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

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ABSTRACT

We are all going to die, this is a given. But how we will die is uncertain. What is certain is that at least half of adults in the United States die a bad death, one which is fraught with needless suffering, dishonoring of patient and family wishes, lack of decency, and unwanted or senseless medical treatments, all at a tremendous financial cost. Additionally, the stresses of navigating end-of-life care often reaches beyond the patient, creating a ripple effect of negative outcomes into the dying person's family, friends, and careproviders. To date, clinical health has been the primary profession working to improve end-of-life care in America, attempting to maximize the likelihood that people will die a good death. The public health profession, on the other hand, has not been engaged in either recognizing end-of-life care as a public health problem or actively participating in improving the health and well-being of people who are dying. This paper, therefore, will articulate why end-of-life care is a public health problem and how public health might use its expertise to improve the well-being of people who are dying. The public health problem-solving paradigm will be used to structure the argument, interspersed with one family's story of navigating the labyrinth of end-of-life care in America.

INTRODUCTION

"Health is not simply the absence of sickness."

(Joanne Greenberg, 1932-)

As defined by the World Health Organization, health "is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). Public Health "is what we, as a society, do collectively to assure the conditions in which people can be healthy" (IOM, 1988). The Johns Hopkins Bloomberg School of Public Health embraces these concepts in its motto: "Protecting Health, Saving Lives – *Millions at a Time.*"

How then, do lives that cannot be saved fit into the public health paradigm? Does public health have a role to play in protecting the health of the dying? Is end-of-life care a public health problem?

To begin to answer these questions, consider the following comparison of a good versus a bad death:

Defining a Good and Bad Death (IOM, 1997)

A Good Death:
- 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

A Bad Death:
- Needless suffering
- Dishonoring of patient and family wishes or values
- A sense among participants or observers that norms of decency have been offended, including those resulting from or accompanied by neglect, violence, or unwanted or senseless medical treatments

Additionally, consider the following comparison of the domains of public health and clinical health professions:

Comparing the Domains of Public versus Clinical Health (ASPH, 2009)		
Public Health		**Clinical Health**
Population	vs.	Individual
Health	vs.	Disease
Prevention & Promotion	vs.	Diagnosis & Treatment

We can now pull these ideas together to begin to consider the questions regarding end-of-life care as a public health problem.

First, though death happens to individuals, it is a population experience. We can say with 100% certainty that each life will end in death, regardless of the interventions employed to protect and save each individual life. Death has a "universal incidence" (Rao et al., 2002). As such, maximizing opportunities for a good death can occur at both the population and the individual level. Second, while clinical health focuses on managing the person's disease, public health must manage the population's health; and one might argue that there is no greater time to ensure an individual's "complete physical, mental, and social well-being" than around the time of death. A person has a right to death with dignity; and as a right, there is a corollary obligation that a particular person or institution must facilitate that right (H. Taylor, personal communication, April 6, 2009). And third, while the clinical health domain would focus on the diagnosis and treatment of an individual facing a life-threatening disease, the public health domain would concentrate on preventing populations of people from experiencing lack of health at the end-of-life, as well as, promoting behaviors, conditions, and policies that would maximize the likelihood of a good death.

Despite this apparent "fit" between health at the end-of-life and the domains of public health, end-of-life care is rarely discussed in public health circles. A PubMed search on "public health" and "end-of-life" in the titles of English language journal articles populated five papers by three authors (Rao et al., 2002, 2005, 2009; D'Onofrio & Ryndes, 2003; Byock, 2001). To compare this with more "mainstream" public health problems, doing the same search, but replacing "end-of-life" with "HIV" yields 303 papers; with "cancer" yields 249 papers; with "violence" yields 152; and with "tobacco" yields 157 papers. Ironic, perhaps, as everyone will experience end-of-life, yet everyone will not experience HIV, cancer, violence, and/or tobacco exposure.

This is not to say that a tremendous amount of important work has not been done in studying and improving end-of-life care. It has, but primarily by the clinical health professions, and not by public health. The purpose, therefore, of this paper is to introduce public health students, educators, and professionals to end-of-life care as a public health problem that warrants consideration and attention. The paper will be structured using the steps in the public health problem-solving paradigm, outlined as follows:

The Public Health Problem-Solving Paradigm

1. Defining the problem
2. Measuring the magnitude of the problem
3. Developing a conceptual framework for understanding the key determinants
4. Identifying and developing strategies
5. Setting priorities and recommending interventions and/or policies
6. Implementing interventions and/or policies and evaluating outcomes
7. Developing a communication strategy

Problem-Solving in Public Health, 550.608.01, R. Lawrence, 2007

The exploration of these steps will be informed by the published literature, public resources, conversations with key informants at the Johns Hopkins School of Public Health, and my recent coursework as an MPH student. And finally, interspersed throughout will be my personal story of navigating the labyrinth of end-of-life care during my father's 18-month journey from being diagnosed with an advanced, incurable illness until his ultimate death.

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I was at the supermarket when I got the call, shopping for
Thanksgiving dinner.

"Sally, it's Dad. Honey, I need your help. I just talked to the doctor. I
have a tumor on my pancreas with three mets to my liver."

There it was ~ the moment of demarcation. Time would now be
defined as either coming before or after that moment.

I was a nurse, a hospice nurse at that. I knew what this meant.

My Dad, my hero, my compass, was going to die of pancreatic cancer.

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DEFINING THE PROBLEM

"*A problem well stated is a problem half solved.*"

(John Dewey, 1859-1952)

Defining the problem is a non-linear and iterative process that is expected to change with time, informed discussion, and research. It is additionally influenced by who is defining the problem and the agenda at hand. As such, there is never one definitive definition of a problem. Nevertheless, the exercise is essential and will guide whatever follows. For this endeavor, the definition of the problem is as follows:

Definition of the Problem

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.

