End-of-Life Care: A Public Health Call to Action

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Capstone Presentation
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Consider the question: Is EOL care a PH problem?

Application of the Problem-Solving Paradigm
- Problem definition
- Magnitude of the problem
- Conceptual framework of key determinants
- Identifying and developing strategies
- Setting priorities and recommending interventions
- Implementation and evaluation
- Developing a communication strategy

Conclusions

Acknowledgements
Is End-of-Life Care a Public Health Problem?

*If,*
Public Health is what we, as a society, do collectively to assure the conditions in which people can be healthy.¹

*And,*
Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.²

*And,*
Death has a “universal incidence.”³

*Then,*
Shouldn’t we, as Public Health, ensure health at the end-of-life?

¹IOM (1988). *The Future of Public Health*
²WHO (1948). *Preamble to the Constitution of the WHO*
What Does Health at the End-of-Life Look Like?

“A Good Death” ¹

- Free from avoidable distress and suffering for patients, families, and caregivers
- In general accord with patients’ and families’ wishes
- Reasonably consistent with clinical, cultural, and ethical standards

¹IOM (1997). *Approaching Death, Improving Care at the end of life*
President Obama:

*I actually think that the tougher issue around medical care ... is what you do around things like end-of-life care*

*I think that there is going to have to be a conversation that is guided by doctors, scientists, ethicists.*
Problem Definition

At present in the United States, at least half of all adults experience pain and suffering in the final months and days of their lives at excessive financial cost and with intense resource utilization; and these outcomes ripple out beyond the dying person to their families, loved ones, caregivers, and communities.
Magnitude of the Problem

- **Quality of Care:** As many as 50% of those with cancer or other terminal illnesses experience unrelieved pain or other symptoms during their final days.\(^1\)

- **Cost:** Patients with higher costs had worse quality of death in their final week of life.\(^2\)

- **Impact on Families and Caregivers:** Being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers.\(^3\)

- **Access to Services:** Despite an overwhelming desire to die at home, only ¼ of Americans die at home.\(^4\)

\(^3\) Schulz, R. & Beach, SR. (1999). *JAMA*, 282, 2215-2219
Conceptual Framework of Key Determinants

**Interpersonal Factors**
- Readiness & Acceptance of EOL
- Functional Status
- Spirituality
- Income
- Culture
  - Literacy
  - Gender
  - Age

**Intrapersonal Factors**
- All of the interpersonal factors, but for the patient's family, friends, and caregivers
- Relationship with family, friends, and caregivers
- Patient-Provider Communication
  - Knowledge of Services
  - Support Network

**Advanced Incurable Illness**
- Technology
- Culture of dying
- Availability of Services
- Support Network
- Prioritization of EOL
- Provider Expertise
- Provider Education on EOL
- Patient-Provider Communication
  - Prognostic Tools & Indicators
  - Readiness & Acceptance of EOL

**Community Factors**
- Transportation Infrastructure
- Support Networks
- Perceptions of EOL
- Organizational Networks
- Resources
- Culture of Dying

**Organizational Factors**
- Prioritization of EOL
- Reimbursement Regulations
- Perceptions of EOL
- System Regulation
- Information Dissemination

**Public Policy**

**A Good Death**

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*EOL*: End of Life
## Identifying and Developing Strategies

### Intervention Strategies

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Setting Priorities & Recommending Interventions

- Important role for Public Health
- End-of-Life is charged with emotion
- Public Health can bring
  - objectivity,
  - methodology, and
  - transparency to the process
Implementation and Evaluation

Contextual Factors
- Inherent indicators; fixed/difficult to change
  - Examples:
    - Age
    - SES
    - Literacy
    - Finances
    - Gender
    - Spirituality
    - Culture
    - Politics
    - Location

Domains for Intervention
- Public Policy
- Community
- Health System
- Family
- Friends
- Caregivers
- Person

Initial Outcomes
- Indicators of knowledge, perception, readiness, etc.
  - Examples:
    - Knowledge of eol care continuum
    - Knowledge of available eol care services
    - Culture of death
    - Political will
    - Appreciation of eol as a public health problem
    - Provider knowledge of patient’s eol wishes

Intermediate Outcomes
- Indicators of behavioral change
  - Examples:
    - Access to eol care services
    - Cost comparisons
    - Patient wishes are documented and communicated
    - Utilization disparities
    - Reimbursement structure for eol services

Long-Term Outcomes
- A Good Death
  - Proxy Measures:
    - Death was free from avoidable distress and suffering for patients, families and caregivers
    - Death was in accord with patients’ and families’ wishes
    - Death was reasonably consistent with cultural and ethical standards
Developing a Communication Strategy

- How can we communicate with the public about something nobody wants to talk about?
- The Viagra model?
Conclusions

- End-of-Life care IS a public health problem – we must get involved
- All of Us
  - Educate ourselves
  - Talk about dying
  - Be sure that our personal wishes for EOL care are known
- PH Faculty
  - Suggest students use EOL as a project topic to apply learning
  - Use EOL as examples in your teachings
- PH Practitioners:
  - Have you given EOL care consideration in your practice?

Even the Lives of the Dying

Protecting Health, Saving Lives – Millions at a Time
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This project is dedicated to my Dad,
Dr. J. Richard Gaintner
1936-2004