

Initiating End of Life Care Conversations

Discussion Brief by Monica Jupp; Reviewed by Tom Bauer, MBA, RT®

End-of-life (EOL) care refers to the support and medical care given during the time surrounding death. An individual may be living, and dying, with one or more chronic illnesses and require care for days, weeks, and sometimes even months. Personal preference, family, culture, faith, and economics all intersect in this journey.

There are many discrepancies between individual's wishes and their actual end-of-life care outcomes; the majority of Americans die in institutional settings despite their wishes to die at home.¹ This is just one indicator of the gap between patient's goals and desires and the current state. This panel examined ways to translate best practices for initiating end-of-life conversations across disparate settings.

Key Points

- Health care providers have a responsibility to begin end-of-life care discussions with patients and families before critical times.
 - Advanced care planning may seem like a one-time action, but these plans should be revisited to ensure they are up-to-date.
 - It is an ethical responsibility to care for patients at vulnerable points where they may be facing their mortality. At times, it will demand a certain level of bluntness.
 - Providers should already know what their patients' values are from discussions with them and their family members
 - These values should be documented to guide care in keeping with their preferences.
- Several disparities in EOL and palliative care may hinder the transfer of information and care to patients.
 - Lack of knowledge about end-of-life care options, wariness of the healthcare system, and poor communication between clinicians and patients is detrimental to autonomy and quality care.
 - It may feel taboo to talk to patients and families about end-of-life; some may think it's not the right time to discuss it.
 - Patients may feel like they are letting their provider down by initiating these conversations, and family members may see initiation of these discussions as "giving up".
 - There is often a lack of adequate pain care in patients and poor management of pain by practitioners.
 - Many countries are restrictive with allowing morphine or other pain-relieving medication for their patients.
 - The value of life cannot be measured in dollars and cents.
 - In some cases, hospice and palliative care systems are more cost effective than standard care at end-of-life.
 - Hospice patients experience less pain and decreased anxiety, which can also correlate to a higher quality of life for caregivers.

- In low- and middle-income countries, doctors, nurses and other care providers may not be properly trained to manage patients at the end-of-life, and often do not have advanced care planning or advanced directives in their management of critical cases.
- EOL care is unique to various groups of people and settings. This can involve many cultural practices even after death.
- Creating distinctions between palliative care, hospice care, “supportive care” and EOL care is crucial to the conversation.
 - While “supportive care” was suggested as an alternative umbrella term to embody palliative and hospice care, it is ambiguous and may leave providers unsure of what care their patients and their family desire.
 - In order to effectively change the name of the service, the mindset about EOL care and the stigma behind it needs to be brought into the conversation.
- There are many considerations to take into account when initiating EOL care conversations.
 - “When you’re well you belong to yourself, but when you’re sick you belong to your family.”²
 - As long the patient is well, they have the autonomy to make their own decisions about their own future.
 - As soon as that person becomes sick, even if they are still able to make some decisions, it is often the family’s decision that dictates the patient management of care.
 - Nurses should be integrated into EOL care conversations as they engage in helping families and friends find support.
 - Community health workers may be able to improve this situation by giving psycho-social support to patients and families, and decreasing costs.
 - Advanced care directives and planning can help reduce unnecessary spending at the end-of-life, leading to better care.
 - These directives can also reduce costs for families and caregivers by other issues that may arise without these directives in place.

Initiatives

- [National Healthcare Decisions Day](#) (April 16) – A day dedicated to helping people across the US understand the value of advance health care planning.
- [The Conversation Project](#) – developed by the Institute for Healthcare Improvement, this initiative provides valuable tools for people facing terminal illnesses and their family members, including resources for completing Advance Directives.
- [Middle East Cancer Consortium \(MECC\)](#) – MECC Palliative Program has been delivered in Middle Eastern countries to train interdisciplinary groups about the management of distressing disease-related problems such as pain and enhance all aspects of a patient's quality of life, including physical, psychosocial, and spiritual dimensions.
- [American Society of Clinical Oncology's Palliative Care Training Program](#) - ASCO collaborates with oncology societies around the world to deliver education about palliative care to health care providers.

Key Resources

- [Being Mortal: Medicine and What Matters in the End](#), Dr. Atul Gawande
- [Dying Healed: Transforming End-of-Life Care through Innovation](#), WISH
- [New guidelines may encourage more talks about end-of-life care](#), Boston Globe

- [The Role of Palliative Care in Population Management and Accountable Care Organizations](#), Journal of Palliative Medicine
- ["Conversation Ready": A Framework for Improving End-of-Life Care](#), IHI White Papers

References

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2. Ntuzimira DC. Dying with Dignity: Hope for Rwanda as a post genocide society. *ehospice*. April 13, 2015. Available at: <http://www.ehospice.com/africa/ArticleView/tabid/10701/ArticleId/14704/language/en-GB/Default.aspx#textStart>.