Before proceeding to considering the magnitude of the problem, several key definitions should be articulated that are central to any discussion of end-of-life care. Palliative Care and Hospice Care will be defined, along with a presentation of a conceptual framework showing the temporal relationships along the care continuum for advanced incurable illness.
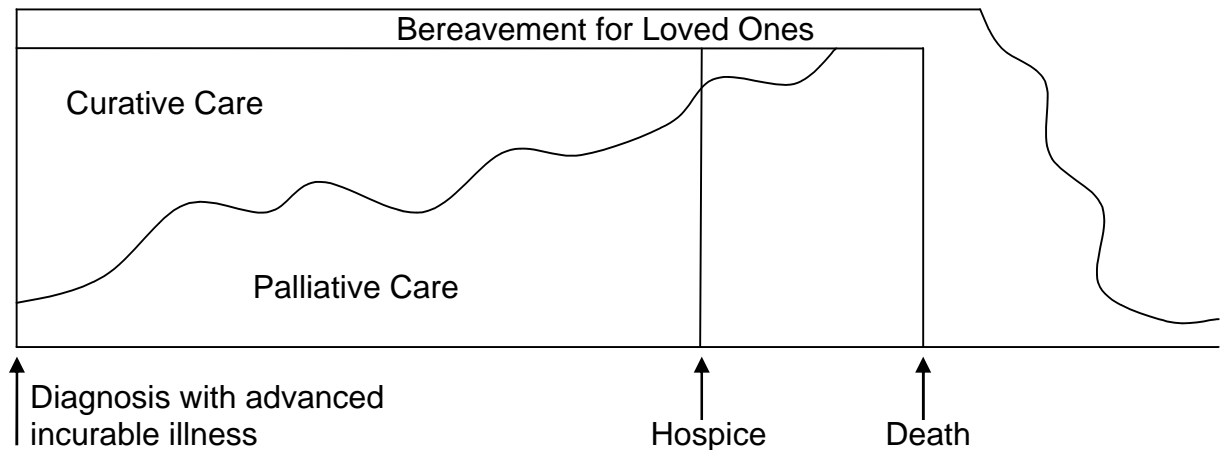
Hospice and Palliative Care both focus on helping a person to be comfortable by addressing issues causing physical or emotional pain, or suffering.
Both have teams of people working together to provide care.

The goals of palliative care: are to improve the quality of a seriously ill person's life and to support that person and their family during and after treatment.

The goals of hospice: focus on relieving symptoms and supporting patients with a life expectancy of months, not years, and their families.

A Continuum of care model for advanced incurable illness

Bereavement for Loved Ones

Curative Care

Palliative Care

Diagnosis with advanced incurable illness

Hospice

Death

This diagram is well know in the hospice and palliative care communities, and varies, depending on its author. The original author is unclear, though thought to be Joanne Lynn, M.D. (S. Dy, personal communication, April 15, 2009).   This particular model has not been copied from any source. Rather, it is a presentation of my understanding of the relationships.

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Effective immediately, I will be terminating my employment. It has been a difficult decision, but one I feel I have no other choice than to make. My Father is quite ill and I need to be present for him and my Mother in these coming months.

Thank you for these many years of service and for understanding the urgency of the situation.

Sincerely,
Sally G. Hess

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MEASURING THE MAGNITUDE OF THE PROBLEM

We are continually faced with a series of great opportunities brilliantly disguised as soluble problems.

John W. Gardner (1912-2002)

To this point, the actual problems associated with end-of-life care in the US have only been alluded to. Certainly most readers have a sense of what the issues are, given the universality of the experience. Indeed, listening to people's stories anecdotally reflects back the magnitude of the problem. In fact, the majority of the faculty interviewed for this paper spontaneously told stories of their loved ones' deaths, which were predominantly stories of bad, not good, deaths. Be that as it may, a careful exploration of the magnitude of the problem, the second step in the public health problem-solving paradigm is essential. Because communication with the public is integral in public health, the magnitude of the problem will be presented in "sound bites," organized by domains of concern, namely quality of care, cost, impact on family, friends, and caregivers, and access to services.

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. (Rao et al., 2002; SUPPORT, 1995; Bernabei et al., 1998; Byock, 2001)
- From both the patient and family perspective, hospice provides high quality care. (Lorenz et al., 2004; Miller et al., 2002; Morrison & Meier, 2004)
- In a large and recent study, patients who chose hospice care lived an average of one month longer than similar patients who did not choose hospice care. (Connor et al., 2007)
- Empathetic physicians who listen to patients and caregivers can reduce some of the burdens on caregivers. (Emanuel et al., 2000)

Cost

- Hospice reduced Medicare expenditures by an average of $2,309 per hospice user. (Taylor et al., 2007)
- Increasing the length of hospice use by just 3 days would increase savings by ~ 10%. (Taylor et al., 2007)
- Patients with advanced cancer who reported having end-of-life care conversations with physicians had significantly lower health care costs in their final week of life. (Zhang et al., 2009)
- Patients with higher costs had worse quality of death in their final week of life. (Zhang et al., 2009)
- If 50% of people had a discussion with their physician about end-of-life care preferences, the cost difference in a year could be more than $76 million. (Connor et al., 2007)
- Medicare costs would be reduced for seven out of 10 hospice recipients if hospice was used for a longer period of time. (Taylor et al., 2007)

Impact on Families, Friends, and Caregivers

- Family members reporting a "too late" referral to hospice also reported (Schockett et al., 2005):
  - lower satisfaction with hospice services
  - higher rate of unmet needs for information about what to expect at the time of death
  - lower confidence in participating in patient care at home
  - more concerns with coordination of care
  - lower overall satisfaction
- Being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers. (Schulz & Beach, 1999)
- Elderly spousal caregivers who report strain associated with caregiving are more likely to die than noncaregiving controls. (Schulz & Beach, 1999)

Access to Services

- Despite experts recommending a three-month hospice stay, the median length of stay in hospice care in 2006 was 21 days, a decrease from 26 days in 2005. (NHPCO, 2007; Christakis & Iwashyna, 2000)

- Roughly one quarter of Medicare beneficiaries use hospice for less than one week. (Taylor et al., 2007)

- 13.7% of bereaved family members reported being referred "too late" for hospice services. (Schockett et al., 2005)

- Despite an overwhelming preference to die at home, only one quarter of Americans die at home. (Grunier et.al., 2007)

- In a survey of nursing homes, on average less than 1% of residents per facility were identified as receiving the Medicare hospice benefit; and 70% of the nursing homes had no hospice patients at the time of the survey. (Petrisek & Mor, 1999)

- Transitioning a patient from curative care to hospice care can be an intricate and highly clinical "dance," balancing the needs and concerns of the patient, caregiver, and treatment team. (D. List, personal communication, October 21, 2008)

- Minorities and individuals with lower levels of educational attainment were each more likely to die in a hospital. (Grunier et al., 2007)

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Eight months had passed. We would come to call it the golden summer. Dad seemed like maybe, just maybe, he would be an outlier in the right tail of the distribution. He carried on like a warrior, forever hopeful, forever steadfast. No different than how he had lived. The cup always half full, no goal ever out of reach.

