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# Nursing Advocacy for Optimal Palliative Care of Patients with Advanced Cancer

Debra A. Kossman  
*University of Pennsylvania*

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## **Abstract**

The purpose of this paper is to review selected research findings about obstacles to palliative care for patients with progressive cancer and discuss the role that oncology and palliative care nurses play in helping to remove these obstacles.

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The optimal care of patients suffering with progressive, life-limiting cancer is a major health care issue for many reasons. To start, the number of patients requiring palliative and end-of-life (EOL) care is growing as older Americans become an increasingly large proportion of the US population (e.g., Economist Intelligence Unit, 2010). The costs of health care delivered in the last weeks and months of life already comprise a disproportionate share of lifetime medical expenses (e.g., Duncan, 2010). Rising per-patient costs along with increasing numbers of patients are escalating the financial burden of terminally-ill care on individuals, families, and society. Improved technology, which contributes to rising costs, has increased the ability to prolong life without always enhancing its quality. For these reasons, society must ask whether life-sustaining measures should be used simply because they are available for use. As patients face death, preservation of human dignity and relief of suffering become priorities that guide comfort care.

Cancer continues to be the second leading cause of death in the US, after heart disease. According to the Centers for Disease Control (CDC), cancer deaths now exceed 567,000 annually and account for about a quarter of all deaths (“Leading causes of death”, 2009). Further, cancer (like many other diseases) challenges the optimal delivery of palliative care because the time from diagnosis with advanced disease to death can be relatively long and unpredictable. Difficulty predicting expected survival time, physicians’ reluctance to stop aggressive treatment, and patients’ and families’ denial of terminal disease contribute to delays in initiating palliative care (Larochelle, Rodriguez, Arnold, & Barnato, 2009; Salladay, 2009; Vivian, 2006).

Oncology and palliative care nurses serve as critical links between physicians on the one hand and patients and families on the other. These specialty nurses have the expertise to understand both the complex medical needs of cancer patients and the diverse psychological and spiritual needs of patients nearing the end of life. They also bear unique profes-

sional responsibility for addressing all of these aspects of patient care. They aspire to give patients “a good death” (Dobbins, 2005) using the best medical, psychological, social, and spiritual interventions in ways that respect dying patients’ values, needs, and desires.

The purpose of this paper is to review selected research findings about obstacles to palliative care for patients with progressive cancer and discuss the role that oncology and palliative care nurses play in helping to remove these obstacles.

## Selected Research Findings

### Perspectives of Oncology Nurses

Moore, Callister, & Bond (2009) recently reported on the major obstacles to delivering EOL care as judged by oncology nurses. A random national sample of 1,000 members of the Oncology Nursing Society who had cared for inpatients with cancer and had experience in EOL care were invited to complete a questionnaire sent to them by mail. A total of 375 invitees were confirmed to be eligible and provided usable responses.

The questionnaire instrument, “Survey of Oncology Nurses’ Perceptions of End-of-Life Care,” was adapted from similar surveys with critical care and emergency nurses, with particular attention to revising it to reflect oncology EOL care. Oncology nurses were asked to rate the magnitude of 25 listed obstacles in giving EOL care to dying patients with cancer using a scale from 0 (not an obstacle) to 5 (extremely large obstacle). The smallest obstacle (“restrictive visiting hours”) received a mean (X) rating of 1.02; the largest obstacle received a rating of 3.56.

Eight of the top 10 obstacles related directly to family attitudes and behavior, including “angry” or “anxious family members” (X = 3.56 and 3.53, respectively); “family not accepting what the physician tells them”, or “being overly optimistic, about patients’ poor prognosis” (X = 3.55 and 3.44, respectively); “intrafamily fighting about whether to continue or stop aggressive treatment” (X = 3.31); and “family members not understanding the consequences of

continued aggressive treatments” ( $X = 3.30$ ). The fifth biggest obstacle was “physicians who insist on aggressive care until patients are actively dying” ( $X = 3.47$ ). The only other types of obstacles ranking among the top ten for oncology nurses were “being called away from patients and families to help with a new admit or to help other nurses care for their patients” ( $X = 3.53$ ) and “patients having pain that is difficult to control or alleviate” ( $X = 3.31$ ).

