Changing the Image of Palliative Care

Lillie D. Shockney, RN, BS, MAS

I am enthusiastic about this 6-part series titled Conquering the Cancer Care Continuum. Each edition of CCC will address an important topic in oncology management and offer expert stakeholder commentaries. Topics will include: palliative care, pain management, hospice care, comprehensive treatment planning, survivorship care, and the role of biosimilars in supportive care. In this issue, we address palliative care.

Palliation in cancer care is a topic that commonly makes people (medical providers as well as patients) uncomfortable. I recently had the opportunity to speak with members of our palliative care team at Johns Hopkins and learned that the word “palliative” comes from the word “palliare,” which means to disguise or cloak. Centuries ago, this word was used for the drapes that covered a casket. Although we continue to drape coffins—most memorably with the flag—the drape is no longer referred to by this term.

The World Health Organization modified its original definition of palliative care as follows: “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.” (http://www.who.int/cancer/palliative/en/).

For too long, however, the image of palliative care has been tied exclusively to end-of-life care and focused solely on pain control.

The articles that follow provide a clear understanding of the intent of palliative care today, with the primary goal of ending its identification solely as cancer care provided for the dying. Instead, palliative care should be associated with quality-of-life care for all cancer patients and survivors, no matter what their clinical outcome.

Your cancer patients may not tell you about the side effects of treatment they are experiencing or about their discomfort due to their cancer diagnosis or its treatment. In many cases they may simply assume that the discomfort “comes with the disease.” However, with the improvements in medicine and the power of science, it doesn’t have to anymore. Do not wait for your patients to initiate a discussion about their symptoms; be proactive and initiate this discussion at the time you are plan-
It is my hope that after you read this supplement, you will begin helping the patients you care for experience the benefits of palliative care...

There is not an abundance of palliative care medical experts despite the fact that the need for their expertise and counsel continues to grow. This results in the need to educate more oncology specialists in palliation as well as to turn to physician extenders who can assume responsibility for addressing the quality-of-life needs of our patients.

Recently, I arranged for my own father to have a palliative care consultation. He has been living with metastatic cancer for many years and had developed acute pain symptoms due to a T5 fracture. I knew he would be a “no show” if I told him that I was arranging for him to see the palliative care team, so I told him that I had arranged a meeting with our quality-of-life coach and the coach’s team. He came. He was asked to name the 3 things that give him the most joy in life, and those 3 things became the shared goals of the quality-of-life team. Amazingly, through their effective interventions, in 2 weeks he was back out on his John Deere tractor (one of his 3 joys). He certainly did not associate the palliative care team with end-of-life care.

I look forward to the day that I can comfortably say to a patient, “We have arranged for you to have a consultation with our palliative care team” and not have the patient equate this statement with “You are going to die of cancer,” when in fact, they may not. We have a long way to go to change this perception. It is my hope that after you read this supplement, you will begin helping the patients you care for experience the benefits of palliative care so their cancer treatment can be the least physically and emotionally burdensome possible.
Overview of Palliation in Cancer Care

Lynne Lederman, PhD

This, the first issue in the second annual Conquering the Cancer Care Continuum series, focuses on palliation in cancer care. Future articles in the series will explore oncology pain management, hospice care options, treatment planning through the cancer care continuum, survivorship care programs, and the role of biosimilars in supportive care. This article introduces and distinguishes the concepts of palliative care and hospice care in the context of cancer care.

Cancer is the second most common cause of death in the United States after heart disease. The American Cancer Society (ACS) estimates that in 2012 nearly 14 million Americans with a history of cancer were still alive. This does not include individuals with noninvasive cancers other than bladder cancer or those with nonmelanoma skin cancers. Over the next 10 years, estimates indicate the number of cancer survivors in the United States will increase to nearly 18 million individuals. This translates into a large number of people who will be potential candidates for palliative and/or hospice care.