I told you before, he was my hero.

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DEVELOPING A CONCEPTUAL FRAMEWORK
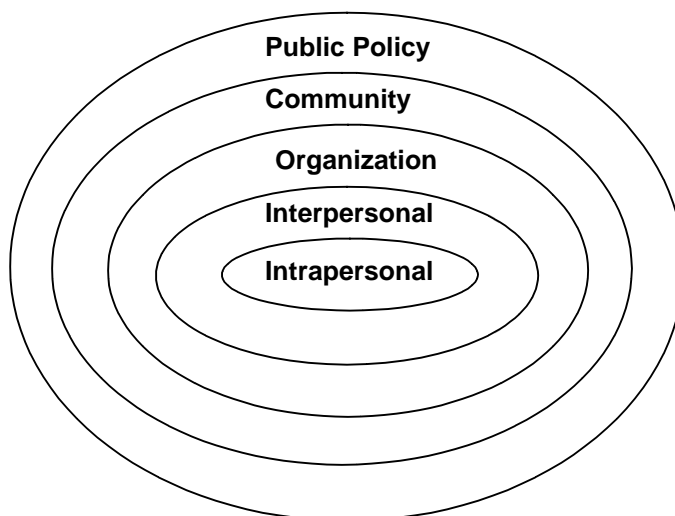# FOR UNDERSTANDING THE KEY DETERMINANTS

The art of simplicity is a puzzle of complexity.

Douglas Horton (1891-1968)

When considering this third step of the public health problem-solving paradigm, the literature becomes quite rich in identifying the key factors that interfere with or facilitate a good death. There are numerous ways of determining, categorizing, and presenting the multitude of key factors that affect a person's experience at end-of-life. And no one approach or model will ever be complete, given the complexities of the human experience. Nonetheless, this section will present a categorization and presentation of the key determinants affecting end-of-life care.

The Ecological Model of Health Behavior (McLeroy et al., 1988) offers a theoretical framework for categorizing the key factors at the end-of-life, keeping the patient central while considering concentric rings of influence.

Ecological Model of Health Behavior (McLeroy et al., 1988)

Public Policy:
- Local, state, and national laws and policies

Community Factors:
- Relationships among organizations, institutions and informal networks with defined boundaries

Organizational Factors:
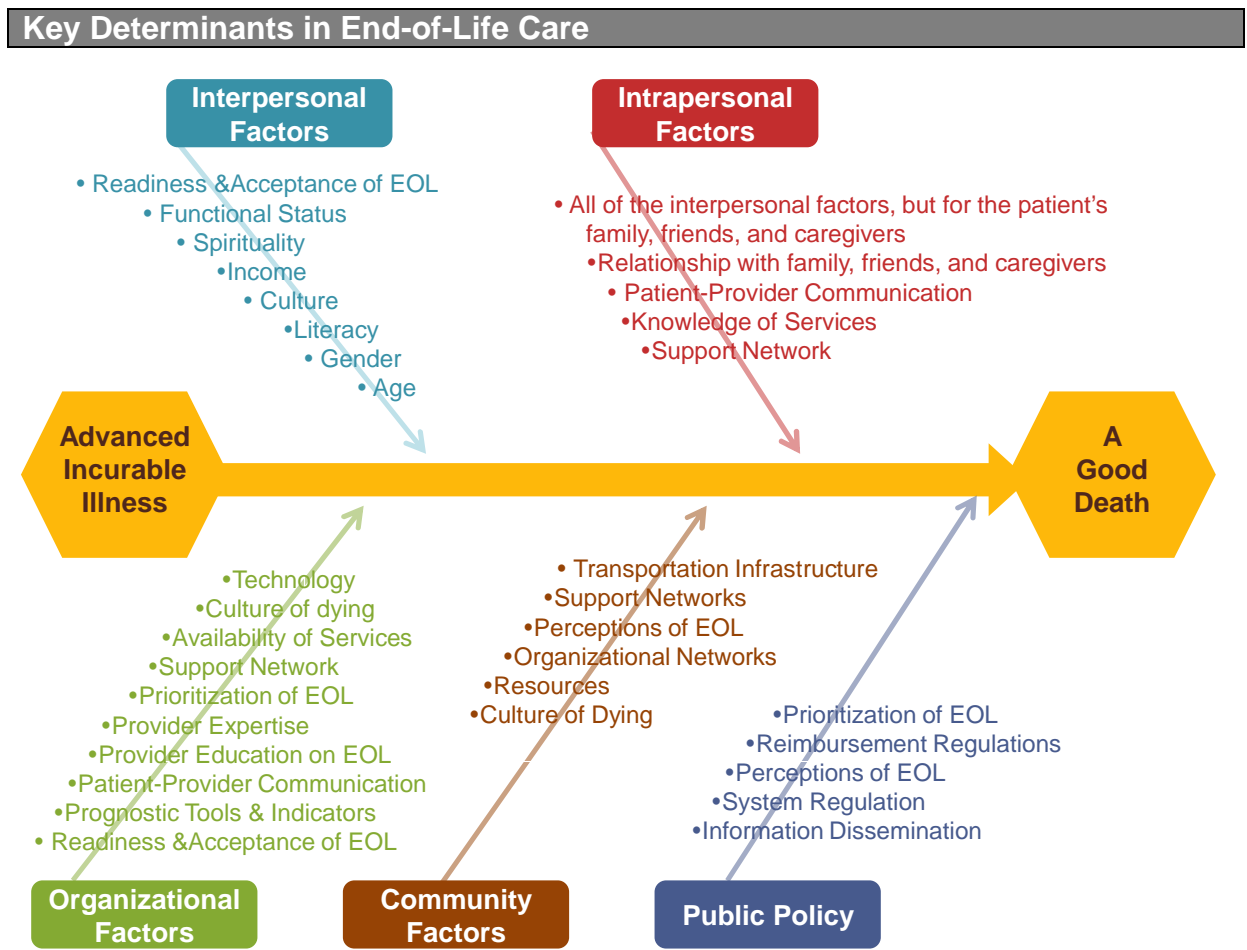- Formal and informal rules and regulations for operation

Interpersonal Factors:
- Social networks and social support systems

Intrapersonal Factors:
- Individual knowledge, attitudes, behavior, skills, etc.

