative care themselves, they just say, "Okay, now, you're going to hospice," and they go from active to care to hospice without that transition . . . which can be to just start to back off of things and see how things go and then take care of your pain.

What . . . intimidates me about hospice is I feel like I would need lots of training to at least help people through it. . . . But, palliation . . . I know the kind of activities that can control nausea and vomiting, opening up the dialogue about hospice . . . making it a bridge.

So palliative care can be symptom management, it can be a transition to hospice.

Far less common was the view that palliative care should be available to any patient, including those who are not on a trajectory toward death. The following

excerpt emphasizes symptom management and quality of life without an attachment to death or hospice.

In my opinion, palliative care is something that should be just prescribed essentially from day one of diagnosis, even if it's not a life-threatening cancer. Palliative care is . . . aggressive symptom management. These [palliative specialists] are experts that their specialty is looking at all of the symptoms and offering the patient the best quality of life. . . . So why can't we prescribe [palliative care] right up front? . . . Not hospice, but palliative care right up front so that we can control nausea better, we can control . . . neurological symptoms better. . . . We do very well today in oncology with treating symptoms, but we can always do a lot better.

Still others had conceptions of palliative care that simply were vague, but they always tended to include symptom control. The following excerpt presents some of the ambiguities felt by some oncology nurses.

Well, they're starting to jump on that bandwagon. I understand it's to help control symptoms, so we're getting into it on this unit and the whole hospital, I think. They have a palliative care . . . team that's being utilized. So, we do see the palliative care team writing notes and they're recommending different things to help the patient, like, for nausea and vomiting, so we're seeing it more and more now, so it's coming into vogue.

### Who Should Receive Palliative Care?

Beliefs about who should receive palliative care largely were framed by the respondents' internalized definitions of palliative care. A few believed that palliative care should be available universally to people with cancer (e.g., "every single person with a cancer diagnosis"). However, respondents more commonly delineated specific criteria for who should or should not receive palliative care. For most, the criteria included factors related to the illness, the degree of suffering, and end-of-life care. Several criteria also were related explicitly to the patient's quality of life. The following quotes exemplify clinical situations that meant to the nurse that it was time to consider palliative care.

When there's nothing you're doing that's going to make the quality of life any better.

If the patient is in so much pain that . . . you're constantly having to keep them sedated just so that they can get through the day . . . to make them comfortable, or . . . the disease is just eating them away internally, and all you're seeing is the demise of that person slowly from one organ failure to another organ failure 'til you have multiorgan failure. . . . Why allow that, because all you're doing is seeing that per-

son suffer? I think, to me, that's the bottom line. . . . Patients should never suffer in the hospital.

Other respondents indicated that people should receive palliative care at the end of life.

It's not just cancer patients that are dying. It's congestive heart failure patients, it's renal patients, but it's anybody that has a chronic illness—we used to say terminal illness but now chronic illness—and all of these people should be treated with palliative care.

[You should get] palliative care when you get to that stage that, you know, there is no more . . . you've failed every kind of regimen or you've made a conscious decision not to get any chemotherapy or not to get any treatment. . . . I think it improves their quality of life.

Other respondents described clinical situations that would preclude access to palliative care. These situations included participants in a clinical trial, a plan to receive cardiopulmonary resuscitation (CPR), or the possibility of an intensive care unit (ICU) admission.

It seems like with a lot of our patients, we do think that they should be on palliative care, they . . . don't want to yet, or they still want to try the CPR, or you'll get a lot of these "[do not resuscitate] times one, or times two, times three [orders]" . . . If I'm going to do CPR on you, I also may need to shock you. I may need to send you to the ICU. If I send you to the ICU and I can't intubate you, what good is this? . . . The problem is . . . the patients will go for anything that will possibly prolong their lives. [They will enroll in a protocol] just grasping at anything. Most likely I will say 9 out of 10 patients will go for it.

Enrollment in a research protocol was perceived as a way to "buy time" and, therefore, incompatible with palliative care. Alternatively, the option for "buying time" was sometimes described as a criterion for receiving palliative care, thus serving as a tacit distinction between palliative care and hospice.

Patients sometimes, they just needed to be able to hang on just so that they could see a birth or see a wedding or a graduation. . . . That is palliative care . . . where we're just trying to have them hang on just a little bit longer so that they could meet that goal.

The beliefs about who should receive palliative care were clarified when contrasted with who should not receive palliative care. Again, prognosis was important.

If there's a chance for the patient to get better . . . it's too premature to call on palliative care.

I guess if there is . . . a real possibility of cure. "You're young. You could probably battle all these

complications that could go with the chemotherapy. It's just a matter of . . . giving us your consent."

One respondent restated a belief in universal access: "No cancer patient should not get [palliative care]."

