End of Life Population Health Clerkship
Development of an End-of-Life Toolkit

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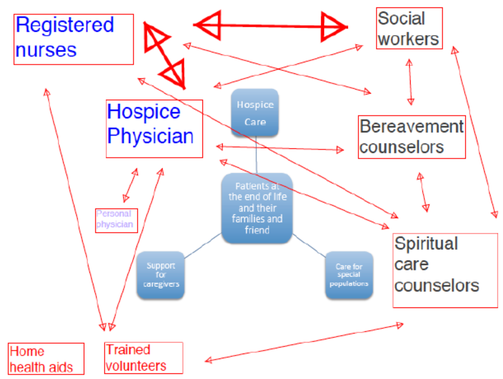
Introduction

- Physicians have limited time to complete training on End of Life (EOL) care.
- While many resources exist to help patients understand end of life care and to initiate conversations about end of life, very few organized and succinct resources on this topic exist for physicians.
- Using a variety of resources, we developed a toolkit for physicians.
- The toolkit includes modules on
  - Hospice vs Palliative care
  - Initiating the end of life conversation
  - The role of a health care proxy
  - Patient misconceptions about hospice.
- Each module is less than 5 minutes long and designed to play on any computer with Adobe Reader installed.
- According to the 2005 Massachusetts Commission on End of Life Care Survey Project, 8/10 patients over age 65 are very or somewhat comfortable talking about death.
- Results of the same survey project indicate that most patients would like their primary care physician to discuss end of life care.

Figure 1



Population Need

- **End of life (EOL) care is medical care for those with a terminal illness or condition that has become advanced, progressive and incurable.**
- In 2010, the total number of deceased individuals in Massachusetts was 52,420, representing a daily all cause mortality of 144.
- Seventy-eight percent (40,950) of deaths in Massachusetts occurred among individuals sixty-five years and older.
- Cancer was the most common cause of mortality (12,973, 25%), followed by heart disease (11,996, 23%) and then stroke (2,5054, 5%) across all ages.
- The most common setting where deaths occurred in Massachusetts in 2010 was in the hospital (20,668, 39%), at home (15,261, 29%), and at a nursing home (13,481, 26%). By contrast, 73-75% of patients surveyed want to die at home. **This highlights a disconnect between patients' known preferences and the state of end of life care.**

Table 6. Top Ten Leading Underlying Causes of Death by Age, Massachusetts: 2010

	Age Groups (number of deaths)								
Rank[1]	<1 year	1-14 years	15-24 years	25-44 years	45-64 years	65-74 years	75-84 years	85+ years	All
1	Short gestation and LBW (68)	Cancer (20)	Unintentional Injuries (166)	Unintentional Injuries (475)	Cancer (3,317)	Cancer (2,925)	Cancer (3,814)	Heart Disease (5,753)	**Cancer (12,973)**
2	Congenital malformations (50)	Unintentional Injuries (18)	Homicide (85)	Cancer (279)	Heart Disease (1,595)	Heart Disease (1,429)	Heart Disease (2,982)	Cancer (2,591)	**Heart Disease (11,996)**
3	SIDS (34)	Homicide (10)	Suicide (78)	Heart Disease (214)	Unintentional Injuries (559)	Chronic Lower Respiratory Disease (460)	Chronic Lower Respiratory Disease (848)	Stroke (1,291)	**Stroke (2,504)**
4	Pregnancy Complications (32)	Congenital malformations (9)	Cancer (22)	Suicide (211)	Chronic liver disease (331)	Stroke (283)	Stroke (679)	Alzheimer's Disease (1,194)	**Chronic Lower Respiratory Disease (2,380)**
5	Complications of placenta (27)	Ill-defined conditions-signs and symptoms (9)	Heart Disease (17)	Homicide (80)	Chronic Lower Respiratory Disease (245)	Diabetes (192)	Alzheimer's Disease (470)	Chronic Lower Respiratory Disease (810)	**Unintentional Injuries (2,043)**
6	Bacterial sepsis of newborn (9)	In situ neoplasms (5)	Ill-defined conditions-signs and symptoms (12)	Ill-defined conditions-signs and symptoms (52)	Suicide (221)	Nephritis (170)	Nephritis (434)	Influenza & Pneumonia (701)	**Alzheimer's Disease (1,770)**
7	Respiratory distress (8)	Heart Disease (3)	Congenital malformations (11)	Chronic liver disease (41)	Diabetes (216)	Unintentional Injuries (140)	Influenza & Pneumonia (340)	Nephritis (606)	**Nephritis (1378)**
8	Circulatory System (7)	Perinatal conditions (3)	Injuries of Undetermined Intent (8)	Stroke (34)	Stroke (207)	Septicemia (135)	Diabetes (289)	Unintentional Injuries (417)	**Influenza & Pneumonia (1,285)**
9	Pulmonary hemorrhage (7)	Suicide (3)	Stroke (4)	HIV/AIDS (28)	Nephritis (143)	Influenza & Pneumonia (122)	Unintentional Injuries (263)	Ill-defined conditions-signs and symptoms (367)	**Diabetes (1,024)**
10	Intrauterine Hypoxia (5)	Injuries of Undetermined Intent (3)	Influenza & Pneumonia (4)	Diabetes (23)	Septicemia (112)	Chronic liver disease (117)	Septicemia (217)	Diabetes (302)	**Septicemia (758)**
All Causes	319	113	453	1,823	8,753	7,423	13,639	19,888	52,420

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Service Project Presentation

- Research for the contents of the toolkit took place during the two week clerkship from October 15-October 25 2013.
- Production of the modules also took place during this time.
- Our community service project was presented on October 28, 2013 at the Advance Care Planning skills session co-sponsored by the Bioethics, Geriatrics, and Primary Care Interest Groups.
- Twelve medical students, 3 graduate nursing students, and 1 physician viewed the presentation and provided positive feedback.
- Ten copies of the disc have been requested for use in future educational activities at Umass Medical School and Graduate School of Nursing.

Conclusions

- Initial reception of the educational module was positive.
- Copies of the module are being produced for use at future events within the school.
- Discussions are ongoing regarding wider distribution of the module.
- This module and other programs like it are critical to training competent and humanistic health care providers.
- Providing accurate information about patients' perspectives on death and dying, including preferences for communication and concerns about the dying process, will empower practitioners to have these discussions.
- Opening this dialogue will impact the well being of individuals with life-limiting illnesses and can affect the physical, emotional and spiritual health of caregivers.

Other Lessons

- Important forms exist that patients need to complete to give legally or medically binding advance care directives; in Massachusetts, health care proxies are legally assigned, Medical Orders for Life Sustaining Treatment (MOLST) are medical orders, and living wills are not legal documents.
- Differences between standard of care, palliative care and hospice care will likely need to be explained to patients.
- Cultural competence/humility is important in addressing end of life in a culturally diverse population; community health workers can facilitate the interaction.
- Currently, there are racial disparities in end of life care.

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