In 2010, a task force of the American Academy of Hospice and Palliative Medicine estimated that there were about 4400 hospice and palliative care medicine physicians in the United States, and that most of them practiced this specialty part time. This task force further estimated that nearly 4500 hospice care physicians and nearly 11,000 palliative care physicians would be needed full time to staff hospice- and hospital-based programs at an appropriate level. Therefore, there is an acute shortage of hospice and palliative care physicians, and the current capacity of training programs will not fill this gap. This shortfall can only be expected to worsen as the number of patients with cancer who need palliative and hospice services increases. Changes in current healthcare regulations and growth in palliative services offered in long-term care and home-based programs could further increase the need for physicians specifically trained in hospice and palliative care medicine. However, the need for more hospice and palliative care medicine physicians could be alleviated, at least in part, by some of their workload being transferred to nurse practitioners and other advanced practice nurses with appropriate training in palliative care.

Palliative care improves quality of life

Palliative care is defined as any type of treatment that focuses on reducing patients’ symptoms and improving their quality of life, and that also provides support for patients, their families, and their caregivers. Even when cure is the goal of cancer treatment, palliative care improves the quality of life of patients, their satisfaction with care, and end-of-life outcomes and reduces the burden on caregivers. Palliative care has also been shown to decrease the inappropriate use of medical interventions, decrease pain and symptom distress, increase survival (for some types of cancer), and possibly improve the survival of family caregivers of patients after the patients have died.

Hospice care is a form of palliative care

The focus of hospice care is on enhancing patient quality of life, and like palliative care, it may also extend survival. Hospice care is palliative care that is given to individuals of any age with any type of cancer who have a life expectancy of 6 months or less. Therefore, at least in theory, palliative care is offered earlier in the cancer disease journey than hospice care. Patients who are receiving hospice care who survive longer than 6 months are still eligible to continue in hospice with recertification. Hospice care is given to
patients who are no longer receiving cancer-specific treatment because their cancer is incurable. Despite promoting this definition of hospice, Cancer.Net, which publishes oncologist-approved information for patients from the American Society of Clinical Oncology, suggests that patients might opt to continue disease-specific anticancer treatment even when their cancer is not responding to treatment if they are unable to accept a terminal diagnosis or to accept that their cancer treatment is futile. This could be an issue for patients covered by Medicare who might not be eligible for both active disease treatment and hospice care simultaneously. It is recommended, therefore, that the agreement to accept hospice care should be accompanied by an informed decision to discontinue curative cancer treatment.

Ideally, palliative medicine practitioners should form part of a multidisciplinary team along with other specialists to manage symptoms and provide support for maintaining an appropriate care setting for patients.

When palliative care is appropriate

Palliative care should begin as soon as possible and continue throughout the continuum of the cancer journey independent of the expected outcome, that is, whether the cancer is deemed curable or not. Patients of any age are eligible for palliative care, including children, and family members and caregivers may also receive treatment, eg, counseling, to help them handle the patient’s diagnosis and burdens of caregiving. Palliative care is not end-of-life care per se, and should not be instituted only after treatment is deemed ineffective. There is no gold standard for palliative care programs. Suggested goals of palliative care include addressing the following patient conditions and concerns:

- physical symptoms, eg, pain or nausea, whether due to the cancer or resulting from its treatment
- emotional symptoms, eg, anxiety, depression
- practical requirements, eg, transportation, financial worries, legal issues, employment, insurance
- social needs, eg, family or other relationship problems
- spiritual needs and care

In addition, palliative care should include addressing the needs and concerns of the patient’s family and caregivers.

Administration of palliative care

Ideally, palliative medicine practitioners should form part of a multidisciplinary team along with other specialists to manage symptoms and provide support for maintaining an appropriate care setting for patients. Palliative medicine is a formally recognized medical subspecialty, with accreditation of Hospice and Palliative Medicine as a subspecialty provided by the American Board of Internal Medicine. Someone with this accreditation would be ideal to lead the multidisciplinary team, although, as mentioned, there is a shortage of these individuals in the United States. Currently there is a wide range of services considered to fall under the umbrella of palliative care, and all appropriate services may not be available or provided in a given setting. Palliative care may be provided in a hospital or other setting such as the patient’s home, outpatient clinic, acute palliative care unit, or in a long-term care facility.

