Palliative Care: The Need for Evidence-Based Guidance

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Introduction

The role of healthcare is to improve health. What is the role of medicine at the end of life?

While we have much evidence-based guidance available about how to manage and treat illness, there is little available guidance on end-of-life care. Death, however, is the one condition that all individuals will experience.

The World Health Organization estimates that 40 million people worldwide need palliative care services each year, but only about 6 million people receive these services.\(^1\) In the United States, fewer than half of eligible Medicare patients were enrolled in palliative care or hospice services in 2016 at the time of their death.\(^2\)

This gap in care has ethical implications: How can the medical community ensure that patients are adequately treated throughout their entire lives? Healthcare providers have an obligation to provide thoughtful, compassionate care to patients during serious illnesses, and that care should include medical, social, emotional, and practical support for patients and their caregivers at the end of their lives. Improving the quality of this care can improve patient and caregiver satisfaction and may positively impact the significant expenditures that occur in the last 12 months of life. There is a lack of evidence-based guidance to address the needs of patients who need palliative care. Clinicians and patients need to better understand the role of palliative medicine, how it can help patients and caregivers, and how it differs from hospice. The development of evidence-based guidelines will provide a framework for clinicians and patients to have constructive conversations that address palliative care. Trustworthy guidelines can provide a common basis for care-planning decisions that will improve patient outcomes.

History of Palliative Care

Palliative care is a relatively new concept in medicine, beginning in the United Kingdom in the years following World War II. Cicely Saunders, a wartime nurse and oncology social worker, built on the experience of district nurses throughout the UK who recorded the suffering of their patients who were dying of cancer at home. Working first as a volunteer, she helped develop a regimen of medications to relieve suffering at the end of life. Over nearly a decade, she helped collect information from over 1000 patients and used that data to show the gap in the National Health Service and persuade others of the importance of end-of-life care. In 1967, she helped open the first hospice, St. Christopher’s in London. She and others proceeded to disseminate their research and experiences worldwide, and in 1987 palliative care became a recognized specialty in the United Kingdom, Australia, and New Zealand.\(^3\) In the United States, hospice and palliative care was not recognized as a distinct specialty by the American Board of Medical Specialties until 2006.\(^4\)

Since its recognition as a medical specialty, there has been growing interest in the medical community about palliative care; however, there has been a relative lack of evidence-based
guidance to support its implementation and practice. There are many reasons for the paucity of guidelines, including misunderstanding of the field by both clinicians and patients and a lack of funding support for palliative care. The development of this guidance is paramount to support patients and families during a vulnerable part of the care continuum. Delivering on the Triple Aim is just as important for patients during the latter part of their lives as it is during the beginning and middle parts.

Palliative Care: What Is and What Is Not Hospice

According to the Center to Advance Palliative Care, palliative care is medical care for patients living with serious illness that focuses on relief of stress and symptoms to improve the quality of life for patients and their families.\(^5\)

According to the World Health Organization, palliative care includes several criteria.\(^1\) Palliative care:

- Provides relief from distressing symptoms, including pain
- Affirms life and regards death as a natural process
- Seeks to neither hasten nor postpone death
- Includes psychological and spiritual care
- Supports patients so they may live as actively as possible until death
- Helps the family cope both during the patient’s illness and in their own bereavement
- Uses a multidisciplinary approach to address the patient’s and his or her family’s needs
- Enhances quality of life and positively influences the course of illness
- Is applicable early in the course of illness, concurrent with other therapies that are intended to prolong life, including investigations needed to better understand and manage distressing symptoms and complications

It is important to highlight that palliative care should ideally be started early in the course of an illness along with therapies intended to prolong life. Palliative care is not intended to hasten death. This is often poorly understood by clinicians and patients, and palliative care is often confused with hospice care.

Hospice care provides a more limited set of services, focusing on symptom management at the end of life when the goal of care has shifted away from cure.\(^2\) Symptom management and emotional support for both patient and family is the mainstay of hospice care.

Hospice care is a subset of palliative care. In many cases, patients, caregivers, and even clinicians do not appreciate the difference between these services and the philosophies of each.

Some of the confusion about the difference between palliative care and hospice care may stem from how the Centers for Medicare and Medicaid Services (CMS) describes these terms; CMS does not distinguish between the terms, using “hospice” to refer to both hospice and palliative care. There is a Medicare hospice benefit, but to receive it, patients must\(^6\):
• Have documentation from a physician that they have a terminal illness with a life expectancy that is likely 6 months or less
• Sign a statement choosing hospice care instead of routine Medicare covered benefits for that illness

Medicare hospice benefits include coverage for nursing care, physician visits for symptom management, physical and occupational therapy, speech language therapy if appropriate, social services, home health aide, medical supplies (including medications), counseling (including nutrition), and even short-term inpatient care including respite care. While these services are important, a Medicare beneficiary cannot receive hospice care while they also receive treatment for their underlying disease. Medicare does not cover palliative care services as defined by the World Health Organization; therefore, Medicare patients do not have a full scope of palliative care interventions available to them.