In the same study, oncology nurses were asked to rate 24 supportive behavior items using a scale from 0 (not a help) to 5 (extremely large help). The top five supportive behaviors included “having family members accept that patients are dying” ( $X = 4.53$ ) and “having the physicians involved agree about the direction of patients’ care” ( $X = 4.51$ ). Nurses consider the biggest help to be “allowing family members adequate time to be alone with patients after death” ( $X = 4.58$ ) and, related, “providing a peaceful bedside scene after patients die” ( $X = 4.50$ ). “Having social work or palliative care staff as part of the patient care team” ( $X = 4.55$ ) is the third biggest support among the survey items rated.

This survey documents the importance that oncology nurses place on having both physicians and families united in accepting a patient’s impending death and in foregoing aggressive care that would undermine rather than promote the relief of patient suffering. Of course, this study was conducted with nurses who care for dying inpatients, and much of palliative oncology care occurs in outpatient, home, hospice, and nursing home settings, where the dynamics of care and obstacles to it may be somewhat different.

### Impact of In-home Palliative Care

Foregoing expensive, aggressive interventions is one strategy to slow or reverse rising costs associated with EOL care. Less obvious is whether in-home palliative care (IHPC) yields any savings and, even if it does, whether it in any way compromises patient satisfaction with care. A randomized controlled trial conducted by Brumley et al. (2007) evaluated the effects of IHPC versus usual and customary care on patient satisfaction with, outcomes of, and costs for the care of cancer patients with a life expectancy of 12 months or less.

Patients were drawn from two group-model, closed-panel, non-profit health maintenance organizations (HMOs). Eligible patients had visited an

emergency department or hospital at least once in the year prior to study enrollment, scored 70% or less on the Palliative Performance Scale, and had a primary care physician who agreed that he or she would not be surprised if the patient died within the next year.

All patients in the study received usual care (e.g., home health services consistent with Medicare guidelines, acute care, primary care, and hospice care). Patients randomized to the intervention arm of the study also received IHPC (e.g., pain management and other comfort care) modeled after hospice programs but modified to increase access and timely referrals to palliative care services. In particular, study patients were not required to have received a 6-month prognosis, did not have to forego curative care in order to receive IHPC, and were assigned a palliative physician who coordinated care, although patients also retained their primary care provider. The IHPC program used an interdisciplinary team approach, with the core care team consisting of the patient and family plus a trio of health care professionals (i.e., physician, nurse, and social worker) with expertise in symptom management and biopsychosocial intervention.

Data from patient interviews and utilization databases were analyzed for a total of 297 patients: 152 patients receiving usual care and 145 patients receiving IHPC. Satisfaction was measured using the Reid-Gundlach Satisfaction with Services instrument.

The study findings showed that the IHPC intervention significantly improved patient satisfaction at 30 days (odds ratio (OR) = 3.37;  $P = .006$ ) and 90 days (OR = 3.37;  $P = .03$ ) after enrollment; increased the likelihood of dying at home (OR = 2.20;  $P < .001$ ); and significantly reduced the costs of care (adjusted mean cost for patients enrolled in palliative care was \$12,670 vs. \$20,222 for usual care;  $P = .03$ ). On the other hand, there was a noteworthy (though not quite statistically significant) trend toward shorter survival in the IHPC. The authors speculated that the attention to patient preferences, family education, and encouragement of creation of end-of-life advance directives in the IHPC arm may have led to greater use of pain and symptom relief and comfort care over aggressive treatment to extend life.

The authors conclude that end-of-life care programs should not be limited to the last six months of survival and argue for a new “pre-hospice” palliative care benefit that would provide “a bridge between standard medical care and hospice care” (Brumley et

al., 2007, p. 999). In recognition of a growing body of evidence-based support for earlier palliative care, the American Society of Clinical Oncology (ASCO) recently issued an opinion recommending that all patients with metastatic non-small cell lung cancer be offered palliative care along with standard cancer therapy, beginning at the time of diagnosis (Narod, 2012). ASCO is also urging consideration of a similar approach for other metastatic cancers and for patients with a high burden of cancer-related symptoms.

Oncology nurses are frustrated when physicians fail to communicate the terminal nature of disease to patients clearly and persist with aggressive care despite the inability to cure (Beckstrand et al., 2009), and nurses must manage the complex emotions and incomplete understanding of family members. Available literature provides evidence of beneficial effects of earlier comfort care. But what are patients' perspectives? When patients are asked directly, what do they say matters most to them as death approaches?