Nurses are important members of the palliative care team and may often be the ones directly delivering physician-ordered care to the patient. There is clinical trial-based evidence that nurse-led educational and follow-up interventions for patients with advanced cancer can improve patient quality of life and mood, but these interventions did not alter symptom control, hospitalizations, and hospice use, possibly because the latter three are usually under the management of a physician. Counseling may be provided for the patient, family, and caregivers by social workers or others with specific psychiatric training. Services can include grief counseling after the patient’s death. Social workers may also help patients and their families resolve financial concerns and can facilitate patient transitions, whether from the hospital to home or, if and when the time comes, from palliative care to hospice care. Patients may also be referred to physical therapists who can help them maintain functional mobility and ensure a safe home environment. Occupational therapists can aid with specific mobility
Models of palliative care

Bruera and Hui describe 3 models that oncologists might use to integrate palliative and supportive care into their practices. Palliative care is sometimes referred to as “supportive” care because surveys show that oncologists find the term less distressing than the term “palliative” and the use of the descriptor “supportive” may facilitate earlier patient referrals to this type of care. The advantages and disadvantages of each care model are summarized in the Table. In the solo practice model the oncologist not only assesses, treats, and manages the primary disease (cancer), but also takes responsibility for the patient’s supportive and palliative needs. This is the model often followed in private practice and in communities where palliative care consultants are not available. In the congress approach, which is an attempt at interdisciplinary care, the primary oncologist refers patients to multiple consultants; the patient would see one consultant for pain, another consultant for neurologic symptoms, a psychiatrist or psychiatric social worker for psychosocial distress, and so on. In the true integrated care model, the oncologist’s primary focus is managing the patient’s cancer, while the supportive/palliative team manages the patient’s physical and psychosocial symptoms and distress. In this integrated care model there is still space for consultations with specialists to handle specific problems, eg, a pulmonary consult in the case of bronchial obstruction, but it is the palliative care team that addresses most of the patient’s concerns.

Although it is possible, and may be necessary, to follow the solo practice model, Bruera and Hui believe that oncologists are better served by following an integrated care model, and they do not recommend the congress approach. They observe that palliative care can be in-

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<th>Model</th>
<th>Advantages</th>
<th>Disadvantages</th>
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<tr>
<td>Solo practice</td>
<td>All patient care provided by 1 healthcare professional</td>
<td>Time constraints, Limited palliative care training, Risk of burn-out from providing all of each patient’s care</td>
</tr>
<tr>
<td>Congress approach</td>
<td>None stated</td>
<td>Exhausting and expensive for patient, May compromise patient care, Lack of interaction among consultants can result in conflicting messages, drug interactions, and additional problems caused while trying to resolve initial concerns</td>
</tr>
<tr>
<td>Integrated care</td>
<td>Oncologist focuses on cancer care while palliative team manages most other concerns, Fewer visits for patients, lower costs</td>
<td>May not be available in small communities</td>
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tegrated into the current model of cancer care that already includes collaboration among practitioners of surgical, radiation, and medical oncology. Muir and colleagues described a pilot study of integrating palliative care into an outpatient, private practice oncology setting that included physicians and nurse practitioners, and was not a solo practice. This resulted in a measurable reduction in symptom burden for patients, savings in oncology provider time per palliative care consultation, cost savings, and an increase in referrals from within the embedded practice. The authors speculate that this model may improve quality of care and should be studied further.

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Nevertheless, the most recent data, available from a 2009 survey of cancer centers approved by the Commission on Cancer, indicate that even though there are palliative care programs at most cancer centers, there is much room for improvement in the delivery of palliative care. Programs across the United States are heterogeneous, and half do not have an outpatient clinic, palliative care unit, or hospice, and less than half had fellowship or research programs. This may be an overestimate because nonaccredited hospitals were not included in the survey. Referrals to palliative care tended to occur late in the course of disease, rather than early, even though late referral limits the effectiveness of palliative care.

