

CARE IN THE COMMUNITY

Integrating Palliative Care Into Outpatient Oncology: A Case Study

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ALTHOUGH A SIGNIFICANT EVIDENCE BASE EXISTS to support the integration of palliative care in the care of cancer patients, difficulty comes from how to actually operationalize it. There is no standard method for integrating palliative care into outpatient oncology practices, and no examples of how cancer centers are doing it. The 2016 edition of the Commission on Cancer standard 2.4 states, “Palliative care services are available to patients either on-site or by referral.”¹ Further, clinical organizations like the American Society of Clinical Oncology support the integration of palliative care into the care of “any patient with metastatic cancer and/or high symptom burden.”² This article will present, as a case study, one program’s integration of palliative care services into outpatient community oncology. The benefits and challenges will be explored, as well as evidence for why palliative care clinicians are an integral part of the outpatient oncology care team.

Defining the Expanse of Palliative Care Services

The first step in successful integration should be defining what palliative care is and is not. Palliative care is a fairly new specialty, having started as an inpatient consult service that recently expanded into the outpatient community. The National Quality Forum developed a consensus report in 2006 on the preferred practices for Palliative Care and Hospice Quality,³ where they defined palliative care as, “Patient and 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 to facilitate patient autonomy, access to information, and choice.”^{3,4}

The following are features of the philosophy and delivery of palliative care:

- Care is provided and services are coordinated by an interdisciplinary team
- Patients, families, and palliative and nonpalliative healthcare providers collaborate and communicate on care needs
- Services are available concurrently with, or independent of, curative or life-prolonging care
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death⁵

Palliative care can be thought of as an umbrella, with the umbrella representing the protection palliation can provide for patients with serious illness.⁶ Palliative care addresses the patients’ quality of life (QOL), symptom management, advance care planning, and goals of care. Once the patient is under the protection of the umbrella, hospice care and comfort are the goals of care. The handle of the umbrella represents bereave-

FIGURE. Palliative Cares Services Provide an Umbrella of Care for Cancer Patients



ment services for families (see **FIGURE**). This model helps with the understanding that palliative care is not hospice or end-of-life (EOL) care alone (hospice is a type of palliative care, but palliative care is much broader). Palliative care should be integrated into care from the time of diagnosis of a serious illness, and it works as an extra layer of support for patients, families, and staff dealing with serious illness.⁶

Case Study

A health network in western Connecticut is home to a robust inpatient palliative care service, which was established late in 2003 and continued to expand over the next decade. In 2013, the palliative care team and the community cancer center decided to explore the trial integration of palliative care into the outpatient oncology practice. Designated cancer centers tend to have more robust palliative care service but largely use consulting services to provide their palliative care.⁷ Although the physicians were familiar with the palliative care advanced practice registered nurse (APRN) from the inpatient service, they still expressed concern and had some misunderstanding regarding the role of palliative care. There was concern that the palliative care team would tell patients they were dying before the patients were ready to discuss death. Some oncologists felt, too, that their patients would get upset hearing the word “palliative.”

As a first step, an APRN with expertise in palliative care was assigned to the cancer center for 1 afternoon every week. The interdisciplinary team included the oncology team, palliative care APRN, oncology social worker, and other support services available in the cancer center. Initially, patients were seen by

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the palliative care service while they were an inpatient and were subsequently seen in the outpatient oncology office for follow-up care. This was a good way to start to get to know the practice and team members and begin to gain trust. The APRN also attended lung and gastrointestinal (GI) tumor boards and completed a palliative care screening on newly diagnosed patients, with the goal being able to identify appropriate patients and see them soon after diagnosis.

The focus of this pilot was on diagnoses that were stage IIIb and above, recurrent or metastatic disease, and solid organ tumors. The patients identified by the tumor board often fell through the cracks due to difficulty in obtaining the oncologist's approval and lack of a clear process for arranging appointments following tumor boards. The barriers identified included:

- Lack of understanding of the APRN's role
- Fear that the patients would not want to hear the term "palliative care"
- Trying to fit another appointment into the patients' already full schedules

A Team Effort

The APRN and the oncology team brainstormed to carve out an ongoing education program for the oncology team, which would cover the role of palliative care in improving clinical outcomes. Further, it was collaboratively decided that the best way to fully integrate the palliative program was to have the APRN meet the patient with the oncologist on their initial consult visit in the outpatient oncology office. The palliative care APRN introduced herself as "another member of the oncology team to provide you with an extra layer of support." The benefit of this model was the oncologist got to experience exactly how the APRN introduced the topic of palliative care to a newly diagnosed patient prior to treatment initiation. This created trust with the oncologists, and referrals started coming in.

Initially, the APRN had enough flexibility within her schedule to be able to see most patients when they were already in the office for other appointments, including for chemotherapy or radiation therapy. Eventually, however, the patient load became too large and patients were being missed. This called for another brainstorming session, so the team sat down again and decided the best way to integrate was to have a palliative care APRN on staff in the practice. Trust with providers about the palliative care service now exists. Once patients are identified by tumor boards, the APRN can see patients once they are identified in tumor boards by scheduling the appointment sooner.

Many lessons were learned as the program grew, with the most important lesson being the oncologist must have full trust in the palliative care provider. For the program to be effective, trust needs to be built with the palliative care team, and the oncologist must witness the interactions that the palliative care providers have with patients and their families. Another lesson learned is how many stage IV patients actually want to know about hospice on their initial visit. This was a shocking discovery and very refreshing. The most frequent question asked was, "How am I going to know when it is time for hospice?" These patients were accepting treatment but had not started it, yet they were already thinking about their EOL care.