The categorization of factors from the Ecological Model can now be used to guide a conceptual framework for presenting the factors central to end-of-life care. A fishbone diagram has been selected for presenting the factors, as it suggests the continuum of time from diagnosis with advanced, incurable illness to death and the factors that influence the progression. The factors presented are by no means exhaustive, but suggest the complexity of processes influencing end-of-life care at the different levels of the ecological model. The framework begins to lay the groundwork for where interventions might take place and in what domains.

Key Determinants in End-of-Life Care

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 → **A Good Death**

Organizational Factors
- 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

Public Policy
- Prioritization of EOL
- Reimbursement Regulations
- Perceptions of EOL
- System Regulation
- Information Dissemination

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We were all in Florida ~ an unusual year when all seven grandchildren had spring break at the same time. We were making the best of our time together, even though Dad was weak and sick. A year and four months of chemo, radiation, ablations, and medications had taken their toll.

"Hi Dr. Long*, it's Sally. I'm worried about Dad. He seems confused at times…slurring his speech…disoriented. What should we do? Should we go to the ER here? Should we take him home? What do you think?

"Okay…Okay… Thanks."

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*Name changed to protect privacy

IDENTIFYING AND DEVELOPING STRATEGIES

If knowledge can create problems, it is not through ignorance that we can solve them.

Isaac Asimov (1920-1992)

The presentation of the key determinants leads one to begin appreciating the strategies that might be developed to improve the likelihood of the outcome of a good death. To date, and as described in the introduction, improving end-of-life care has largely fallen in the domain of clinical health. Rao and colleagues (2002 & 2005) suggest, however, that intervention strategies for end-of-life care are well-aligned with the core functions of public health outlined by The Institute of Medicine (1988) nearly two decades ago. These core functions of assessment, assurance, and policy development are detailed as follows:

Core Public Health Functions (IOM, 1988)

Assessment:
"…every public health agency [should] regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems. …intergovernmental and interagency cooperation is essential. …This basic function of public health cannot be delegated."

Assurance:
"…public health agencies [should] assure their constituents that services necessary to achieve agreed upon goals are provided, either by encouraging actions by other entities (private or public sector), by requiring such action through regulation, or by providing services directly. …each public health agency [should] involve key policymakers and the general public in determining a set of high priority personal and communitywide health services that governments will guarantee to every member of the community. This guarantee should include subsidization or direct provision of high priority personal health services for those unable to afford them."

Policy Development:
"…every public health agency [should] exercise its responsibility to serve the public interest in the development of comprehensive public health policies by promoting use of the scientific knowledge base in decision-making about public health and by leading in developing public health policy. Agencies must take a strategic approach, developed on the basis of a positive appreciation for the democratic political process."

Rao and colleagues (2005), through a process described later in the paper, developed a set of strategies for improving end-of-life care which were then aligned with the core public health functions, detailed as follows:

Strategies for Improving End-of-Live Care by Core Public Health Functions			
Strategy	**Assessment**	**Assurance**	**Policy Development**
Public education	✔		
Patient, family, and caregiver education	✔		
Professional education		✔	
Help for patients, families and caregivers		✔	
Access to important/support services		✔	
Quality of services		✔	
Funding & financial issues			✔
Policy and planning			✔
Research, epidemiology, and evaluation	✔		

This exercise of aligning interventions with the core public health functions facilitates the "argument" for public health to become involved with improving end-of-life care; as well, keeping central the core functions of public health might alleviate any tension between domains of public and clinical health when identifying and developing intervention strategies.

It would be well-beyond the scope of this paper to detail specific interventions, though several are described below to give the reader a sense of some of the approaches to improving end-of-life care that fall within the scope of public health practice.

Examples of Public Health Interventions in End-of-Life Care

Open Access Hospice: This is a new movement in hospice whereby patients are able to elect hospice without forgoing curative treatments (Taylor et al., 2007). It is a new approach, though gaining hold as insurance companies are piloting its feasibility and reimbursing for this type of blended care (Abelson, 2007).

Case Management: There are many barriers to patients and families accessing services in end-of-life care. Some are associated with the patient and caregiver, some with the treatment team, and some with more distal mechanisms, such as the built environment and insurance complexities. A case manager offers a means by which the barriers can be identified and minimized while keeping the best interest of the patient at the core. (L. Piet, personal communication, October 21, 2008).

Medical School Training: Here the focus is on developing and providing adequate and appropriate training for medical students in end-of-life care. Understanding the needs of the students and integrating quality and proven training mechanisms is essential. Opportunities for students to engage with clinicians, patients, and families and to experience palliative care medicine for themselves are key. Student learning also must incorporate legal and ethical aspects of end-of-life care, pain management, and communication skills (Salim, 2008).

Living Wills: Ensuring that people's wishes for their deaths are well understood is critically important and is a key element in the definition of a good death. Therefore, facilitating the documentation and discussion of end-of-life care wishes is crucial. Five Wishes (Aging with Dignity, 2007) is a tool that was developed to do just this, and is now legally binding in 40 states. Public health might work to further the dissemination and implementation of such a tool and possibly consider making it a mandatory exercise at key points of entry into the public system, say when obtaining a drivers license (A. Gielen, personal communication March 30, 2009) or when becoming eligible for social security (R. Lawrence, personal communication April 13, 2009). Or at the very least, careful completion of a living will might become "protocol" for individuals at high risk for dying.