### **Patient Aspirations and Awareness**

Dobbins (2005) cites a classic study of chronically ill patients' criteria for quality end-of-life care that identified the following five goals (Singer, Martin, & Kelner, 1999): to avoid inappropriately prolonged dying, to strengthen relationships with loved ones, to relieve the burden on their loved ones, to receive adequate pain and symptom management, and to achieve a sense of control. For health care professionals to work together with families to try to provide end-of-life care that reaches these goals, patients need to understand and accept that they are nearing the end of their lives. This means that the start of optimal palliative care begins with some type of communication with patients about their prognosis.

When hospitalized critically ill patients receiving an initial consultation about palliative care are asked what is most important for them to achieve, the most common individual responses are going/being at home (32%) and pain and symptom management (22%). By contrast, less than 16% express the hope or desire to "recover," "improve," "fight," or seek "cure." These results were obtained through a retrospective descriptive content analysis of the records for 215 patients treated at the University of Rochester Medical Center who received palliative care consultations in 2002 and 2003 (Quill et al., 2006). A nurse practitioner, resident, or medical student posed the question routinely to all palliative care candidates during an

initial intake interview. Responses were independently categorized by four of the investigators, and then collectively grouped using an iterative analytic process until common categorization was achieved for a majority of the responses.

The study authors emphasize that if a hallmark of high-quality palliative care is meeting patient-specific goals, then (a) research that inquires directly into what patients want and (b) palliative care services consistent with those desires are essential. These authors do, however, describe a limitation of their research because of the vague nature of the question they posed – "What is most important for you to achieve?" – and the fact that it was posed to hospitalized patients. Given the vague question, the inpatient setting almost certainly shaped the interpretation that patients gave to what would count as sensible answers. If patients had been asked the same question in outpatient or home care settings, the order of responses might have been different. Further, the authors note that the question deliberately did not ask patients what is important for them to achieve at the end of life because patients differ considerably in their understanding and acceptance of their terminal condition and their proximity to death.

A qualitative study of terminal patients and their relatives conducted in The Netherlands indicates how patient awareness that death is near affects timely requests for, access to, and delivery of care (Francke & Willems, 2005). A total of 19 terminal patients, and 23 relatives of deceased patients who were directly involved in providing patient care, were interviewed between 1998 and 2000. Criteria for inclusion consisted of the patient's suffering from incurable cancer or other chronic terminal disorder, life expectancy less than six months, the mental and physical ability to participate, and, for relatives, the patient's having died within the past year. The sample of patients and relatives represented both cancer and noncancer patients treated in a range of care settings (home, hospital, nursing home, or hospice). The semistructured interviews consisted of a set of open-ended questions and the responses were analyzed using an iterative process of identifying keywords that captured the themes of patient and family member responses.

The results indicate that patients who understood fairly early that death was imminent were more focused on maximizing the quality of their remaining time, were more likely to have given thought to what they did and did not want in the way of ongoing

tests and treatments, and were more likely to ask for specific interventions and assistance. By asking for care, these patients were more likely than less aware patients to remain at home, to avoid indignity, and to reduce the burden on their family. Further, the study indicated that patient awareness of the imminence of death was often modulated by the clarity with which physicians had communicated the incurable nature of their disease to patients.

### **Initiating Discussions about Prognosis and End-of-Life Issues**

The studies presented above are just a few of many that document the way in which both physicians and family members at times pursue or insist on care that is at odds with patient goals and nurses' views of patients' best interests in palliative care (e.g., Dobbins, 2007). They are but a few of the many that document that early understanding and acceptance of a terminal diagnosis, and education about palliative care options, improve patient satisfaction. The studies are among many that affirm the importance of identifying patient goals and preferences and using them to guide interventions designed to enhance the quality of patients' remaining time.

Conversations with patients about their condition are essential, but when should such conversations occur, who should speak with patients, and what messages are important to communicate?