All of the palliative care APRN visits were billable, as long as another APRN had not seen the patient on the same day. Over time, we also learned that it is important to continue to provide education on palliative care and assess the model of care being provided. The model may need to change over time, and palliative care teams need to be able to flex their services based on the needs of their patients and families.

Evidence-Based Integration of Palliative Care

So, what does the evidence support? From a clinical perspective, a vast amount of research supports the benefits of palliative care in outpatient oncology. Patients are living longer with a serious illness and heavy symptom burden. Nearly half of patients diagnosed with a metastatic cancer will live for years following diagnosis,² and those years may be riddled with multiple on-going symptoms that may have a negative impact on the patients' QOL. According to a study by Ferrell et al, patients with non-small cell lung cancer (NSCLC) who received palliative care intervention had significantly better QOL scores, better symptom control, better spiritual well-being, and lower psychological distress.⁸ The intervention group had a higher advance directive completion rate and higher referrals to supportive services, with greater improvements in their stage IV disease. A study by Greer et al had similar results, showing higher QOL scores and less depression in patients with incurable lung and GI cancers when palliative care was included in the treatment plan.⁹ This group also reported discussing their EOL preferences more than patients who were not seen by a palliative care specialist.

The benefits of quality palliative care on patient survival remains a topic of ongoing research. A groundbreaking study by Temel and others was the first to show the survival benefit of palliation in patients with NSCLC—up to 2.7 months longer for patients who received palliative care compared with those who did not.¹⁰ The "why" of these results, however, is yet to be determined.

A heavy symptom burden can affect patients: physically, psychologically, spiritually, and existentially. Uncontrolled pain and symptoms can lead to poor QOL, loss of purpose, loss of financial resources, and lack of sleep and can prevent the body from functioning optimally. Palliative care looks at the whole patient and addresses all aspects of care to assist with better symptom control and better QOL, resulting in patients living longer.

Educating Providers

Education has been identified as a barrier to quality palliative care services in oncology. The 2014 Institute of Medicine (IOM) report, *Dying in America*, recommends that "Educational institutions, professional societies, accrediting organizations, certifying bodies, healthcare delivery organizations, and medical centers take measures to both increase the number of palliative care specialists and expand the knowledge base for all clinicians."¹¹ Physicians and nurses often feel ill-prepared to discuss palliative or EOL care with their patients and families. A study among 675 nurses and physicians identified need for more basic information on palliative care, improved training on communication skills, and knowledge of how to take better care of the patient's caregivers.¹² When Horlait et al examined what oncologists identified as barriers in discussing palliative care with their patients, they found that these discussions were perceived as a "complex and emotional task," which in turn led to palliative care referrals being made late in the course of the illness.¹³

The benefits of palliative care can be seen at any age level. Mahmood et al found that not only is palliative care feasible for children with high-risk cancer, but was also acceptable to the children, families, and pediatric oncologists.¹⁴ Caring for older adults with cancer can be challenging because they often suffer multiple co-morbidities and decreasing functional status, which need to be taken

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into consideration when discussing treatment options. Palliative care should be provided from the moment of diagnosis to ensure adequate symptom management and to ensure that treatments are aligned with the patient's preferences and values.¹⁵ Palliative care can prove beneficial to a host of individuals, including cancer survivors,¹⁶ hematopoietic transplant patients,¹⁷ patients with hematological malignancies,¹⁸ adolescents and young adults,¹⁹ as well as patients participating in clinical trials.²⁰

Cost of Care

Another barrier identified in the literature is cost. Several studies have identified a perceived barrier related to the cost involved in implementing palliative care programs in cancer centers. Palliative care programs have struggled to provide cost benefit analysis of their services. Cost savings are a secondary outcome and can be realized when patient preferences are documented and obeyed. Palliative care does not convince patients to follow a conservative plan of care or sign-on to hospice. To the contrary, palliative care practitioners are expert at eliciting the patient's goals and values and helping integrate them in the treatment plan. Patients may identify not wanting that "last resort" treat-

ment or not wanting to go to the hospital any longer. Some patients may decide they want everything done so they can see their first grandchild born. Patients and families often do not understand that they have a choice in treatments—they may even feel guilty about wanting to stop treatment and expressing this to their oncologist. Also, it is often difficult for patients to tell their own family members that they have had enough treatment and that they would like the focus of their care to be comfort

only. Palliative care teams have the skill to advocate for their patients' preferences and assist the patient in discussing those preferences with their oncologist and family. Aligning treatment with patient goals can also save costs via reduced hospitalizations and by avoiding expensive treatments and procedures that are not aligned with the patient preferences.

In conclusion, there is a strong evidence to support integrating palliative care into cancer centers. However, an understanding of what palliative care is and what it isn't is crucial for this integration. A majority of patients with cancer consider their disease a "serious illness," and they will most definitely benefit from a palliative care intervention. A standard approach will also decrease the misunderstanding that palliative care is hospice or EOL care, and ensure that patients benefit from palliative care programs. Early palliative care can prolong survival for some diagnoses, improve QOL, decrease symptom burden, and improve patient and family satisfaction. The example in this paper reviewed some of the challenges that may be encountered during integration, and some solutions to overcome them. As the field of palliative care continues to grow, cancer centers should share examples of how they have successfully integrated palliative care into their centers, so others can learn from their successes and challenges. ♦

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