Another way to capitalize on the strengths and expertise of public health is to consider interventions that align with the public health disciplines, namely Biostatistics, Epidemiology, Social and Behavioral Sciences, Health Policy and Management, and Environmental Health Sciences (Calhoun et al. 2008). To follow is a discussion of identifying and developing intervention strategies within each of the public health disciplines.

Biostatistics and Epidemiology

Both Biostatistics and Epidemiology can contribute to determining and understanding the problems associated with poor end-of-life care. The roles might include: surveillance to monitor for shifts in key indicators of the problem; design and implementation of research studies; and analyzing data in a manner that incorporates state of the art techniques for appreciating causality, influence, and change.

With regards to study design, one can imagine the challenges in randomization, bias in the patient population, and potential lack of compliance with interventions (M. Diener-West, personal communication, March 26, 2009). Nonetheless, experimental design is essential to understanding and improving care for the dying. As well, carefully conducted quasi-experimental designs as well as observational studies with sophisticated statistical analysis can contribute significantly to a clear understanding of this body of work. Two examples from the literature exemplify the roles for biostatistics and epidemiology in understanding and improving end-of-life care.

The Study to Understand the Prognoses and Preferences for Outcomes and Risks for Treatments (SUPPORT, 1995) was a large-scale two phase study, conducted in five US teaching hospitals, designed to improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying. The first phase was a two-year observational study with 4031 patients; and phase two was a two-year controlled clinical trial with 4804 patients and their physicians randomized to intervention and control groups. The intervention was multifaceted but generally targeted enhancing opportunities for more patient-physician communication.

The point here is not to detail the study, but to exemplify that large scale, carefully designed studies can and do occur in end-of-life care and biostatistics and epidemiology have a crucial role to play in crafting the design of these studies such that resources are spent on study designs that will result in convincing and generalizable knowledge that is not fraught with doubt because of weakness in study design or statistical analysis. For general interest, the major outcomes of the SUPPORT study are summarized as follows:

- "The phase I observations confirmed substantial shortcomings in care for seriously ill hospitalized adults."

- "The phase II intervention failed to improve care or patient outcomes."

- "To improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed."

Another, more recent study, exemplifies the role that surveillance, an important purview of epidemiology, has to play in end-of-life care. Rao and colleagues (2009) utilized a novel approach for identifying items for public health surveillance in the realm of end-of-life. The results of their work crafted an approach for identifying potential items for public surveillance from the universe of existing questions on end-of-life issues. The authors note that "if end-of-life items are included in population-based surveillance systems, they have the potential to yield information that will provide a broader perspective on end-of-life issues than has been available to date."

Social and Behavioral Sciences

Perhaps of all the disciplines, the Social and Behavioral Sciences are the most well-poised to intervene on behalf of the dying. "The social and behavioral aspects are immense – not just for the patient, but for the family also" (M. Diener-West, personal communication, March 26, 2009). This "fit" is because so many of the factors and barriers influencing a good death are psycho-social-behavioral in nature. There are numerous methodologies developed and practiced by this discipline which would directly apply to understanding and improving of end-of-life care. One such example was alluded to earlier (Rao et al., 2005), when outlining end-of-life care interventions as they are aligned with the core functions of public health. This work utilized the technique of Concept Mapping to determine public health initiatives for improving end-of-life care. This technique is worth describing, as it articulates an approach to gathering and organizing population-level concepts (Trochim, 1989; Burke et al., 2005).

Concept mapping is "a structured process, focused on a topic or construct of interest, involving input from one or more participants, that produces an interpretable pictorial view (concept map) of their ideas and concepts and how these are interrelated" (Trochim, 1989). Rao and colleagues applied concept mapping to developing public health priorities for end-of-life initiatives by convening key stakeholders to respond to the question: "to enhance the lives of seriously ill, injured, or dying people, a specific thing that the state or local health department could do or enable others to do is…" The outcomes of the concept mapping process were then used to populate and prioritize the interventions outlined earlier.

Concept mapping is just one example of how the social and behavioral sciences can contribute to understanding and improving end-of-life care. Certainly there are others, which would include, but not be limited to: developing and testing conceptual frameworks, health education, developing and testing theory, patient-provider communication, social marketing (Stanley, 2003), qualitative data collection and analysis, community based participatory research, and public communication.

Health Policy & Management

Similar to the social and behavioral sciences, Health Policy and Management has a tremendous wealth of expertise to contribute to improving end-of-life care in America. Most importantly, this discipline can perhaps bring a level of objectivity to the discussion. Given that in public health, populations, not individuals, are of primary concern, "there are no human complications to manage" (H. Taylor, personal communication, April 6, 2009). In clinical care "you cannot avoid death and loss of individuals. But with public health, it is all rather abstract – mortality, crude mortality, age adjusted mortality…" (R. Lawrence, personal communication, April 13, 2009). Thus, the suggestion is that public health, and specifically Health Policy and Management, can capitalize on this "removed" stance from the individual and focus on interventions that maximize the likelihood that the population can access and experience optimal end-of-life care. Following suite, clinical care can then focus on the nuances of the individual cases, within the framework laid out by public health.

This synergy between public health policy and management and clinical health has occurred successfully with other health problems, forming a "natural partnership" (G. Rebok, personal communication, March 25, 2009) between the two professions.

For example, clinical health providers manage the patients in trauma centers, yet public health has helped to operationalize the management of the trauma systems and create policies to fund and ensure the sustainability of the centers. Might the same collaboration occur for individuals facing advanced incurable illness? The clinical health providers would manage the individual patients as they navigate the trajectory from diagnosis to death. Public health would simultaneously be ensuring that the systems of care function in a manner that would maximize the likelihood that that trajectory was seamless, fair, and of the highest quality.

