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Culture Clash No More: Integration and Coordination of Disease Treatment and Palliative Care

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Learning Objectives

1. Describe the limitations of the Medicare hospice benefit
2. Define three models of palliative care
3. Identify the benefits and barriers to early palliative care referral and intervention
4. Identify reasons patients are lost to follow up
5. Recognize the importance of health literacy to care decisions
6. List possible disease treatments that fit into the hospice model

The Case

A 77-year-old man with no significant medical history initially presented to the Emergency Department (ED) for abdominal pain. During the patient's evaluation, he was found to have a rectal mass. The patient declined any surgical intervention or chemotherapy after discussing goals of care with an oncologist. He underwent two rounds of targeted radiotherapy and then was lost to follow up. The patient re-presented to the ED after a fall at home. He had been living independently. In the ED, slight left sided weakness was noted that contributed to dysarthria, difficulty ambulating, bathing/toileting, and feeding himself. Lung and brain imaging revealed new metastatic lesions in both lungs and numerous enhancing lesions in the brain. The patient was started on high dose steroids to reduce cerebral edema. Further discussions of the goals of care revealed that the patient desired to focus on comfort and on maintaining independence for as long as possible. He was discharged to an inpatient hospice for comfort care.

The inpatient hospice team discussed the potential role of brain radiotherapy for palliation to meet the goal of maintaining independence. The patient agreed to a radiation oncology evaluation and successfully completed a course of central nervous system (CNS) radiation in five divided doses. The patient’s strength, energy, and speech improved, and he was able to feed himself, groom himself, and ambulate several feet with assistance. He was able to spend time with his friends and family and have clear conversations with them and participate in activities due to his improved function.

The Commentary

By Hannah Spero, MSN, APRN, Angela E. Usher, PhD, LCSW, Brian Howard MS1, and Frederick J. Meyers, MD

When Policy Lags Behind Care: The Hospice Benefit

This case came to attention because of a perceived delay in palliative radiation, an “error” in care. The impact of the delay was lessened by the hospice team who role modeled integration of disease directed therapy with palliative care, a departure from the historic model of separation of hospice from disease treatment.

In 1982, the Medicare hospice benefit was a landmark recognition that hospice care, a form of intensive and comprehensive palliative care, was a standard of care. Many other insurance companies and programs adopted the regulations of the Medicare hospice benefit for their own reimbursement schemes. However, the capitated benefit included a major prerequisite: that all care related to the terminal illness be paid for by the hospice organization responsible for a patient and their family. The visionary goal of this regulation was to eliminate family concerns about costs related to medications, nursing, team-based support, on-call services, etc. Hospice insisted on physicians and patients declaring their intention to forego all so-called “curative” treatments, also known as disease-directed therapies.

Although the regulation was written to focus care on the “goals of hospice”, emphasizing comfort at the end of life, the consequences included limitations in care that may lead to delayed patient consultation with hospice teams. Fixed levels of reimbursement, at a per diem rate, for each hospice setting do not typically change based on the specific care provided. Hospice programs had a financial interest in avoiding costly interventions for their patients, even measures that would contribute to patient comfort or to new

knowledge, such as clinical trials.[1] In this case, the cost associated with preparing for and administering radiation therapy, in addition to potential medical transportation needs, represented a significant cost to the hospice agency, a cost that was unlikely to be covered by the reimbursement available. Other examples of costly palliative interventions include transfusions, home inotrope therapy, and paracentesis. It is commendable that this hospice took on this palliative effort for their patient, but it is not a common occurrence. Many hospices at the outset specify which costly palliative treatments they will or will not "approve."