## Who Makes Decisions About Palliative Care?

Participants were asked who should make decisions about palliative care, a purposefully broad question to allow for a range of dimensions. Nurses revealed personal understandings about not only who should have input into decisions about palliative care, but also the factors affecting those decisions. Responsibility for decision making was ascribed primarily into two categories: patient (with or without family) or physician (of several specialties).

The patient should decide; the patient, first and foremost. And then . . . if they're unable, then whoever they appointed. . . . We shouldn't make that decision.

Ideally, I think the patients. . . . I think it's important to really create your own destiny and make your own healthcare decisions; however, I do think that a lot of patients have advocates.

That depends on the physician. . . . Some physicians don't "get" palliative care.

Physicians often were described as the decision maker about access to palliative care; however, a variety of factors were perceived as influencing the physician's decision.

The person who is the attending [physician] and giving the main care for the patient does make the decision.

Generally speaking, it is a physician and patient and nurse practitioner-patient decision that is made. Ultimately, I would like to think this is a decision made by the patient.

The patient-physician relationship was a consideration in decision making for some patients.

[Many patients feel that] they're letting down the doctor or the team by, if they were to quit the treatment, when in reality . . . you need to look at them.

The opportunity for a patient to begin or to continue in a clinical trial was described as a factor in decision making. Participation in a clinical trial often was considered to be a patient's right, rather than being considered from the perspective of the patient's best interest. The goals of researchers were described as sometimes distinct from those of clinicians.

And sometimes, you know, the researchers . . . they want to meet their end, and I'm not saying all of them are like that because that sounds very callous.

Another perspective on decision making was that palliative care physicians could be perceived as "stealing" patients. Palliative care was perceived to be different from other consultative services. Some believed that the palliative care team becomes the primary care provider.

I think the attending doctor, whether it's the kidney doctor or the oncologist, feels like, "You're trying to steal my patients."

Several respondents were very clear that an interdisciplinary team should contribute to decision making about whether or when a patient should receive palliative care.

[Nurse, physician, social worker], anyone who's in contact with that patient should be able to see signs of a need for pain issues, nutrition issues, declining health. Usually, [the nurse practitioner] suggest[s] [a palliative care consult], and then Dr. H is always, he's fine with me. My other [challenge] is that there's a medical oncologist. . . . I have to see what their thoughts are because, if the patient is still getting perhaps some palliative chemotherapy or getting some kind of treatments . . . they need to be aware of it. So, I will call them [and say] . . . "I think it would be a good idea for us to suggest [a palliative care consult]." . . . A lot of times, they go, "Oh, okay, fine, as long as you're going to do it."

The authors found that decisions were made on more than just clinical factors. The relationship between physician and patient and the perceived expectations of each were substantial factors in decision making. The role of the staff nurse was not seen by any respondent as primary; however, several respondents believed that staff nurses had an important but secondary and sometimes covert and indirect role in decision making. Interestingly, this was the only circumstance in which decision making was described as a process, rather than as a singular event.

I would say [decisions] are made before the nurse would say anything. . . . I think it's made between the doctors and the patients. And then if they do get made on the floor, generally it is between the doctors, patients, and the stirrings of the nurse. You know, the encouragement or support or wherever the patient is with the nurse.

The physicians can certainly order [a palliative care consult], but if they still don't know about palliative care, then we as nurses should ask for a consult.

## Discussion

By far, most nurses in the sample had a positive view of palliative care, and even an enthusiasm for how it could benefit patients and families. However, most also

had incomplete or incorrect personal understandings of palliative care, what it is, and for whom it is intended.

Most commonly, palliative care was equated with hospice care. The benefits of hospice were appreciated. Hospice (and often palliative care synonymously) was perceived as a valuable resource when the patient could no longer benefit from curative therapies. That is, most respondents had an understanding of palliative care as separate from oncology care, which is consistent with Pavlish and Ceronsky's (2007) finding of a "dichotomous view of cure versus palliation" (p. 794). Still, being able to offer end-of-life care, albeit through a referral, meant another opportunity for oncology teams to "do something," even though someone else would be providing the care.

The presence of palliative care teams in several of the institutions shaped some respondents' understanding. However, unlike other referral services, palliative care was not perceived as an expansion of the current cadre of professionals caring for the patient. Rather, the palliative care team often was perceived as the new primary team. Dudgeon et al. (2008) referred to this as the palliative phase of an illness. That is, the involvement of the palliative care team was not uncommonly perceived as relieving the oncology team of its primary responsibilities for the patient. The authors suspect that this perception contributes to patients' and families' feelings of abandonment. Patients' desire to stay with their oncologist was evidenced by nurses' reports of patients making decisions based on the perceived desires of the oncologist.

