WebM&M

Morbidity and Mortality Rounds on the Web

Spotlight

Culture Clash No More:

Integration and Coordination of Disease Treatment and Palliative Care

AHRQ Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

PSNet
PATIENT SAFETY NETWORK

Source and Credits

- This presentation is based on the November 2021 AHRQ WebM&M Spotlight Case
    - See the full article at https://psnet.ahrq.gov/webmm
    - CME credit is available
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Objectives

At the conclusion of this educational activity, participants should be able to:

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

CULTURE CLASH NO MORE: INTEGRATION AND COORDINATION OF DISEASE TREATMENT AND PALLIATIVE CARE

A case describing a perceived delay in palliative radiation – an “error” in care – and the importance of early palliative care referral and intervention

Case Details (1)

- 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, presumed secondary to locally advanced cancer.
- The patient declined any surgical intervention or chemotherapy after discussing goals of care with an oncologist.
- He underwent two rounds of targeted radiotherapy (to relieve pain and obstructive symptoms) and then was lost to follow up.

Case Details (2)

- The patient re-presented to the ED after a fall at home.
  - 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.

Case Details (3)

- After thoroughly evaluating the patient, the inpatient hospice team discussed the potential role of brain radiotherapy for palliation to meet his 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.

CULTURE CLASH NO MORE: INTEGRATION AND COORDINATION OF DISEASE TREATMENT AND PALLIATIVE CARE

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

When Policy Lags Behind Care: The Hospice Benefit (1)

- 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, which role modeled integration of disease directed therapy with palliative care, a departure from the historic model of separation of hospice from disease treatment.

When Policy Lags Behind Care: The Hospice Benefit (2)

- 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.

When Policy Lags Behind Care: The Hospice Benefit (3)

- Although the regulation was written to focus on comfort at the end of life, the consequences included limitations in care that may lead patients and primary providers to delay 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. Examples of costly palliative interventions include transfusions, home inotrope therapy, and paracentesis.
  - It is commendable that this hospice covered radiotherapy as a palliative intervention, but this is not a common occurrence. Many hospices at the outset specify which costly palliative treatments they will or will not “approve.”
  - **In this case, the cost associated with preparing 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.**

When Policy Lags Behind Care: The Hospice Benefit (4)

- This case also highlights the language of hospice: “foregoing disease-directed therapy” **– this language is now the “culture” for hospice programs.**
- Hospice regulations have led to persistent non-referral of patients to hospice or referral during the last days of life.
  - Studies show the median duration of 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.

When Policy Lags Behind Care: The Hospice Benefit (5)

- 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 this approach involves the conscious decision to prioritize patient care over outdated reimbursement schemes that fail to do so.

HEALTH LITERACY AND PALLIATIVE CARE/HOSPICE ACCESS

Health Literacy and Palliative Care/Hospice Access (1)

- This case also illustrates potential barriers related to health literacy and care access.
  - 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.

Health Literacy and Palliative Care/Hospice Access (2)

The reasons for loss-to-follow-up (LTFU) in patients can be thought of in four broad categories:

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

Health Literacy and Palliative Care/Hospice Access (3)

- It should be noted that each of these categories contribute to the formation of a patient's self- efficacy: their belief in themselves to execute a task.
- **That being said, an individual's self-efficacy should never be considered the sole reason for their LTFU.**
  - It may be that a combination of factors from these categories contributed to the patient in the case having lower self-efficacy and/or it could be that larger systems-level and societal factors failed him.

Health Literacy and Palliative Care/Hospice Access (4)

- All healthcare systems should make efforts to understand and re-engage LTFU patients, as LTFU can lead to permanent disability and premature death.
- There are often solutions to socioeconomic and care-related reasons for LTFU, such as:
  - 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 symptom management
- Structural reasons may require larger scale efforts to effect change but are important for organizations to understand how to improve their care systems.

Health Literacy and Palliative Care/Hospice Access (5)

- 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.
  - Although this patient chose to forgo aggressive measures, his choice could have been compromised by an inability to fully understand his options.

Health Literacy and Palliative Care/Hospice Access (6)

- 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.
  - 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

Palliative Care and Hospice as Patient Safety (1)

- Efforts in systems-based interprofessional disease management, health sciences education, palliative care research, and public recognition of the value of palliative care have effectively, but incompletely, erased the false division between palliative care and disease-directed care.
- **Together, the two approaches to care improve both quality and patient safety.**

Palliative Care and Hospice as Patient Safety (2)

- 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 an important patient safety goal, preventing death is no longer a safety-related goal.
  - For example, resuscitating a patient who is DNR (“do not resuscitate”) can lead to injury to the patient and poorer symptom control; the same life-saving measures that are implemented 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 through more patient-centered, timely, and effective care.

Palliative Care and Hospice as Patient Safety (3)

- A prime example of 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.
  - Examples include chemotherapy, radiation, hemodialysis, and therapeutic paracentesis. As with traditional hospice, patients must still accept DNR status.
  - 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.
  - Additionally, recent research supports the notion that palliative and hospice care, both with and without disease-directed therapies, improves patients' overall quality and duration of life.

Palliative Care and Hospice as Patient Safety (4)

- 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 in the Medicare Advantage plan (and children) are currently planned or underway.

Approaches to Improving Safety: Upstreaming Concurrent Care

Upstreaming Concurrent Care (1)

- The last twenty years have seen erosion of the false dichotomy between disease-directed therapy and palliative care.
- For example, the 2002 World Health Organization statement eliminated the phrase “at the end of life.”
  - This insightful assessment and 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.

Upstreaming Concurrent Care (2)

- 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.

Upstreaming Concurrent Care (3)

- Leaders in the field have developed several models of early care intervention (“upstreaming”) to include palliative care into the disease management of patients and their families with malignant and non-malignant disease.
- Randomized clinical trials comparing best supportive care or usual care to concurrent or simultaneous care all confirmed the benefit to patients and their families across several quality-of-life domains, duration of life, and improved caregiver quality of life.
- 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 in active role in 1) managing his symptoms, 2) clarifying and advocating for his goals of care, and 3) facilitating earlier transition to hospice.

Upstreaming Concurrent Care (4)

- Many health 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 and improved patient-reported quality of care 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, leading to reduced length of stay, higher patient satisfaction, smoother handoffs to home hospice, and development of geographically distinct inpatient hospice units (such as that exemplified in this case).
  - These systems-based interventions help to upstream palliative care and "palliate" the unnecessary antagonism between treating teams and palliative care teams.

Approaches to Improving Safety: Proactive Psychosocial Assessment and Care

Proactive Psychosocial Assessment and Care (1)

- Referrals to social workers 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.
  - 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.

Proactive Psychosocial Assessment and Care (2)

- 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 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.
- 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.

Approaches to Improving Safety: Caregiving Considerations

Caregiving Considerations (1)

- 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.
- 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.

Caregiving Considerations (2)

- 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.
- 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.
  - One study demonstrated the statistical and clinical benefit of palliative care interventions for caregivers of cancer patients.

Approaches to Improving Safety: Treatment planning as an on-going process, not a one-time decision

Treatment Planning (1)

- The patient in this case 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.
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Treatment Planning (2)

- Frameworks such as SPIKES (Setting, Permission, Invitation, Knowledge, Emotion, and Support/Summary) can help guide a conversation that may include difficult news.
- 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.

Improving Patient Safety and Communication

Improving Patient Safety and Communication (1)

- 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

Take-Home Points (1)

- 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.

Take-Home Points (2)

- 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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