In addition to the financial implications of costly palliative interventions for hospices, it is also important in this case to address the language of hospice: "foregoing disease-directed therapy". This language is now the culture for hospice programs. Sadly, the regulations of hospice have led to persistent non-referral of patients to hospice or referral during the last days of life. Studies show the median hospice enrollment rarely exceeds two to three weeks. The consequences of delayed referral include financial instability for hospice programs and the self-fulfilling expectation that hospice care is merely "brink of death" care. As a result, the culture of hospice and palliative care has become estranged from clinicians who deliver diagnostic and therapeutic interventions. The cultural evolution epitomizing teamwork between palliative care and disease treatment, as modeled in this case, is relatively new, but it makes the conscious decision to prioritize patient care over outdated reimbursement schemes that fail to do so.[2]

Health Literacy and Palliative Care/Hospice Access

This case also illustrates implicit questions about health literacy and care access.[3] This patient initially declined surgical and chemotherapeutic interventions. After two rounds of targeted radiation, he was "lost to follow up." Although we do not have all the socioeconomic or care-related details of this patient's life, these details are vital to an understanding of why he stopped going to his appointments.

The reasons for lost-to-follow-up (LTFU) in patients can be thought of in four broad categories: socioeconomic, psychosocial, structural, and care-related. Examples of reasons in each of these categories can be found in Table 1.

TABLE 1: Lost-to-Follow-Up Factors

Lost-to-Follow-Up (LTFU) Factor Categories	Examples
Socioeconomic	• Low health literacy and/or low overall literacy • Low- or fixed-income status • Food insecurity • Housing insecurity • Transportation difficulties

Lost-to-Follow-Up (LTFU) Factor Categories	Examples
Psychosocial	• Anxiety • Depression • Fear • Isolation • Denial • Poor social support • Strained relationships
Structural	• Lack of automated appointment reminders • Unclear patient instructions • Staffing limitations • Care setting limitations (home visit capacity vs. clinic capacity) • Limited availability of specialty care • Minimal protocols to address LTFU
Care-Related	• Poor symptom control • Negative patient experiences

All healthcare systems should make efforts to understand and re-engage LTFU patients, especially in the cancer population, as LTFU can lead to permanent disability and premature death.[4] There are often solutions to socioeconomic and care-related reasons for LTFU, such as a social work referral for transportation or caregiver resources, additional visits with a registered nurse or an advanced practice provider to improve understanding of care, and more aggressive symptom management efforts in patients with severe side effects. Structural reasons may require larger scale efforts to effect change but are important for organizations to understand how to improve their care systems.

Specific to this case, health literacy also impacts the decision-making process. One study found that health literacy, rather than race, predicted end of life decisions. Patients with lower health literacy were more likely to choose “aggressive treatments” at the end of life.[5] Although this patient chose to forgo aggressive measures, his choice could have been compromised by an inability to fully understand his options. Patients with lower health literacy are also less likely to have an advanced directive, more likely to experience negative palliative care outcomes, and often have greater healthcare spending at the end of life compared to those with higher levels of health literacy.[6] Did this patient have an advanced directive? Did he have a previous negative experience with disease-directed or palliative care? It is vital in all patient encounters, particularly with acutely and terminally ill individuals, that healthcare professionals not only assess patient understanding and overall health literacy, but also include care plan adaptations and interventions to

address any gaps.

Approaches to Improving Safety

Palliative Care and Hospice as Patient Safety

Systems-based interprofessional disease management, health sciences education, public recognition of the value of palliative care, and numerous studies of palliative care integration[2,7-10] in care have effectively, but incompletely, erased the false division between palliative care and disease-directed care. Together, the two approaches to care improve quality, including patient safety.

This case illustrates how the care paradigm is shifting for patients with advanced and serious illness. When a patient is not on hospice, safety concerns focus on keeping the patient alive and free from complications. This mindset shifts on hospice. While preventing complications remains part of patient safety, preventing death is no longer a safety goal. For example, resuscitating a patient who is DNR ("do not resuscitate") can lead to injury to the patient and poorer symptom control; the life-saving measures meant to keep other patients safe do not keep the hospice patient safe. Protecting the patient's safety in this case involved identifying and implementing measures to protect his comfort and quality of life.

