INVITED COMMENTARY

Expanding Use of Palliative Care in the Oncology Setting

Janet H. Bull, Amy P. Abernethy

The use of palliative care for patients with serious disease improves quality of life, reduces symptoms, and saves money. Unfortunately, too many patients endure needless suffering. Expanding awareness about palliative care among patients, providers, and policymakers will hopefully generate momentum for use of such services, thus benefitting patients with cancer and other advanced diseases.

From the first day of medical school, physicians are taught that they should focus on curing a patient’s underlying disease. Relieving symptoms and improving overall quality of life are often viewed as byproducts of eradicating illness—goals to be hoped for, but a secondary focus at best. In reality, both diseases and their accompanying treatments can lead to increased symptom burden and associated suffering. This is particularly true in cases of advanced serious illness, which not only threatens longevity but also is punctuated by challenging symptoms, progressive loss of function, existential concerns, and multiple threats to quality of life.

When symptoms, medication side effects, and functional status worsen, a palliative care specialist may be called in to help with the patient’s care. The palliative care team takes a holistic approach—addressing the physical, psychological, social, and spiritual domains of care—with a focus on enhancing quality of life. Unfortunately, about 70% of Americans have little understanding of palliative care, and many physicians still incorrectly equate palliative care with hospice care. This leads to late referrals at the end of life, after curative life-prolonging care has failed [1].

The term palliative comes from the Latin word palliare, meaning “to cloak.” Palliative care, which may also be referred to as supportive care, focuses on relief of pain and symptoms, discussion of goals of care, advance care planning, emotional and spiritual care, caregiver support, and navigation of a fragmented health care system. Palliative care may be provided along with curative care, or palliative care may be the sole focus, depending on the needs of the individual. As illness progresses and death nears, the proportion of the sick person’s health care that is palliative in focus increases, until palliative care becomes the dominant type of health care in the later stages of illness (see Figure 1).

There is much confusion about the difference between palliative care and hospice care. As Figure 1 shows, hospice care and bereavement are parts of palliative care. The easiest way to think about this continuum is to realize that hospice care is a kind of palliative care that is typically provided when the ill person is in the last weeks to months of life. Practically speaking, the differentiating features are a byproduct of reimbursement mechanisms—specifically, how Medicare pays for end-of-life care. To qualify for hospice care under the Medicare hospice benefit, the patient must have no more than 6 months to live (a prognosis that must be confirmed by 2 physicians), and the focus of treatment must be noncurative care and comfort. Although hospice care is appropriate for patients in the last 6 months of life, hospice care is underutilized, with approximately one-third of patients dying within 1 week of first receiving palliative care services. In 2012, the average length of stay for patients in hospice care was 71.8 days, with a median length of stay of 18.7 days [2]. By diagnosis, cancer patients have shorter lengths of stay (53 days) than patients with neurological conditions (132 days), chronic obstructive pulmonary disease (107 days), debility (98 days), or heart/circulation diagnoses (76 days) [3]. Hospice care at the end of life is considered to be the gold standard for high-quality care, and it has been demonstrated that palliative care increases access to hospice services [4].

In contrast to hospice care, palliative care is reimbursed by the same mechanisms used to reimburse curative care (eg, fee-for-service reimbursement, reimbursement as a hospital-funded consultation service, or reimbursement as part of a bundled payment benefit). Unfortunately, the misperception that palliative care is the same as end-of-life care means that patients with serious illnesses who have longer prognoses and are continuing to receive curative treatments may miss out on the chance to receive palliative care. Ideally, palliative care should begin early in the disease process, preferably when a patient is first diagnosed with a chronic, debilitating, or life-threatening illness.

Palliative care takes a patient-centered approach and...

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focuses on treating a patient with dignity and respect while understanding his or her values and cultural beliefs. In the traditional medical system, providers often talk about lung cancer patients as if they were all the same, since the physician’s focus is on the illness. In a patient-centered approach, the focus is on the particular patient with lung cancer: What are his or her beliefs, treatment goals, preferences, hopes, and fears? How does the patient fit within his or her family structure? Understanding these key concepts helps providers deliver individualized care that is consistent with what is important to the patient.

Palliative care is best delivered by a team of specialized individuals. Core members of this team should include physicians, nurse practitioners, physician assistants, nurses, social workers, chaplains, and the patient and family. Psychologists, physical and occupational therapists, dieticians, and pharmacists may also be included as part of the expanded team. Interdisciplinary care involves incorporating the patient and family in decision making, determining values that direct the goals of the care plan, collaborating and using the expertise of various disciplines, and identifying appropriate interventions that align with the holistic nature of care. Palliative care can be offered in any care setting and is best when delivered across the continuum of care. Many cancer centers now embed palliative care teams in their clinic settings.