Hospice care settings

The same types of providers involved in palliative care are responsible for hospice care. However, when a patient receiving palliative care becomes eligible for hospice care, their palliative care team may not be the same team responsible for their hospice care. A palliative care specialist can help the patient make that transition. Hospice care is most often administered to patients in their own homes. However, hospice care can also be delivered in hospitals or in nonhospital inpatient settings such as hospice centers or skilled nursing facilities.

Looking forward

Although there has been resistance to palliative care comanagement among some oncologists, palliative care not only has benefits for patients with cancer and their caregivers when initiated at diagnosis, it is relatively low in both risks and costs when compared with active anticancer treatments. The requirement for access to palliative care by certifying organizations, such as the American College of Surgeon’s Commission on Cancer, is likely to improve patient access. In addition, the Affordable Care Act will require hospice to report to the Centers for Medicare & Medicaid Services on quality measures by October 2013. Pain experienced by cancer patients at all stages of the disease is a significant problem and is associated with other symptoms and complications. Pain management in oncology is the subject of the next article in this series.

References

I will never forget the first patient I saw during my training in a forward-thinking, early interventional palliative care clinic. It was the spring of 2008 and I was completing my hematology/oncology pharmacy residency at Emory Healthcare in Atlanta, Georgia. The patient was an older man with small cell lung cancer. He wasn’t the type of patient that was accustomed to complaining about physical ailments. Yet, as he sat before us, family at his side, he shared openly the symptoms he suffered from a Pancoast tumor in the apex of his right lung that had left him with diminished usefulness of and neuropathy in 2 fingers of his right hand. Acting in accordance with clinical practice guidelines at that time, many medical oncologists might have chosen to begin chemotherapy and reassure the patient that his symptoms would likely improve as his disease responded to the cocktail of drugs chosen for him. Rather, the palliative care team made the decision to seek radiation therapy designed to provide symptom relief and improvement in his quality of life first, then pursue chemotherapy. Philosophically, the lessons in palliative care medicine that have stayed with me from that experience come less from the medical decision making and more from the empathy and care demonstrated by that physician and team in the time they spent getting to know the patient and understanding the goals he was establishing for his own treatment. Rather than waiting until this patient was in his final days of life to initiate palliative care through hospice, this physician and this clinic emphasized the value of the life this patient had remaining and worked proactively to remove barriers such as financial concerns, legal issues, and spiritual issues from his path so that his focus could remain on fighting his cancer. 

As Dr Lederman illustrates in this first installment of the series on Conquering the Cancer Care Continuum, “palliative care should begin as soon as possible... whether the cancer is deemed curable or not.” She argues that an effective way of improving the quality of palliative care a patient receives is by palliative medicine practitioners forming part of a multidisciplinary team along with other specialists. As an oncology pharmacist, I represent a profession that plays a clear and valuable role in the multidisciplinary delivery of palliative medicine for patients with cancer. In fact, I am frequently asked by pharmacy students and medical residents what impact or function the pharmacist has in this environment. My role and that of other pharmacists involved in palliative medicine echoes the vision found in a position statement on this topic from the American Society of Health-System Pharmacists (ASHP). Participation in the care of these patients frequently requires making recommendations on the “appropriateness of medication orders and ensuring the timely provision of effective medication” management.\(^1\) Not only does the ASHP position statement encompass those medications used for the direct management of disease- or treatment-related symptoms or those required for comfort care, but often it also involves decision making related to maintenance medications for chronic diseases whose treatment may become less important in patients with limited life expectancy.

Additionally, pharmacists routinely spend significant time educating members of the healthcare team, as well as patients and their families, on specific medications or...
Caring for cancer patients has always been more than just administering treatments targeted against the cancer itself. Treatment of the entire patient includes addressing other medical issues, cancer-related symptoms, side effects from the treatment, psychosocial issues, and interpersonal dynamics with friends and family. However, for multiple reasons (time, resources, and abilities) tackling each of these issues is increasingly more difficult for a single practitioner. The care of a cancer patient requires an integrated team approach, including nursing support, advanced practice nurses and/or physician assistants, nutritionists, and social workers. In addition, a team of specialists in palliative care is increasingly being realized as essential to be integrated in many, if not all, patients’ teams.