Clayton, Butow, Psych, & Tattersall (2005) conducted focus groups and interviews with 19 palliative care patients, 24 carers, and 22 palliative care health professionals in Sydney, Australia about these questions. Participants had been diagnosed with an incurable and progressive illness or were a carer for such a patient. Health care professionals had at least two years of experience working in palliative care. Study participants were recruited to ensure diverse socioeconomic and cultural backgrounds, care settings, and professional disciplines.

As in the other qualitative research studies presented above, transcripts of the interviews were analyzed by developing categories using participants' own language where possible to describe study responses. All investigators reviewed the final categories to ensure consistency.

The results of the study show little consensus among health care professionals, carers, or patients about communication timing. Some health care professionals urge early candid discussion of

prognosis, others insist that health care professionals should tackle the topic only when patients unambiguously indicate a desire to know or when failing to do so would result in harm. Patients and carers tend to say that professionals should be guided by common sense and intuition about when to initiate discussion of end-of-life issues. There is clear agreement, though, that patients want to speak with a trusted, compassionate health care professional with whom patients have developed a rapport.

While this is only one study, and it consisted of only small numbers of participants, the study results nonetheless converge with the conclusions reached by Parker et al. (2006) in their review of 123 studies addressing patient and caregiver preferences in communications about prognosis and end-of-life. It is important to tailor the timing, style, and content of communications to individual patients and caregivers with diverse cultural backgrounds, education levels, personalities, and coping abilities. As a result, health care professionals must be skilled at listening, speaking, and adapting to patients when navigating the difficult terrain of a terminal diagnosis (Dawson, 2008; Kristjanson, 2005). Further, patients' and families' information needs and goals change with "transitions from cure to comfort care, transitions related to loss, changes in care settings, and psychosocial and spiritual transitions" (Duggleby & Berry, 2005, p. 425).

### **Conclusions and Solutions**

Studies indicate that nurses spend more time with patients at the end of life than any other profession (Wallace et al., 2009). Oncology nurses consider the biggest obstacles to optimal palliative and end-of-life care to be (a) physicians who urge aggressive treatment longer than nurses believe best serves patients and (b) families that are unable to accept that patients are terminally ill. Patient preferences – whether expressed explicitly in advance directives/living wills or solicited by attentive, skilled health care professionals during ongoing delivery of care – often call for less emphasis on continued aggressive treatment and more on comfort measures and quality of life, and for doing the most possible to permit death at home. Thus, while physicians and families tend at least at times to pursue care that diverges from patient goals, nurses' perspectives often converge with those of the patients they serve.

Oncology nurses are uniquely positioned to be advocates for initiation of palliative care for patients

with progressive disease much earlier than typically occurs today (Skalla, 2006). They possess the knowledge and skills needed to address the complex end-of-life problems that cancer patients can experience. The nursing profession also has a defining commitment to the “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations” (“ANA’s definition of nursing”, 2003).

Nurses see firsthand how well-intentioned actions by physicians and families can result in the pursuit of ineffective options that increase cost, prolong dying, and reduce quality of life. Nurses can speak authoritatively about the avoidable suffering and loss of dignity that can result from deferred palliative care. Despite the best of our current knowledge and efforts, some disease is incurable, we are all going to die, and there is a peace that comes from being supported with compassion and comfort care as that unavoidable day approaches.

Of course, dramatic strides have been made in recent decades in the ability to cure and delay recurrence of some cancers (e.g., testicular cancer, non-Hodgkin’s lymphoma, childhood leukemias) and to significantly prolong periods of disease-free survival in patients with metastatic disease (e.g., HER2-positive metastatic breast cancer, chronic myelogenous leukemia, multiple myeloma, metastatic prostate cancer). On the other hand, for diseases such as metastatic pancreatic adenocarcinoma, lung cancers, and ovarian cancer, cure is not possible. Further, treatments are often expensive and toxic, with only some patients reaping any clinical benefit from attempts at aggressive therapy.

Whether to pursue aggressive treatment remains unclear for many metastatic diseases, and in many cases there are no right or wrong choices. It is clear, though, that full disclosure of the benefits and risks of treatment, and full engagement of patients in decision-making processes, are essential if patients are to weigh the consequences of therapy and be afforded their rights of autonomy and self-determination. Nurses can be leaders toward remedying this breach. As Dobbins declares, “Nurses have already reformed the way babies come into this world. Now it’s time for us to help reform the way people depart from this world” (Dobbins, 2005, p. 45).

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