When the palliative care team is involved early, the benefits to patients and families are widespread and impressive. Studies of palliative care have found a significant reduction in symptom distress [5-7], lower rates of emergency department visits [8, 9], fewer and shorter hospital and intensive care unit admissions [8, 10], better mood and less depression [11, 12], enhanced quality of life [5, 11, 12], and a longer median duration of survival [12]. Conducting end-of-life discussions with patients has been associated with significant reductions in use of ventilation, resuscitation, and intensive care, and having such conversations increases the likelihood that patients will be enrolled in outpatient hospice for longer than 1 week [13]. Other studies confirm that palliative care helps clarify the patient’s assessment of his or her diagnosis, which contributes to less aggressive end-of-life care and less resource utilization [12, 14].

Accordingly, a byproduct of palliative care is a reduction in the cost of care [8, 10, 15]. Although cost saving is never the reason for consulting palliative care specialists, initiating palliative care early—rather than after all else has failed—can reduce health care expenses. Specifically, use of palliative care has been shown to reduce spending on inpatient care (by as much as $2,500 per admission [16]), to reduce spending on outpatient care (by 33% per patient [8]), and to result in less use of acute care services, fewer admissions, fewer emergency department visits [12, 17], and overall cost reductions at the end of life [18, 19]. Finally, palliative care is associated with greater satisfaction on the part of patients and families [5]. Table 1 lists typical quality measures for palliative care.

Given these favorable outcomes, it is somewhat surprising that utilization of palliative care is not higher. In 2011, hospital-based palliative care was available in 63% of US hospitals with more than 50 beds—an increase of 138% since 2000 [20]. In North Carolina, 94% of hospitals with at least 300 beds offer palliative care, and 75% of hospitals with at least 50 beds have a palliative care service [21]. However, smaller, public, or for-profit hospitals are significantly less likely to offer palliative care [22]. Another challenge is that many of the people who need palliative care are not in the hospital, and outpatient palliative care is not yet widely practiced, despite the benefits realized by patients who are able to remain at home [12, 23-26]. For example, in 2011 only 8% of hospitals in California supported an outpatient palliative care program [27].

One of the main reasons why adoption of palliative care (outside of hospice) has been slow is that reimbursement models continue to be unclear and erratic. Four Seasons, a nonprofit organization in Western North Carolina that delivers palliative care to a large population, has outlined a sustainability model for community palliative care [28]. Such models need to be tested to determine their practicality, effect on

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**TABLE 1. Measures of the Quality of Palliative Care**

<table>
<thead>
<tr>
<th>Types of measures</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>Pain, fatigue, dyspnea, nausea, depression, anxiety, insomnia, dysphagia, constipation</td>
</tr>
<tr>
<td>Advance care planning</td>
<td>DNR form signed, health care surrogate designated, MOST form signed</td>
</tr>
<tr>
<td>Psychosocial and spiritual factors</td>
<td>Emotional well-being, quality of life, spiritual well-being</td>
</tr>
<tr>
<td>Functional status</td>
<td>Palliative Performance Scale*</td>
</tr>
</tbody>
</table>

Note. DNR, do not resuscitate; MOST, medical orders for scope of treatment.

*The Palliative Performance Scale (PPS) uses 5 observer-rated domains (ambulation, activity level, self care, intake, and level of consciousness) and is correlated to the Karnofsky tool. The PPS has been validated and correlates well with actual survival times with cancer patients. More information about the PPS is available on the Medical College of Wisconsin Web site (http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_125.htm).
Pediatric Oncology and Palliative Care

Ray Barfield

Overall, we now cure 70% of the children who are diagnosed with cancer, and in the 30% of cases that are still not curable, we can almost always add time to the child’s life. As our ability to cure cancer has improved, we are now paying increased attention to the goal of avoiding or alleviating the suffering associated with cancer and its therapy. Risk stratification aims to avoid undertreatment of children with high-risk cancers and to avoid overtreatment (with all of the associated side effects of therapy) of children with lower-risk cancers. This goal has become an important part of designing treatment protocols over the past 15 years.

Whether or not a child will be cured, we know that all children with cancer suffer, as do their families. Pediatric oncology is committed to curing cancer, but palliative care is committed to improving a child’s quality of life, irrespective of the potential for cure. Oncology and palliative care are thus twin endeavors, both of which seek what is best for a child and his or her family [1]. Within the 2 broad categories of curing disease and alleviating suffering, there are many specific goals unique to each patient. Palliative care seeks to relieve the physical, emotional, social, and spiritual distress produced by complex, chronic, or life-limiting conditions; to assist in making difficult decisions and setting goals; and to enhance children’s quality of life [2].

More than a decade has passed since the American Academy of Pediatrics [3] and the Institute of Medicine of the National Academies [4] called for the integration of palliative care into ongoing medical management of life-threatening illnesses (such as cancer) in children, from diagnosis to the end of life. Since these calls were issued, models of integrated pediatric palliative care have been developed in which curative therapy and palliative care coexist. For children whose lives are going to be short, adding a few months of good-quality life can be transformative. Adding 6 months to the life of a child who would otherwise have died at 3.5 years of age is extending his or her life by nearly 15%.

