

2005-9 Supporting Public Health's Role in Addressing Unmet Needs at the End of Life

The American Public Health Association has supported a major role for federal, state, and local government health agencies in assuring health care is maximally responsive to the public's needs.¹ A public need which has been inadequately addressed is the prevention of many of the adverse consequences of living with chronic terminal illness. Persons with cancer and other chronic terminal illnesses suffer both physically and emotionally across all stages the illness,^{2,3} and much of this suffering could be prevented.⁴⁻⁶ Also, families and caregivers of persons with chronic terminal illnesses often experience increased morbidity or premature mortality resulting from the stress and strains associated with a loved one's terminal decline.⁷⁻¹⁰ Health care providers, public health professionals, and state and local health departments [together with their collaborators (e.g., aging networks, state units on aging, and others)] have a role in preventing this suffering,¹¹ and thus, in assuring maximum responsiveness to public needs.¹ The promotion of quality of life for dying individuals and their survivors is integral to the achievement of the Healthy People 2010 goal of increasing the quality and years of healthy life,¹² and to promoting death with dignity.¹³

Therefore, recognizing that:

1) Death is a universal experience affecting nearly 2.5 million persons annually in the United States,¹⁴ and three-quarters of all deaths are of persons 65 years of age and older, with the vast majority being from chronic disease,¹⁵⁻¹⁷ and dying persons and their loved ones frequently suffer preventable negative consequences of terminal illness and decline;⁴ and that much of this suffering is amenable to population-based interventions.^{18, 19}

2) Palliative care (including hospice care—a specialized form of palliative care) is underutilized in the United States,^{5, 6, 20} even though its goal is to provide “effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s),”²¹ and even though hospice care has been shown to

be associated with greater family satisfaction and fewer patient/family unmet needs^{3, 22, 23} and with improvements in pain assessment and management.^{24, 25}

3) With the aging of the population, the proportion of deaths associated with chronic terminal illness will increase, resulting in increased needs and important opportunities to develop effective interventions for improving advance health care planning and end-of-life care.^{26, 27}

4) The Association of State and Territorial Chronic Disease Program Directors (CDD) and the Centers for Disease Control and Prevention (CDC) facilitated a systematic process which considered input and ideas from nationally prominent stakeholders with expertise in end of life, public health, aging, and cancer and resulted in priority recommendations aimed at assisting State Health Departments in identifying the role of public health in addressing end-of-life issues,¹⁹ recommendations congruent with and complementary to existing APHA policies and priorities.^{1, 13, 28}

The APHA endorses and supports:

1. An active public health role in advocating for and addressing end-of-life issues, including honoring of a patient's self-determination about end-of-life decisions.

2. Promotion of advance planning for end-of-life care through public and professional education by health care providers, public health professionals, government entities and/or community coalitions.²⁹

3. Promotion of the use of hospice and palliative care through education of its availability and benefits by health care providers, public health professionals and government entities.

4. In relation to the above, APHA supports the intent of the CDC and CDD priority recommendations for state health department action, which are listed below and which many states are moving towards implementing.^{26, 30-32}

- Identify a chronic disease point person within the state health department to coordinate/liason end-of-life activities with relevant issues (e.g., aging, cancer).

- Collect, analyze and share data about end of life through state surveys such as the Be-

havioral Risk Factor Surveillance System (BRFSS).

- Incorporate end-of-life care into state comprehensive cancer control plans.
- Educate the public about the availability of hospice and palliative care.
- Educate the public about the importance of advance directives and health care proxies.
- Eliminate financial barriers to third party payment for early and comprehensive hospice and palliative care; including at least elimination of Medicare's requirement that such care may only be reimbursed when efforts to cure have been terminated.

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