Scope of the Problem

In 2016, 3 million Medicare beneficiaries died; of those 3 million, 1.4 million were enrolled in hospice for at least 1 day; 64% of the patients enrolled in hospice were age 80 years or older. The median length of hospice service was 24 days.

The most common diagnoses of Medicare patients receiving hospice care included cancer (27%), cardiac (19%), dementia (18%), respiratory (11%), and stroke (10%).

The average cost of medical care in the last year of life is $80,000. The average cost of a day in the intensive care unit is $4000, and the average cost of a day on a hospital ward is $2300. The average cost of caring for a patient through palliative and hospice care is $11,800. A recent federal advisory panel recommended creation of a palliative care model for Medicare patients. This panel estimated that while only 4% of Medicare patients would utilize these services, that population accounts for 25% of Medicare spending each year.

Given the potential financial implications, clinicians, patients, and healthcare policy makers should ask whether palliative care provides clinical value for patients.

The Case for Palliative Care

Despite increasing interest in palliative care, there remains a lack of high-quality research to help guide that care. A systematic review of 107 trials evaluating therapeutic interventions in palliative care found that while the volume of research has steadily increased over time, the methodological quality of those studies remains suboptimal. A lack of randomized trials (only 11% of the included studies), a lack of standardized assessment tools, and the heterogeneity of patient populations were all cited as reasons for the poor methodological quality of the evidence.

Some have argued that enrolling palliative care patients in placebo-controlled trials is problematic, as this population is vulnerable, and the withholding of potentially beneficial therapy is unethical. A systematic review of 8 studies evaluated patient and family attitudes about being included in such research and found that this group had similar opinions to the
general population about being included in placebo-controlled trials. Patients and families cited autonomy, personal gain, and altruism as benefits of inclusion.\textsuperscript{13}

It is also possible that placebo-controlled randomized controlled trials may not be the optimal method for studying palliative care patients given the unique and heterogenous populations involved.\textsuperscript{14}

Some patients believe that palliative care shortens life. The available evidence does not conclusively address this concern. A systematic review of 43 randomized trials (23 of which were included in a meta-analysis) including 12,731 patients and 2479 caregivers evaluated outcomes of palliative care and found that palliative care was associated with improvements in patient quality of life and symptom burden, but no difference in survival at 1 or 3 months.\textsuperscript{15} However, the authors noted a number of limitations, including heterogeneity of populations and that no distinction was made between early and late palliative care. Further trials were recommended.\textsuperscript{15}

Another trial randomized 207 patients with a diagnosis of advanced cancer to early (at diagnosis) or delayed (3 months after diagnosis) palliative care and found, at one-year follow-up, that early palliative care was associated with improved survival, but no difference in quality of life.\textsuperscript{16} It is clear that more good-quality research is needed to address this concern.

Fortunately, there have been some guidelines published in high-quality journals, and more are being published.

The American College of Physicians (ACP) published guidelines in 2008 with 5 recommendations:

- Clinicians should regularly assess patients for pain, dyspnea, and depression at the end of life.
- Clinicians should use therapies with proven effectiveness to manage pain, including NSAIDs, opioids, and bisphosphonates.
- Clinicians should use therapies with proven effectiveness to manage dyspnea, including opioids and supplemental oxygen.
- Clinicians should use therapies with proven effectiveness for managing depression, including SSRIs, tricyclics, and psychosocial intervention.
- All patients with serious illness should get advanced care planning.\textsuperscript{17}

In 2018, the European School of Oncology/European Society for Medical Oncology (ESO/ESMO) published palliative care guidelines for patients with advanced breast cancer. The recommendations were all based on expert opinion. Some of the included recommendations:

- Patients should be offered palliative care services from the time of diagnosis.
- A multidisciplinary team should be available to discuss palliative care.
- Goals of care should be discussed at the time of diagnosis.
• More randomized trials need to be done on palliative care interventions.18

Barriers

There are several barriers that need to be overcome to improve implementation of palliative care services in the United States and elsewhere.

Patients and their families often have misconceptions about palliative care. To many, the goal of medicine focuses exclusively on prolonging life. Palliative care will need to be thoughtfully introduced to help patients and families understand how it is an integral part of medical care.

The concept of palliative care dates back only 70 years and it has been a recognized specialty for only 30 years. For centuries before that, the goal of medicine has been to prolong life. To improve palliative care utilization, palliative care as a concept must be rebranded for patients and families in order to overcome this seeming discrepancy.

As a relatively new specialty, the medical community also needs education about the field of palliative care. Fortunately, palliative care is now part of the curriculum of medical schools and many residency programs. Additionally, educational materials and recommendations from specialty societies are available online.

