End of Life Care Population Health Clerkship
Understanding the Resources Available for Patients

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Introduction

Discussions regarding planning for the end of life are typically initiated only with patients who have a terminal prognosis. However, end of life decision making is a process and should not be limited only to seriously ill patients. Two major barriers to having these conversations early are the lack of education in both clinicians and patients, and the discomfort and uncertainty surrounding death present in many cultures. Currently, the curriculum at many medical and nursing schools has little room for end of life care education, and physicians may not receive any end of life care training. This poster provides a general overview and introduction to end of life care planning, including services available to the patient and family, the team involved in end of life care, medical and legal documents, special populations within end of life care, and tools to help both clinicians and patients initiate the conversation about planning for the end of life.

Roles of the Interdisciplinary Team

Establish Goals of Care

- Assist patient in developing short and long term goals of care
- Identify and address spiritual, ethical, financial, emotional, and physical concerns
- Integrate medical care with patients’ wishes and goals
- Advocate for patient autonomy

Educate

- Educate and connect patient and family to necessary resources
- Encourage questions and clarify terminology
- Acknowledge uniqueness of each situation and own limitations; seek appropriate guidance to enhance own understanding

Support

- Support patient, family, and fellow team members
- Arrange family meeting to align expectations of goals of care
- Maintain flexibility and open-mindedness
- Provide bereavement services to families after patients’ passing

Population Demographics:
- The population of interest is comprised of anyone who suffers from a terminal diagnosis

Hospice Demographics*:
- 46.3% Male; 53.7% Female
- 76% White/Caucasian; 7.6% African American; 3.1% Asian, Hawaiian or Pacific Islander; 3% American Indian or Alaskan Native; 13.1% Multiracial or other race
- 92.9% Non-Hispanic; 7.1% Hispanic or Latino
- 99.2% of patients are 35 years of age or older
- 67.1% of patients are 75 years of age or older
*Statistics taken in 2014.

Special Populations

Veterans
- Combat
- PTSD
- Feelings of guilt
- Societal perception

Pediatric Patients
- Different goals of care
- Can receive both curative treatment and hospice

Non-English Speaking Patients
- Working with interpreters
- Other cultural differences surrounding death

Patients who Lack Capacity
- Complications in decision making
- Can be more difficult to manage tension within the family

Advance Directives and Planning

The following are resources that can be used to document the wishes of the patient or aid in initiating discussions regarding end of life decisions.

Advance Directives

- CC/DNR
- MOLST Form
- Health Care Proxy
- Living Will

Planning Resources

- Luminate
- Honoring Choices
- Elder Services
- Vaill Talk and Ariadne
- Online planning tool allowing for consolidated and distributable documentation of end of life wishes
- Organization that educates physicians and patients with making plans for end of life care
- Agency that connects older adult and their caregivers with available care resources
- Resources to assist the healthcare team in planning effective end of life care discussions

Language Services

- Medical and Legal Documents
- Populace

Palliative Care and Hospice

In general, people associate terms like hospice and palliative care with death and dying, “giving up”, or “abandonment” by healthcare providers. They are stigmatized because it is not well understood that they are simply resources that are available to improve the quality of care during a serious or chronic illness.

- Medical specialty that aims to relieve suffering and improve quality of life
- For people of any age and at any stage in a serious illness, whether that illness is curable, chronic, or life-threatening
- Delivered by an interdisciplinary team of practitioners that address the physical, intellectual, emotional, social, and spiritual needs of patients and their families

Lessons and Conclusions

- Start early! End-of-life care decisions are a process and shouldn’t be decided in an emergent situation or a single visit.
- Don’t underestimate the value of listening and allowing for silence in conversations with patients and families.
- Adjust the care plan to align with patients’ goals of care.
- Advocate for patients by utilizing all relevant resources.
- Know the team. Define and integrate team members’ roles to ensure effective care.
- Inquire about cultural and religious backgrounds as cultural competence and respect for religious beliefs is critical in providing personalized, appropriate care.
- Stigmas exist for end-of-life care. Providers should work throughout their careers to improve their own comfort and familiarity with end of life topics and discussions, and work to normalize these conversations with their patients.

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Honoring Choices Massachusetts.

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