The sequential involvement of palliative care *after* oncology care is likely to run counter to the needs of the patient for another reason. Nurses in this sample uniformly described patients' experiences with tremendous physical suffering. Each vividly portrayed how difficult cancer and its treatments could be for patients and families. Complex and often advanced disease necessitates an interdisciplinary approach (Sesterhenn et al., 2008); patients often would benefit from the expertise of the oncology team *and* the palliative care team. In addition, such cooperation between oncology and palliative care is a goal of families (Morita et al., 2005).

Nurses in this sample did not perceive themselves or their nursing colleagues to have a formal role in the decision-making processes about any components of palliative care. Rather, they saw themselves as requestors or "suggestors" to another non-nurse provider or nurse practitioner who would then relay the request to the physician decision maker. Several respondents encountered resistance or had to defend a request for a palliative care consultation. Some nurses indicated that a request for a palliative care consultation was taken as a criticism of the oncology team's ability to manage a symptom, whereas others viewed it as a judgment that the patient was dying. One nurse did indicate that the

suggestion would be viewed as a valuable clinical recommendation from a colleague. However, in general, the physician was seen as the gatekeeper for palliative care services. This view is consistent with Willard and Luker (2005), who also described what they termed supportive care to be perceived as "an optional extra."

Nurses uniformly described patients' significant symptom burdens and indicated that the symptoms frequently were not managed adequately. Both out-of-control symptoms and end-of-life care commonly were described as precipitating palliative care referral. The introduction of palliative care, therefore, was not seen as a routine clinical treatment decision but rather as a decision necessitated by the patient's symptom burden or by the related recognition of impending death. The notion is decidedly incongruent with the reality of palliative care as a separate knowledge base and a component of care to which all patients are entitled (NCPQPC, 2009; NQF, 2006; ONS & AOSW, 2007; von Gunten et al., 2001). The incomplete understanding of palliative care identified in this sample was consistent with other research across disciplines (de Veer et al., 2008; Pavlish & Ceronsky, 2007; Reinke et al., 2008).

Nurses in the current study were eager to provide excellent care to people with cancer. They were professionally active and they pursued opportunities for learning. Therefore, it would be erroneous to place responsibility for incomplete knowledge on these individuals.

Although it is daunting to consider adding one more body of knowledge and set of competencies to what nurses should know and do, no other choice exists. Basic knowledge of palliative care must be a part of what *all* nurses know. This goal requires a culture change, first to understand palliative care as distinct from hospice and then to integrate the dimensions of palliative care into nursing practice.

The ONS and AOSW position statement (2007) suggested that the provision of adequate palliative care requires education and training not only at the undergraduate and graduate levels, but also in mandatory continuing education programs. In part because "educational preparation for end of life has been inconsistent at best, and sometimes neglected within nursing curricula" (American Association of Colleges of Nursing [AACN], 2004, para. 3), AACN developed a list of competencies for the provision of end-of-life care. Though focused on end of life, the competencies include specific recommendations regarding symptom management, supported decision making, and other factors of palliative care. Therefore, in conjunction with other tools, the AACN competencies are a resource for nurses across diverse settings.

The professionalism of the sample of oncology nurses suggests that education well provided would be adopted eagerly. The prevalence of misconceptions reinforces the need for education to be provided by experts

with the knowledge base and clinical experiences in palliative care. Several mechanisms of education exist for practicing nurses. Perhaps the best known of these is ELNEC.

The ELNEC program is a very good introduction to certain concepts of palliative care; however, it remains only an introduction. In addition, the title of the program is likely to reinforce among those with a misunderstanding that palliative care is solely about end-of-life care. This certainly is not the intention of the providers, who have developed a specialized ELNEC focusing on the needs of patients with cancer and their families. Coyne et al. (2007) emphasized that this curriculum addresses “specialized needs of oncology nurses to provide excellent care to patients with cancer throughout the disease continuum and during the final hours of life” (p. 803). If palliative care is presented solely in the context of death as an inevitability (e.g., Bruce, 2006), the likelihood of resistance not only by patients and families but perhaps even more by the oncology team is increased dramatically.

Many barriers to implementing a palliative care program exist. A primary concern is the lack of nurses with specific education in palliative care. Palliative care education that is expected to lead successfully to sustained change must include a practice component in which an expert nurse models excellence in palliative care.

Another barrier is time—not only time for education and training, but also the time to provide additional care (Dudgeon et al., 2008; Pavlish & Ceronsky, 2007). For example, adequate pain assessment is more time consuming than merely asking patients to rate their pain on a 0–10 scale. Other barriers are systemic, interpersonal, and intrapersonal. These include funding, attendance at workshops, patient and family beliefs, and disagreements over the goals of a patient’s care (Coyne et al., 2007; McCall & Johnson, 2007; Pavlish & Ceronsky, 2007).