Many clinicians remain reluctant to refer their patients to palliative care. Some providers fear that discussion of palliative care may upset patients or be interpreted as abandonment or an admission of failure. This reluctance may be due to lack of understanding of palliative care and the benefits of referral, lack of confidence in consulting a palliative medicine specialist, and lack of experience in co-managing a patient with a palliative medicine specialist.6

Many clinicians are not yet comfortable having conversations about end-of-life care and determining the optimal time for those conversations. Fortunately, several subspecialty societies are now providing some guidance. For example, the American Society of Clinical Oncology now has practice guidelines on integrating palliative care into standard oncology care, including the recommendation that all cancer patients be educated about palliative care services early in the disease course, concurrent with active treatment.19

Pain management is a critical component of end-of-life care. In the current environment of the opioid crisis, physicians have become more circumspect in prescribing opioids; the CDC notes a 13.1% decrease in opioid prescriptions between 2013 and 2015.20 While these changes are appropriate to stem the growing problem of opioid overuse, and most opioid prescription guidelines specifically address cancer pain, there are concerns that patients may not have appropriate pain management for end-of-life treatment. Additionally, the opioid crisis has impacted patients’ perceptions about pain management. A study of 100 terminally ill patients found that 43% were afraid of using opioids because of concerns of addiction, side effects, or death.21

Another challenge in delivering palliative care effectively is resource limitations. In 2016, 1/3 of hospitals with at least 50 beds had no palliative care services available.22 In 2015, only 17 states scored an “A” in a report from the Center to Advance Palliative Care (meaning 80% or more of hospitals had palliative care practitioners and services) and 16 states scored “C” or “D” (60% or fewer hospitals had such services).23 Facilities that have palliative care services do not
always utilize them to maximum effect. For example, the Department of Veterans Affairs (VA) has mandated that palliative care services be available for all patients since the late 2000s. In 2012, a retrospective analysis of VA patients age 65 years or older who died of cancer found that 71% of them received hospice care at a median of 20 days before death, and that only 52% received palliative care services at a median of 38 days before death. There is a well-documented shortage of physicians trained as palliative care specialists; 325 physicians complete fellowship training each year, while the projected need is 500 to 600 graduates per year.25

Finally, implementation of palliative care is intimately tied to reimbursement for those services. Fortunately, more private insurers are reimbursing for palliative care services, though there is not consistency regarding what services are paid for. As noted previously, CMS provides reimbursement for hospice services but does not provide coverage for palliative care services. A federal advisory board has recommended that this change in order to help manage overall costs.11

Need for Evidence-Based Guidelines

Evidence-based guidelines can be used to overcome several of the barriers to effective palliative care, and thereby ensure that the right patients get the right care at the right time.

Guidelines encourage communication between clinicians and patients and can help change and normalize the perception of palliative care, much like the American Cancer Society did with its recommendation to stop smoking.

Guidelines provide an easier way for clinicians to broach the topic with their patients and give them an organizational tool to have the conversation. Additionally, guidelines can be used to trigger automatic consults to palliative care, if certain criteria are met (for example, if a patient is diagnosed with advanced cancer, a certain class of heart failure, a threshold pulmonary function test, or has documented weight loss associated with dementia). Such a trigger would ensure that appropriate patients are at least given the opportunity to discuss their palliative care options. This would also help overcome communication barriers and ensure that conversations happened early with appropriate patients.

Thoughtful, evidence-based guidelines help ensure appropriate pain management for this population. Given the goals of care for this vulnerable population, palliative care should be routinely addressed in the discussions about the use of opioids.

Evidence-based guidelines will also allow clinicians, payers, researchers, and policy makers to determine which interventions improve outcomes; research should focus on both clinical outcomes and patient-centered outcomes that include quality-of-life measures.

Conclusion

The US Census Bureau estimates that by 2035 there will be 78 million people 65 years of age and older in the US. This population will increasingly live with multiple chronic conditions and develop terminal conditions. Although modern medicine has traditionally focused exclusively on
curing disease, there is an increasing recognition that medicine also has an obligation to provide care and support to patients throughout life.

The field of palliative medicine provides comprehensive care to patients in a manner that supports their beliefs and goals; it can include active treatment and is designed to enhance the quality of life. It affirms both life and death as natural processes. As the population ages, introducing palliative care to patients and families offers an opportunity to discuss patient preferences and to support them throughout the care continuum. Evidence-based guidance for palliative medicine will support this on an individual and a population level.

Cicely Saunders, who founded the hospice movement in the mid-20th century said, “You matter because you are you, and you matter to the end of your life.” There is more to medicine than curing disease; we have a duty to our patients and their families to ease suffering.

Guidelines will help us perform to the top of our ability.

References