In addition to ensuring optimal management of systems and creation of policies supporting the population's trajectory to a good death, Health Policy and Management has the important role of understanding and optimizing the cost implications of end-of-life care. As described in the magnitude of the problem, multiple studies have taken place to understand how cost contributes to a good death. The issues of cost are complex and at first blush, and if not handled carefully, could be offensive and disconcerting in a discussion about end-of-life care. Yet cost is so central to the problem that ways to understand and present cost in a manner that adds to the discussion and enhances our appreciation of the multiple factors at work is essential. It seems clear from the evidence presented thus far, that a good death is by no means correlated with a more expensive death. In fact the opposite appears true, that a good death is actually cheaper than a bad death. So it stands to reason that Health Policy and Management has a unique role to play in collecting and presenting data to the public and to policy makers that would not only improve the population's end-of-life experiences, but also save money at the same time.

Environmental Health Sciences

Of all the disciplines, Environmental Health Sciences might have the least "fit" with end-of-life care. Certainly the "environment" plays a role in the experience of dying, but not in the traditional public health sense. When environment is thought of at the time of death, it is in reference to place, such as home, hospital, hospice, etc. And the environment of these "places" is not a population consideration, but quite individual. Improving the characteristics of these places is certainly important to improving the end-of-life experience, but perhaps not a role to be carried out by public health.

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"Sally…Sally…wake-up, Honey. It's your Dad. He's in trouble."

"Hang in there Dad, we'll be there soon. Take deep breaths. It's going to be Okay. We're going to be there soon."

"The CAT scan shows a perforation in the intestine, near where the stint was placed. We're going to need to operate."

"Dr. Long, it's Sally. I'm sorry to call so late, but we're in the ER. They want to do surgery. Is that right? Is this what we should do? What would happen if we did nothing? Are you sure? Really? Okay…Okay…Thanks."

"I love you Dad. Good luck in there. We'll see you soon. I love you…"

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SETTING PRIORITIES AND RECOMMENDING INTERVENTIONS AND/OR POLICIES

Decide what you want, decide what you are willing to exchange for it. Establish your priorities and go to work.

H.L. Hunt (1889-1974)

One need not look further than the front page of the newspaper to appreciate the myriad of problems facing our health care system. Obesity, environmental health hazards, cancer, access to care, disparities, pharmaceuticals, infections, the list is endless. Setting priorities has always been essential, but now, more than ever, determining how to prioritize interventions is critical. Public health has multiple tools for determining what to do and in what order. Certainly applying these techniques in end-of-life care is no different than with other population-based interventions.

Eugene Bardach (2008) developed an eight step process for developing policy that is well suited to making decisions about which intervention(s) to focus on when resources are limited. The step are: (1) Define the problem; (2) Assemble some evidence; (3) Construct the alternatives; (4) Select the evaluation criterion; (5) Project the outcomes; (6) Confront the tradeoffs; (7) Decide; (8) Tell your story. The process is similar to the public health problem-solving paradigm, with greater emphasis on the decision making process.

For the purposes of improving end-of-life care, steps four through six are particularly important in setting priorities and determining interventions and policies. Step four forces evaluation to be part of the process at an early stage and encourages the interventions to be based on outcomes considered to be the most important. Step five then takes the selected evaluation criterion and enters them into a decision matrix, weighting each on its importance. The alternative interventions are then scored for

each outcome criteria, based on its projected capabilities for each outcome. What

results is a score for each intervention that aids in step six, confronting the tradeoffs of

choosing one intervention over another. Following is an example of what a decision

matrix might look like for a health care institution deciding how to prioritize educational

interventions around end-of-life care.

Bardach Decision Matrix for Projecting Outcomes					
	weight	Status Quo	Public Education	Patient, Caregiver, Family Education	Provider Education
Ease of Implementation	10%	0	-1	+2	+1
Patient/caregiver acceptance	25%	0	+2	+2	+2
Provider acceptance	25%	0	+2	+2	+1
Population benefit and equity	30%	0	+2	+1	+2
Cost	10%	0	-2	-1	-1
Total	100%	0	1.3	1.4	1.35

In this case, the total scores were similar, though the scores within the matrix

varied. Thus, further decision making would ensue, perhaps adding more outcome

criteria, or perhaps using a second process for prioritization, such as stakeholder

weighting of interventions. In Rao and colleague's work with concept mapping (2005),

in a second phase (after the concept mapping produced the interventions), the

stakeholders were asked to rank the proposed interventions on importance, feasibility,

and whether the outcomes would show benefit in the short, intermediate, or long term.

A ranking process then ensued to determine which interventions should have priority

and in what order. Prioritization of interventions is essential, whether prioritizing within

the spectrum of health care as a whole, or specifically within end-of-life care

interventions; and this is an important contribution for public health to make.

With regards to the second component of this step of the problem-solving paradigm, recommending interventions, it is far beyond the scope of this paper to suggest which interventions should be implemented. However, in interviews with Johns Hopkins faculty for the paper, one intervention was repeatedly recommended and thus bears a brief description.

Our society has developed "guides" for most major life events: weddings, funerals, buying and selling a home, and giving birth (W. Ward, personal communication, March 31, 2009). Yet we have no such guide for navigating the trajectory towards death, once diagnosed with advanced incurable illness. Therefore, a public health intervention to improve end-of-life care might be to develop such a system of guides. It would ideally grow from the community, not from the health care system, and would involve a cadre of individuals who have navigating end-of-life care as their domain of expertise (H. Taylor, personal communication, April 6, 2009). It might follow the community health worker model which has been utilized successfully in navigating other public health problems (L. Wissow, personal communication, March 25, 2009). Because there never will be a one-size-fits-all intervention for end-of-life care (H. Taylor, personal communication, April 6, 2009), this concept of creating end-of-life care guides might be a means of assisting patients and families in optimizing their chances of reaching a good death while keeping cost and resource utilization at a reasonable level.

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"He made it through the surgery. I did my best. But he has extensive damage to his intestines from the radiation. I'm not sure if the internal sutures will hold. We'll just have to wait and see. We'll just have to take it day by day."

"Okay. We understand. But please, promise you will tell us when there is no more hope for recovery. We want to bring him home to die if it gets to that. We want hospice at the end. Please, promise that you will tell us. Please."