Dr Lederman’s article cites the many benefits of the addition of palliative care specialists in the care of cancer patients. While I agree with all of the elements of the article, a few additional considerations are worth noting. One provocative and potentially groundbreaking study on palliative care integration was not cited in the article. Dr Jennifer Temel at the Massachusetts General Hospital conducted a small pilot study with 151 patients recently diagnosed with metastatic non–small cell lung cancer.1 All patients were under the care of a medical oncologist at a single institution and were to start first-line palliative chemotherapy. Patients were randomly assigned either to have a palliative care team comanage their care from the start of first-line treatment onward or receive standard oncology care only (with the option to consult the palliative care team at some point during care). As hypothesized by the investigators when the study was designed, patients who were assigned to early palliative care showed statistically significant improvements in quality of life and depressive symptoms. Further, patients assigned to early palliative care received less aggressive direct cancer treatments at the very end of life. However, despite maintaining cancer treatments longer in the standard oncology care group, those assigned to early palliative care had a statistically significant improvement in overall survival (11.6 months vs 8.9 months, P=0.02). An improvement in median survival by 2.7 months is longer than seen in most clinical trials of newer, expensive therapeutics. However, the cautions that are worth noting in interpreting this trial are that the trial was a single-institution experience which always has issues with generalizability. Additionally, survival was not a primary end point of the study and thus should be considered more exploratory than definitive evidence of a survival benefit, and all patients had a single type of cancer, raising questions whether these findings apply to other metastatic cancers (some of which will have more effective, better-tolerated treatments).

A second issue to consider in deciding upon a model of integrating palliative care (Table in Dr Lederman’s paper) is that while an integrated care model may be the most streamlined, I strongly believe that the role of a medical oncologist (as well as radiation and surgical oncologist) still involves the care of the whole patient. In my own practice, I definitely utilize our palliative care specialists frequently for patients with more challenging and complex symptoms. However, I believe my role is to offer palliative chemotherapy as well as provide best...
supportive care to all patients, which includes treating pain, helping with nausea (disease- or treatment-associated), etc. I do not think medical oncology practitioners should fully outsource all care of the patient with the exception of writing the chemotherapy orders. While I do not think Dr. Lederman’s article implies this, in practice, particularly at times on our inpatient wards, we have providers immediately consulting our excellent palliative care team for what should be straightforward symptom management. Given that most areas still have a limited number of palliative care providers, medical oncology practitioners need to maintain and update their skills and knowledge in symptom management and use palliative care providers for patients that require a higher level of management, often related to failure of standard measures for palliative symptoms.

Finally, the issue of reimbursement of palliative care team models requires discussion on many levels, from insurance companies, hospitals, and the government. This may become increasingly more relevant if certain reimbursement models, such as accountable care organizations, prove worthy of pursuit. Although there is clear recognition on all levels that integrative palliative care is better for most patients and, at the end, saves money, how to distribute reimbursements that may come in bundle format will be critical questions for many practices.

In summary, Dr. Lederman’s overview brings forth a critical topic that is very relevant and pressing to the changing face of cancer care. More research and education will ultimately continue to move the field forward.

Reference

Stakeholder’s Perspective (Continued from page 7)

symptom management strategies. Bruera and Hui remind us that patients should be able to “take advantage of the expertise of both the oncology and the palliative care teams in optimizing quantity and quality of life.”

In this setting, the pharmacist can serve as a drug information resource, as a drug therapy expert, and as an educator. Each of these roles provides value in alleviating some of the preparation time the physician spends addressing an individual patient’s needs, instead shifting these responsibilities to trained and capable members of the larger multidisciplinary team.