The hospice team recognized the potential value of disease-directed, but also palliative, treatment for brain metastases and facilitated the patient's whole brain radiation therapy to meet his goals. A prime example of the integration of disease-directed and hospice/palliative care is the Veterans Health Administration (VHA) hospice benefit, which operates on a concurrent care model, allowing veterans on hospice to continue to receive disease-directed therapies.[7] Examples include chemotherapy, radiation, hemodialysis, and therapeutic paracentesis. As with traditional hospice, patients must still accept DNR status. As the largest health system in the country, charged with caring for our nation's veterans, the VHA's decision to adopt a concurrent model of care represents a purposeful decision to improve care and patient safety for veterans at the end of life. In one study of veterans with advanced lung cancer on hospice through the VHA, allowing hospice care without restricting cancer treatment was associated with less aggressive treatment and lower care costs.[7] Additionally, recent research supports the notion that palliative and hospice care, both with and without disease-directed therapies, improves patients' overall quality of life and duration of life.[11]

Although the purpose of this patient's radiation was for symptom management and not for cure, it was still, technically, directed at his cancer. Policy-makers have discussed the possibility of including concurrent care in the Medicare hospice benefit. Pilot studies for adults[12,13] and children[14] included in the Medicare advantage plan are planned or underway.

Upstreaming Concurrent Care

The last twenty years have seen the erosion of the false dichotomy between disease-directed therapy and palliative care. The World Health Organization, long a champion of palliative care, had always emphasized the value of patient and family focused care delivered by an inter-disciplinary team at the end of life. Their 2002 statement eliminated the phrase "at the end of life."[15] This insightful assessment and the recognition of the persistent late referral of patients to hospice led to educational programs sponsored by NIH and others to promote more effective conversations regarding palliative care and earlier referral to hospice.

However, systems-based barriers, both structural and cultural, persist. Providers would never delay referral to cardiology for someone with new-onset heart failure, and there are often system flags in place to identify those patients for referral. A delay in such referral would be considered unsafe for the patient. So why isn't it the same with palliative care and hospice? At the time of diagnosis, a cancer patient will likely need support for symptom control whether or not they pursue disease-directed treatment. Palliative care should be viewed as part of standard care to promote patient safety and quality of life.

Accordingly, leaders in the field have developed several models of early care intervention[16] ("upstreaming") to include palliative care into the disease management of patients and their families with malignant and non-malignant disease. Randomized clinical trials that compared best supportive care or usual care to concurrent or simultaneous care all confirmed the benefit to patients and their families in several quality-of-life domains, duration of life, and improved caregiver quality of life.[9] At the time of diagnosis, the patient in this case should have been referred to palliative care. Whether he decided to pursue treatment or not, the interdisciplinary palliative care team would have played an active role in 1) managing his symptoms, 2) clarifying and advocating for his goals of care, and 3) facilitating earlier transition to hospice.

Many systems have established pre-hospice or home-based palliative care bridge programs. Although financial support for these programs may be problematic in a fee for service environment, the net cost savings[17,18] and better patient-family centered quality of care outcomes[19] strongly favor this type of system support. Inpatient palliative care consultation teams have been organized to support families and patients in both intensive care settings and on med-surg units. This led to reduced length of stay,[20] higher patient satisfaction, smoother handoffs to home hospice, and the development of geographically distinct inpatient hospice units (such as that exemplified in this case).[10] These systems-based interventions helped to upstream palliative care and "palliate" the unnecessary antagonism between treating teams and palliative care teams.