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IMPLEMENTING INTERVENTIONS AND/OR
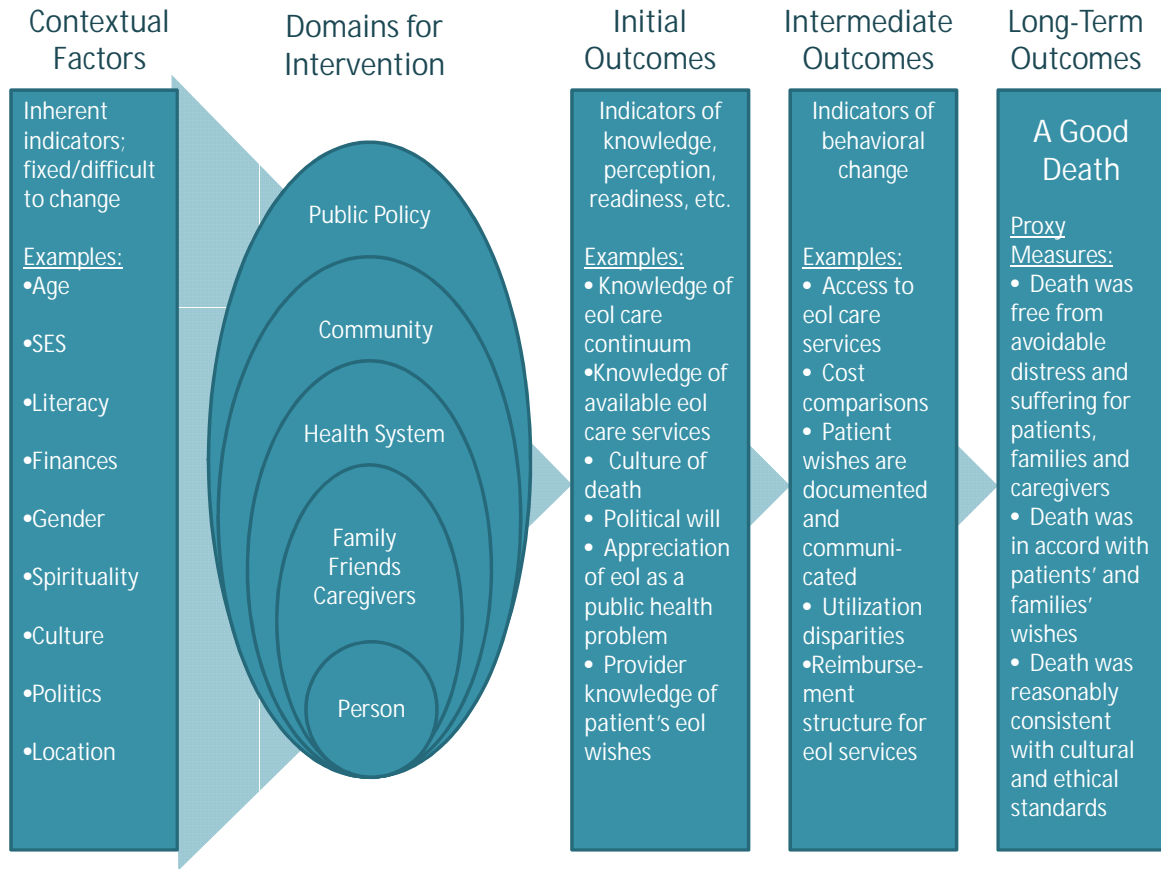## POLICIES AND EVALUATING OUTCOMES

True genius resides in the capacity for evaluation of uncertain, hazardous, and conflicting information.

Winston Churchill (1874-1965)

Step six of the problem-solving paradigm guides us through implementing programs and evaluating outcomes. Careful implementation and evaluation is critical to ensure that resources are used judiciously and thoughtfully and that the intended intervention is implemented as planned and is yielding the intended results. The principles of program evaluation (Fundamentals of Program Evaluation, 380.611, J. Bertrand, 2009) are well suited for carefully considering implementation and evaluation of any program and include the following components: (1) *Process Evaluation:* Monitoring of implementation to consider quality, access and reach. Did the program do what it said it was going to do? and (2) *Summative Evaluation:* Monitoring of outcome measures. Did the program cause the desired change?

An essential step preceding both process and summative evaluation is developing a conceptual framework that "articulates the pathways by which an intervention is expected to cause the desired outcome" (Fundamentals of Program Evaluation, 380.611, J. Bertrand, 2009). The following conceptual framework offers a template for concepts and indicators to consider when designing, implementing, and evaluating a program intended to improve end-of-life care. The framework highlights the importance of delineating measurable outcomes into initial, intermediate, and long-term timeframes while considering contextual factors that should be accounted for but are not necessarily changeable. Additionally, the framework reintroduces the ecological model for considering the domains of intervention.

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Template of a Conceptual Framework for Evaluating Interventions to Improve End-of-Life Care

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 communi-cated
• Utilization disparities
• Reimburse-ment 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

This framework was influenced by personal communication with J. Bertrand, April 13, 2009 and the conceptual framework of the "Communication Pathways to a Health-Competent Society" presented in Fundamentals of Program Evaluation, 380.611, J. Bertrand, 2009

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When I was in Florida, I wanted to be at home, watching Eli's lacrosse games or listening to Sophie's adventures in adolescence. When I was home, I wanted to be in Florida, monitoring every conversation, understanding every procedure, making sure Dad was Okay and Mom was holding up.

But the answer was always the same. "Let's give it another day. Let's see how he looks in the morning. Let's see what the scan shows."

Six weeks, every day, always the same response.

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DEVELOPING A COMMUNICATION STRATEGY

"Everything becomes a little different as soon as it is spoken out loud."
Hermann Hesse (1877-1962)

The final step in the problem-solving paradigm is communicating with the target audience, a specialty all its own within the field of public health. It seems, however, that society does not want to talk about or hear about death. We live in a death denying culture (G. Rebok, personal communication, March 25, 2009). Living is success. Death is failure. No one wants to talk about death.