To help maximize both quantity and quality of life for children with terminal illnesses, the Patient Protection and Affordable Care Act of 2010 contains the Concurrent Care for Children Requirement [5]. This provision states that palliative and hospice care services must be reimbursed if they are administered to a child with a life-limiting illness who is eligible for Medicaid or the Children’s Health Insurance Program, even if the child is still receiving disease-modifying treatments. In this context, concurrent care is defined as the introduction of palliative care principles at the time of a life-threatening diagnosis, with increasing support over time as the disease progresses; this approach includes a multidimensional assessment to identify, prevent, and alleviate suffering [6]. At the end of life, the model allows for hospice services without requiring the patient to stop all traditional medicine, which may include antibiotics, transfusions, and palliative chemotherapy.

Such models have been supported by studies of adult patients that have demonstrated that palliative care prolongs life [7], is effective in improving quality of life and mood [8], and decreases caregiver burden [9, 10]. In 2012 the American Society of Clinical Oncology released a provisional clinical opinion, based on available evidence from clinical trials, advocating for the early integration of palliative care into standard cancer treatment for malignancies with high symptom burden [11]. However, many challenges exist in the implementation of these integrated models, patients and families, and financial impact on the health system. Although North Carolina’s Medicaid program and most plans offered by Blue Cross and Blue Shield of North Carolina cover palliative care consultations on a fee-for-service basis, the amount of money reimbursed does not cover the cost of running a palliative care program, which is why there are currently few community programs that offer such services.

The lack of widespread adoption of palliative care suggests that barriers to implementation are impeding uptake. The most notable barrier is the difficulty of introducing the topic. Many physicians are uncomfortable conducting end-of-life conversations with their patients [29], and they receive little medical training in communication skills such as breaking bad news or delivering prognoses. In a large study of physicians caring for hospice patients with cancer [30], the predicted survival estimates communicated to patients were 3.5 times greater than actual life expectancy, and the closer the physician–patient relationship, the greater the overestimate. Without accurate information, patients often die in places they would not choose while receiving treatments that offer little benefit.

Another roadblock is the hesitancy of policymakers to address end-of-life care. Public misperceptions and finger-pointing about “death panels” during debates over the Patient Protection and Affordable Care Act of 2010 spooked advocates and resulted in legislators subsequently becoming more guarded. Change is in the air, however; there is early bipartisan support for the Patient Centered Quality Care for Life Act [31] and for the Palliative Care and Hospice Education and Training Act [32], both of which currently rest with the Health Subcommittee of the House Energy and Commerce committee. Passage of the latter bill would increase funding for training of the palliative care clinical workforce and would bring attention to important palliative care needs of patients and families.

One further roadblock can be best summarized as lack...
including the pressure to reduce overall health care costs, lack of necessary tools and skills on the part of health care providers, and the mistaken tendency to equate palliative care with end-of-life care.

The Concurrent Care for Children Requirement has been challenging to implement in many states, including North Carolina. Despite the fact that palliative care is now widely recognized as a critical part of excellent care for children with life-limiting diseases such as cancer, patients continue to receive this care very late in their illness trajectory [12, 13]. In 1 study, the median time between palliative care consultation and death was only 8 days [14]. However, as evidence grows that introducing palliative care early in the course of therapy benefits children with cancer, and as the medical culture becomes more aware of the evidence demonstrating the value of such an approach, pediatric oncology and palliative care will continue to become more integrated. This will benefit children, their families, and the staff members who care for them. NCMJ

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of awareness. Without public and clinical understanding of the role of palliative care, it is hard to expand its availability. Therefore, multiple clinical professional organizations have sought to increase awareness of palliative care among their members.

For example, in 2012 the American Society for Clinical Oncology issued a provisional clinical opinion about integrating palliative care into the standard practice of oncology [33]. This document makes the following points: First, palliative care leads to better patient and caregiver outcomes, including symptom improvement, better quality of life, greater patient satisfaction, and reduced caregiver burden. These benefits can be achieved either when palliative care is used in combination with standard cancer care or when palliative care is the main focus of care. Second, when palliative care is provided early in the treatment trajectory, referrals to and use of hospice care are more appropriate, and futile use of intensive care is reduced. Third, no trials to date have demonstrated harm to patients and caregivers, or excessive costs, from early involvement of palliative care. Fourth, patients with metastatic non–small-cell lung cancer should be offered standard oncologic care and concurrent palliative care, preferably at the time of the initial diagnosis. Fifth, standard oncologic care and palliative care should be combined early in the course of illness for patients with metastatic cancer and/or high symptom burden. Finally, future research should focus on how early palliative care impacts essential patient and caregiver outcomes (eg, quality of life, survival, utilization of health care services, and costs) and how it impacts society.

The potential benefits of palliative care to patients and families often remain unrealized and underappreciated. The limited penetration of palliative care into mainstream treatment of serious disease—despite the evidence that palliative care results in better quality of life, reduction of symptom load, and cost savings—means that an inordinately high fraction of patients with serious illness will endure needless suffering. Hopefully the expanding base of compelling evi-
dence regarding palliative care will raise awareness of the benefits of such care among patients, providers, and policymakers. NCMJ

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