As a pharmacist and contributor to the palliative care management of patients with cancer, I view it as essential that we tirelessly work as a multidisciplinary team to overcome the stigma associated with palliative care. Today, as I serve as preceptor and mentor to trainees of my own, I remind them that the terms palliative care and hospice are not synonymous and want them to understand that hospice is not a place, rather, it is a philosophy of care. More broadly, palliative medicine is a philosophy of care that deserves its rightful place alongside life-prolonging therapies begun in the earliest stages of patient care following diagnosis. Ultimately, we must remember that each member of the multidisciplinary palliative care team has unique skills and knowledge that, when empowered to practice their own specialized discipline, reduces the burden of work of each team member and, most importantly, directly benefits the patients whom we have been called to serve.

References
Dr. Lederman provides a thorough overview of palliation in cancer care in the article. This much is clear: Palliative care improves the quality of life of cancer patients. Thus, palliative care services should begin as soon as possible in patients with cancer. In fact, one study has shown palliative and hospice services can increase one's life expectancy. The general purpose of this commentary is to describe how palliative care services are used within my practice and to review a study that demonstrates how a nurse-led palliative care intervention can improve quality of life and mood.

The majority of my patients have a diagnosis of multiple myeloma (MM). MM is an incurable cancer of the bone marrow plasma cells. The overall survival of MM has improved significantly in the past 10 years. However, symptoms of the disease and treatment (such as pain and peripheral neuropathy) can plague patients for the duration of the illness. Therefore, it is important to address each of these issues as early as possible and with a multidisciplinary approach.

Bone pain is a common presenting physical symptom of MM. Pain management is the most common reason why patients within my practice are referred to palliative care. An estimated 90% of patients will develop bone lesions during the illness. Bone pain related to MM occurs as a result of osteolysis and increased cytokine activity. Bone lesions form and often cause the individual to experience pain that can be severe. Further, osteolysis can cause hypercalcemia of malignancy and an increased risk of bone fractures. The vertebral bodies are particularly vulnerable.

Bone pain as a result of MM can be difficult to manage and usually requires a multidisciplinary approach which palliative care services provide. Medical management includes treatment of the disease with chemotherapy or radiation therapy, opioid analgesia, and adjunct agents. Surgical management with a balloon kyphoplasty procedure or tumor excision may also be necessary. Physical therapy and rehabilitation are often required to improve strength.

I am fortunate to have a world-renowned, multidisciplinary palliative care team of experts at my institution, the Cleveland Clinic. The group of physicians, nurses, social workers, and case managers with whom I work are uniquely qualified to provide aggressive symptom management and spiritual care to improve patient and family outcomes. As palliative care services provide valuable resources to treat physical and psychological symptoms of MM and disease sequelae, patients in my practice with MM and in need of symptom management are often referred to palliative care at diagnosis. The palliative care team follows each patient throughout the disease trajectory.

A team approach to palliative care is a key component to the success of a palliative program. Nurses are a critical link to improved patient outcomes. This has been demonstrated in a randomized controlled trial.
study of 322 patients with cancer was conducted between November 2002 and May 2008. The study compared a palliative care intervention with usual care for persons newly diagnosed with advanced cancer. The palliative care intervention was administered by advanced practice nurses and consisted of case management and educational approaches to encourage patient activation, counseling, self-management, and empowerment. The intervention was administered to the intervention group on a weekly basis for the first month, then monthly until death. The intervention included a bereavement follow-up phone call to the caregiver.

Patients who received the nurse-led, palliative care–focused intervention, which addressed physical, psychosocial, and care coordination with oncology care, had higher scores for quality of life and mood than the usual care group ($P = 0.02$). The median survival for the intervention group was 14 months (95% CI, 10.6-18.4 months) and 8.5 months (95% CI, 7.0-11.1 months) for the usual care group ($P = 0.14$). Although the overall survival was not statistically significant as the study was underpowered, there is clearly a clinical significance to the study findings.

I have been caring for individuals with cancer for more than 15 years. I have witnessed first-hand the unique ability of the palliative care team to integrate psychological and spiritual care into medical care. The oncology practitioner should be aware of the benefits of palliative care and the role of the nurse, and encourage patients to use palliative care resources earlier rather than later.

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