Yet consider the communication explosion in recent years about erectile dysfunction. Do you think before the advertizing blitz for Viagra we wanted to talk about erectile dysfunction? Now it has become a common term that barely raises an eyebrow. Might we not do the same for death and dying? Imagine a communication campaign where we see families in the process of a "good death" and the final message goes something like, "If you or someone you care about is facing an advanced, incurable illness, talk with your doctor about your options for care." Or, "talk to your doctor about palliative care because palliative care begins the minute you have a problem …palliative care is for the living" (L. Wissow, personal communication, March 25, 2009). The essence would be to help the public understand that there are *choices* in end-of-life care and considering those choices should start early on (A. Gielen, personal communication, March 30, 2009).

Communication is central to whatever public health endeavors take place. A good idea or significant discovery is useless if not communicated; and public health has an important role to play in organizing and disseminating the information.

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It was a Friday. I was the first to arrive in his room that morning, letting Mom Sleep in, as sleep only seemed to visit her early in the morning.

He did not awaken as I gently pulled back the sheet to look at his abdominal wound.

I knew then that it was time.

We were not going to wait another 24 hours.

"Dr. Long, it's Sally. We are going to take Dad home ~ today. It is time."

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A NOTE ABOUT HOPE

I am prepared for the worst, but hope for the best.

Benjamin Disraeli (1804-1881)

Before concluding, it would be remiss to not mention the concept of hope,

something fundamental to discussions about end-of-life, but not yet discussed in this

paper. Hope is one of those words we use a lot. *I hope it's not going to rain today. I*

hope I get an A on this paper. I hope my mammogram is OK. I hope I don't get laid off.

And on and on it goes. Hope has even gained a new notoriety with the election of

President Obama in 2008 and the centrality of "Hope" to his campaign.

Much attention has been paid to hope in both the scientific and lay literature, with

most agreeing that hope is crucial to recovery from illness. Hope keeps people focused

and motivated for treatment, willing to tolerate discomfort and inconvenience for the

hope of recovery and cure. But there comes at time, with advanced incurable illness,

when what a person is hoping for must shift. At some point, hope for cure and recovery

must shift to hope for a good death. To follow, what the person hopes for also shifts ~

hoping to die at home or in a hospice facility; hope for one last visit with a beloved

friend; hope for no more pain; hope for one last sunrise.

Put another way, false hope must be replaced with true hope. "False hope does

not recognize the risks and dangers that true hope does. False hope can lead to

intemperate choices and flawed decision making. True hope takes into account the real

threats that exist and seeks to navigate the best path around them" (Groopman, 2003).

Perhaps public health can bring objectivity to this distinction and help to create a "vision

of the trajectory" (M. Diener-West, personal communication, March 26, 2009) from

advanced incurable illness to a good death that would keep hope central, but shift its focus from false hope to true hope.

CONCLUSIONS

In the life of a spirit there is no ending that is not a beginning.
Henrietta Szold (1860-1945)

As we move further into the 21st century, the problems surrounding end-of-life care will only intensify with the aging of the baby boomers. "Older people are disproportionately at greater risk for dying" (G. Rebok, personal communication, March 25, 2009); and thus, the magnitude of the problem will heighten as more people wrestle with these issues. Additionally, with the current financial crisis and loss of savings for many people, what had been well-planned for may no longer be a possibility (J. Bertrand, personal communication, April 13, 2009). But planning for such large-scale health inevitabilities is what public health is all about.

One can also argue that Public Health has contributed to the end-of-life care crisis by gradually shifting mortality from infectious to chronic disease.   So now, rather than dying a quick and unexpected death from an acute infection, most Americans will die at an "advanced age following a period of chronic illness and decline" (Rao et al., 2002). Additionally, advances in "technology and the capacity to maintain vital signs [far exceeds] our growth and sensitivity in the complex psychological, cultural, and cosmic issues around death" (R. Lawrence, personal communication, April 13, 2009).

So for many reasons, Public health must play a key role in improving the health of people who are living with advanced, incurable illness, as well as their families, caregivers and loved ones. Throughout this paper, suggestions have been made as to

how and why public health should be involved in both recognizing end-of-life as a public health problem and intervening to promote a good death for the majority of Americans. Much of what is learned and utilized in public health is directly applicable to end-of-life care, "we just do not think about applying it" (A. Gielen, personal communication, March 30, 2009).

The roles that public health students, educators, researchers, and practitioners might play are as diverse and varied as the experiences of the people who fill these roles. Yet there is one common place every public health professional can begin, and that is by recognizing the problems of end-of-life care in America, "we should all be educated about end-of-life care" (G. Rebok, personal communication, March 25, 2009). Thereafter, we all might take further steps to incorporate problem into our scope of practice. Public health students might consider doing a lab assignment or a paper on end-of-life care. Faculty might incorporate examples of end-of-life care into their teachings to diversify the saturated use of "typical" public health examples. Public health practitioners might consider how to improve the lives of the dying, given their unique set of skills and perspective. Researchers and interventionists should be certain that where applicable, end-of-life care is incorporated into the spectrum of care in his/her work.

And if nothing else, all of us in public health can remember that we have a responsibility for "Protecting Health, Saving Lives – *Millions at a Time*" – even the lives of the dying.

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My Dad died peacefully at home, sixty hours after he left the hospital.

My brave Mom told him what to do. "Sail on, my love. The wind is at your back. It's a beautiful breeze. Sail on…"

We were all with him. Mom, Wendy, Jenny, and me. Just as it was supposed to be. Just as we had imagined. Just as Dad had wanted.

It was time.
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ACKNOWLEDGEMENTS

And finally, this paper is fully and completely dedicated to my father,
Dr. J. Richard "Dick" Gaintner
1936-2004

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Determination Notice

Date: March 9, 2009

To: George Rebok, Ph.D.
            (Sally Hess)
            Department of Mental Health

Re: **Study Title:** "How We Die: The Public Health Implications of Curative versus
                            Palliative Care"
            IRB #: 00001943

The JHSPH IRB has reviewed your study application. We have determined that the
proposed research involves prospective data collection of key informant data only.
Therefore, the proposed research does not qualify as human subjects research as defined
by DHHS regulations 45 CFR 46.102, and does not require IRB review.

With this determination, the investigator assumes the responsibility for notifying the JHSPH
IRB if any changes should develop in the methodology that might require human subjects
review.

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(410) 955-3193 or via email at irboffice@jhsph.edu.

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