Proactive Psychosocial Assessment and Care

Although licensed clinical social workers are integral to palliative care teams, social workers may also function independently. Referrals for psychosocial assessment and care planning can assist patients and families in dealing with the impact of diagnosis and treatment on their lives and ability to access care.[19] Routine assessment for social risk factors, including untreated distress, psychological health, social support, practical needs, cognitive and physical autonomy, and confidence/self-efficacy in navigating health systems, contributes toward a better understanding of patients' psychosocial functioning and deficits. Perhaps this patient did not want to burden a loved one with daily trips to radiation appointments and decided not to continue after his second treatment. While this might seem at the surface to be a transportation need, it could have also been a relational issue. Not wanting to be a burden to loved ones is common for persons with serious and terminal illness.[21] Medical social workers can assist in facilitating communication with and among family members and even between patients and care teams to help clarify patients' wishes, goals, and desires.[22]

Caregiving Considerations

As oncology treatment and procedures have migrated to outpatient settings, the family caregiver has had to take greater responsibility for the day-to-day care of the patient.[23] Family caregivers of patients with

advanced cancer need to devote increasing time and energy to caring and learning complex care regimens, which can have significant impact on their financial, physical, and emotional health.[24] The safe handling of patient medications, equipment, ostomy and port sites, among other care needs, can lead many family caregivers to feel overwhelmed and inadequately prepared.[25] Adding to the complexity, the majority of caregivers are spouses, close partners, or children. For older cancer patients, this may mean a greater likelihood that the caregiver is an older adult with their own health and/or cognitive concerns.[26] One study demonstrated the statistical and clinical benefit of palliative care interventions for caregivers of cancer patients.[27]

Treatment planning as an on-going process, not a one-time decision?

A final lesson learned from this case is that the patient may have benefited from multiple conversations about his care options and potential benefits. It is unfortunate that a loss to follow up was part of his treatment trajectory, but consultations with subsequent medical providers helped this patient find an acceptable level of treatment that brought the most benefit in comfort, functioning, and quality of life. Engaging in an advance care planning conversation, where a patient can clarify their values, wishes, and goals for end of life care can provide valuable information for developing a care plan that is congruent with the patient's desires while promoting patient autonomy within shared decision making.[28] It is sometimes helpful to use a framework, such as SPIKES (Setting, Permission, Invitation, Knowledge, Emotion, and Support/Summary), to guide a conversation that may include difficult news.[29] Creating an environment where the patient is able to digest information in smaller pieces can help with adjustment and coping, as well as increase comprehension of their disease and treatment options. A medical social worker, chaplain, or other psychosocial provider may help patients and family to process the meaning of the illness and the expected impact; this process often takes time and may require multiple appointments.[30]

Improving Patient Safety and Communication

An alternative summary of this case, embedding principles of patient-centered care, safety, and advanced care planning, would read as follows:

A 77-year-old man presented with rectal carcinoma and declined definitive therapy. A psychosocial assessment was ordered, and a medical social work consultation identified caregiver support and respite needs. A "Physician Orders for Life-Sustaining Therapy" (POLST) form was completed as the patient indicated his clear views regarding advance directives and durable power for health care. A family conference in the home was completed to avoid any surprises at the expected time of decline. A referral to home based palliative care was also completed and the physician-nurse-social worker-chaplain team visited the patient regularly to enhance the caregiver's confidence and knowledge, and to improve medication safety. The social worker noted the neurologic decline on a routine visit. Outpatient imaging revealed brain metastases. He was admitted for steroids and for inpatient hospice care. A family conference that included the home-based team, his primary physician, and the inpatient hospice team reinforced his POLST-defined wishes. Whole brain radiation therapy was administered. The patient was able to meet his goals of care and, in fact, strengthen relationships at the end of life, improving survivorship of his friends and family.

Take Home Points

- The hospice benefit does not always allow for all palliative interventions for patients.
- The dichotomy between disease-directed therapies and palliative care can create barriers to palliative interventions for patients on hospice.
- Research studies and the VA Health System have proven the value of concurrent care.
- Early palliative care referral and intervention can reduce aggressive measures at the end of life, increase quality of life, and reduce costs of care.
- Healthcare organizations can improve care through understanding of socioeconomic, psychosocial, structural, and care-related reasons for loss-to-follow-up.
- Health literacy affects patient's care choices and subsequent outcomes; it should be assessed in all patient encounters with implementation of appropriate interventions to address gaps.

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