It's Not Just About the End: The Broader Story of Palliative Care for Nurturing Resilience

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Abstract

When most people, including healthcare professionals, hear the words palliative care, they immediately think about hospice or end-of-life care. While palliative care and hospice care both focus on comfort and quality of life for people with serious illness, palliative care should be administered throughout the cancer diagnosis, regardless of prognosis or treatment, instead of only in the last months of life. When palliative care is provided early, people with cancer tend to have a better quality of life, enhanced mental health, faster recovery and increased survival rates (Wantonoro, et al, 2023). Although the American Society of Clinical Oncology recommends that all patients with cancer receive palliative care (Ferrell, et al, 2016), palliative care is underutilized in all settings.

Common Myths About Palliative Care

"Palliative care is for people who are dying."
- 63% of people believe that palliative care means being close to death

"Palliative care is only available if I stop treatment."
- 58% thought palliative care was a last resort when all other treatments failed
- 65% agreed that palliative care does not offer hope to patients

"Palliative care means hospice care."
- 57% equate palliative care with end-of-life care
- 66% of people believe that palliative care is only provided when a patient could no longer take care of themselves

"Palliative care is only to treat pain and prescribe opioids."
- 89% of people in the United States have inadequate knowledge of and/or misconceptions about palliative care

Knowledge = Utilization + Positive Experiences

Those with knowledge of palliative care have accurate perceptions and experiences.

- 94% understand that managing pain and other symptoms are goals of care
- 93% know social and emotional support are part of palliative care
- 91% agree that palliative care helps friends and family cope with a patient's illness
- 82% recognize that accepting palliative care does not mean giving up
- 75% do not believe that accepting palliative care requires stopping treatment

Palliative Care vs. Hospice Care What's the Difference?

Question	Palliative Care	Hospice Care
What is the focus?	Provides comfort and symptom management, alongside curative care	Provides comfort care only
Who receives it?	Anyone with a serious illness	Only those at end-of-life (EOL) who are not receiving treatment
When is it provided?	From initial diagnosis, regardless of prognosis, and throughout the disease trajectory	In the last six months of life
What services are available?	Pain management, symptom control, psychosocial support, spiritual counseling, help with medical decision-making and advanced care planning	Primarily pain management and medication to enhance quality of life and emotional and caregiver support
Where is it given?	All in-patient and out-patient settings	Primarily in the home or specialized facilities
Who pays for it?	Paid for through insurance/Medicare Part B	Paid for through insurance/Medicare Hospice Benefit

What You Need to Know About Palliative Care

Palliative Care Is...

- An approach to care focused on relieving or alleviating physical and psychological suffering and improving quality of life of patients with a serious disease or injury
- Care provided to patients and their families to whom the term "dying" is not necessarily appropriate to apply yet have the need to reduce suffering (Wantonoro, et al, 2023)
- Aimed at improving one's ability to manage their diagnosis throughout the disease
- Reflects an interdisciplinary and holistic approach to care

Goals

- Establish care goals aligned with the patient's wishes
- Facilitate effective communication between the patient and their care team
- Build a support network with psychological, psychosocial and spiritual care for patients, their families and other caregivers
- Provide individualized patient care and patient/family-centered care

Benefits

Patients	Caregivers
• Higher quality of life • Enhancement of human dignity • Lower rates of depression • Greater satisfaction with care • Better symptom management • Longer survival • Strengthened coping ability • Increase in referrals to other services • More advanced EOL planning and less aggressive EOL care • Decreased health care costs	• Lower levels of depression • Reduced stress • Less psychological distress • Decreased caregiver burden • Improved social and spiritual well-being • Strengthened coping ability

Barriers to Palliative Care

Patient/Caregiver

- Socio-demographics
  - Race/ethnicity – minorities
  - Sexual/gender identity
  - Religion
  - Gender and age – male, younger than 60
  - Education level – high school or less
  - Low socioeconomic status
  - Immigration status
  - Geography - rural areas
- Misconceptions
- Fear
- Patient and family resistance
- Family fragility/emotional reactiveness
- Lack of awareness and understanding of resources
- Type of insurance or no insurance

Healthcare Provider

- Lack of formal training during both undergraduate and post-graduate education
- Misconceptions about palliative care
- Misunderstanding of palliative care services
- Lack of understanding of patient's beliefs
- Discomfort with difficult discussions, particularly EOL
- Unease to refer if client is not at EOL
- Concerns about negative reactions from patients and their families
- Reluctance to discuss religious and cultural issues affecting care
- Difficulty coping with their own mixed feelings
- Structural challenges within the health care system

Cultural Considerations

- Language gaps - misinterpretation
- Religious and cultural beliefs, particularly about pain and death
- Respect for traditional or alternative remedies (non-medical)
- Willingness to discuss death

Talking About Palliative Care

When people understand the benefits of palliative care, utilization increases significantly, regardless the patient's age or disease stage.

- Broach the subject during initial conversations about the diagnosis and treatment approach, regardless of the prognosis
- Develop language to increase comfort with the subject, such as supportive or comfort care
- Highlight the distinction between palliative care and hospice care
- Connect the discussion to specific client needs, such as relieving typical side effects for the specific diagnosis or preparing for medical emergencies
- Address known resistance early in the conversation, e.g., misconceptions and cultural beliefs

Integrating Palliative Care into Your Practice

- **Assess the medical team's understanding of palliative care** and their ability and willingness to address it with patients and their families.
- **Facilitate conversations with the medical team** to ensure patients receive the highest level of care possible.
- **Understand the sociodemographic factors associated with lack of awareness and utilization** to better counsel patients about palliative care.
- **Educate patients and their families/caregivers** about palliative care services and their benefits, and how it differs from hospice care.
- **Use professional translators in lieu of family members** to facilitate accurate communication.
- **Evaluate patients for quality of life and the physical, psychological, spiritual, and social domains of care** to determine palliative care needs.
- **Provide referrals to supportive care services** such as pain management specialists, psychiatrists, therapists, OT/PT, spiritual advisors, dieticians, and integrative therapy.
- **Coordinate with other care providers** to facilitate communication and utilization.
- **Address caregiver concerns and stressors** to determine caregiver preparation, competence and support.
- **Help families navigate conversations about treatment options, medical decision-making or EOL**, so caregivers can learn what the patient wants and carry out those wishes.
- **Assist with advance care planning**, such as helping prepare documents for a living will and health care proxy.

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