Institutional barriers to establishing a standard of access to palliative care also exist (NQF, 2006; ONS & AOSW, 2007). Establishing excellent palliative care across healthcare settings is a challenge to healthcare organizations (Ferrell & Virani, 2008). Framing palliative care as a means to improve the care of patients (Ferrell & Virani, 2008) may increase the acceptance and integration of palliative care. This goal not only focuses on quality of life and individual growth, but also on prevention of suffering across the disease trajectory.

Perhaps the most significant barrier to appropriate use of palliative care among oncology nurses is the tendency to equate palliative care with end-of-life care. This misunderstanding leads to underutilization of palliative care services. Providers’ misperceptions also may influence the beliefs of patients and families, who will pick up on the belief that palliative care is only about the end of life.

In their interviews with nurses about palliative care, Pavlish and Ceronsky (2007) found that few nurses expressed the need for specialized palliative care services. The current study’s findings were very different. Every nurse interviewed in the current study believed that palliative care could be appropriate for patients with cancer, which is consistent with ONS and AOSW (2007) and NCPQPC (2009) statements. However, nurses had no level of agreement on when, why, for whom, and how palliative care should be provided.

The nurses believed that they were qualified, had access to people who were qualified, or that they could become qualified to provide palliative care. In a study comparing beliefs and attitudes about who should speak with patients about do-not-resuscitate orders, Sulmasy, He, McAuley, and Ury (2008) found that nurses were significantly less likely than physicians to describe speaking with either a patient or a surrogate as difficult. Nurses’ comfort with these extremely difficult discussions (e.g., addressing the supported decision-making dimension of palliative care) reinforces the notion that nurses are willing to engage actively across the dimensions of palliative care if they have the necessary tools to do so.

The establishment of a comprehensive set of standards for an oncology service, including symptom management, quality of life, and aggressive decision support, would shift the focus of clinical decision making from an individual provider or patient. Therefore, perception of a palliative care referral as criticism or failure might be diminished. An accepted mechanism for the integration of such standards is a continuous quality improvement (CQI) model. A CQI model would allow the implementation of standards based on the specifics of each oncology service and also would support ongoing evaluation of the utilization of these standards.

One component of a CQI model could be triggers for palliative care consultation for patients with cancer. Although current standards (NCPQPC, 2009; NQF, 2006; ONS and AOSW, 2007) support the integration of palliative care into the care of all patients with cancer, the development of “palliative triggers” would establish objective clinical criteria that, when reached, would lead automatically (and blamelessly) to a palliative care consult. Palliative care triggers already exist for ICU patients (Campbell & Guzman, 2003, 2004) and for people in long-term care (e.g., those developed by Tuch for Genesis Health Care, reported in Strumpf, 2004; Strumpf, Tuch, Stillman, Parris, & Morrison, 2004). Development of such triggers for oncology would address some of the perceived impediments to usage of palliative care.

The current study had several limitations. Half of the respondents were advanced practice nurses, a higher percentage than would be found in most practice environments. Most respondents described interest in palliative



care, all expressed some knowledge of the content, and most had access to palliative care specialists in their work environments. How the experiences affected the respondents' knowledge and beliefs or whether the findings might be transferred appropriately to other oncology nurses and settings is unclear.

## Conclusion

Palliative care was recognized as a valuable resource for certain patients, but it also was misunderstood. The findings indicate a need to provide broader education about and clinical experience with palliative care. To date, nurses who currently are practicing are not likely to have had palliative care education integrated into their undergraduate or graduate studies. Therefore, a need exists to bring education to the work place. However, education alone is unlikely to change practice. Models of palliative care in the care of specific patient populations are necessary. Many institutions lack personnel with direct education and practice experience in palliative care. Many nurses who call themselves palliative care nurses lack education and formal training in this specialty.

Nurses can be taught to begin to identify situations in which palliative care should help. If a goal is to develop primary palliative care as a component of oncology

care, experts will have to be integrated into extant care teams. The process has many barriers across individuals, professions, and institutions. Ongoing research will be necessary to understand how practice changes affect and are affected by the barriers. Certainly Dudgeon et al.'s (2008) finding that change takes time is consistent with other efforts to advance standards of care. Dudgeon et al.'s (2008) suggestion that efforts at change be embedded in a CQI model is more likely to result in sustained change that would help to overcome the multiple, interwoven barriers with providing appropriate palliative care. Two approaches for supporting palliative care within a continuous quality improvement model include (a) the development of a broad set of quality standards in oncology that include the goals of palliative care, and (b) establishing palliative care triggers that facilitate palliative care consults.

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