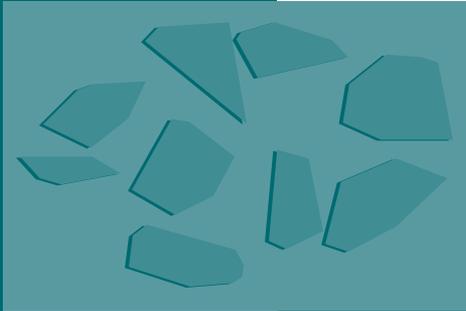


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THE ROLE OF STATE HEALTH DEPARTMENTS IN ADDRESSING END-OF-LIFE ISSUES





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EXECUTIVE SUMMARY

The Association of State and Territorial Chronic Disease Program Directors (CDD) and the Centers for Disease Control and Prevention (CDC) facilitated a process to identify and prioritize public health activities related to end of life issues. Concept mapping and a modified Delphi process yielded the following five priority recommendations for state health department action:

1. Identify a chronic disease point person within the state health department to coordinate/liaison end-of-life activities with relevant issues (e.g., aging, cancer).
2. Collect, analyze, and share data about end of life through state surveys such as the Behavioral Risk Factor Surveillance System (BRFSS).
3. Incorporate end-of-life care into state comprehensive cancer control plans.
4. Educate the public about the availability of hospice and palliative care.
5. Educate the public about the importance of advance directives and health care proxies.

Follow-up to this project will focus on these recommendations and will include an environmental scan of current state health department efforts regarding end-of-life issues.

PURPOSE

The purpose of this report is to assist state health departments and other organizations in identifying the role of public health in addressing end-of-life issues. The Association of State and Territorial Chronic Disease Program Directors (CDD) conducted this project, which was supported by the Divisions of Cancer Prevention and Control and Adult and Community Health at the Centers for Disease Control and Prevention (CDC).

BACKGROUND

Over the past decade, issues related to the dying process have gained a heightened visibility in the health care system. Only recently has end of life begun to capture the attention of the public health community as a health concern that merits public health involvement.¹ Although death itself is ultimately not preventable, much of the suffering that may accompany the dying process is amenable to population-based interventions.

The health care system has already begun to address end-of-life issues. Public health agencies, particularly state health departments, have many opportunities to contribute to these efforts, but they need a greater understanding of their appropriate role with respect to end of life. In October 2002, CDD began a project to solicit recommendations for public health action on end-of-life issues.

This project had two phases. In each phase, stakeholders with expertise in end of life, public health, aging, and cancer generously shared their knowledge, ideas, and assistance in developing recommendations and identifying priorities. Phase I involved a concept mapping process, facilitated by Concept Systems, Inc., to develop recommendations for public health action relevant to end of life. Phase II involved a modified Delphi process to develop consensus on the initial priorities for state health departments.

PHASE I: CONCEPT MAPPING

A concept mapping process was used to collect, organize, and visually represent the ideas submitted by stakeholders. Concept mapping combines qualitative and quantitative methods to develop maps that provide a framework for stakeholders to use as they formulate recommendations.² More than 200 individuals from a broad array of institutions, including state and federal agencies, academia, and foundations participated in this phase.

CONCEPT MAPPING METHOD

1. Participants generated ideas to complete the following focused statement: “To enhance the lives of seriously ill, injured, or dying people and their families, a specific thing that the state or local health department could do (or enable others to do) is...” More than 200 participants generated 647 statements that were consolidated into a final set of 124 ideas.
2. A core group of 38 members organized the 124 ideas into categories to identify themes or patterns.
3. All participants provided input by rating the importance and feasibility of each idea.
4. Multivariate statistical techniques were used to organize and visually present the ideas in a series of concept maps. These maps show the relationships between the ideas, the clustering of ideas into themes or categories, and how participants rated the ideas.
5. In the final step of this process, members of the core group participated in two regional meetings to review and interpret the maps and develop recommendations.

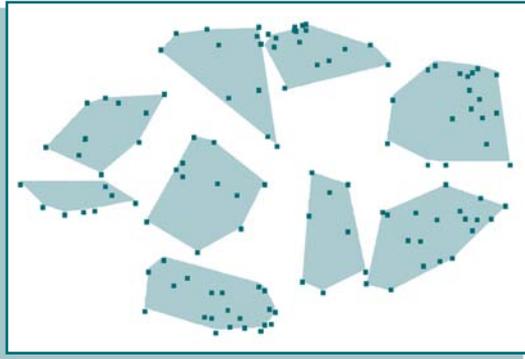


Figure 1: Cluster Point Map: End-of-Life Recommendations for State Health Departments

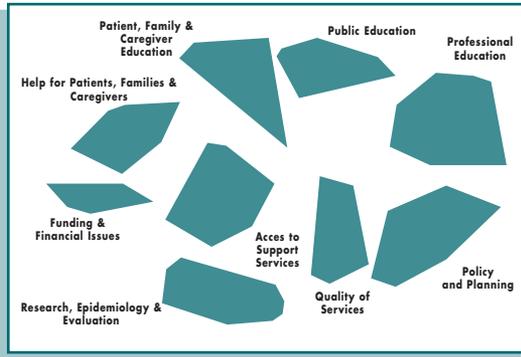


Figure 2: Cluster Map: End-of-Life Recommendations for State Health Departments

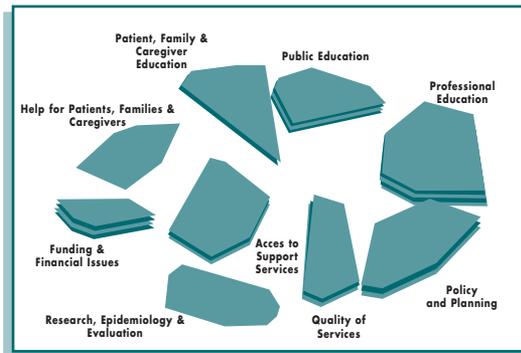


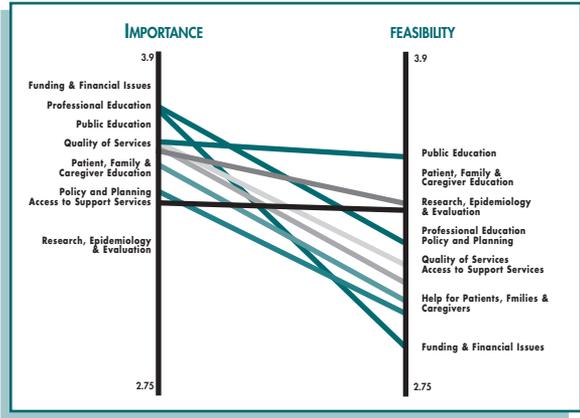
Figure 3: Cluster Importance Rating Map: End-of-Life Recommendations for State Health Departments

FINDINGS

The concept mapping process resulted in several concept diagrams or maps. The Cluster Point Map (Figure 1) shows each of the final 124 ideas as a point on the map. Points that are close together are considered conceptually similar. This map also shows the nine clusters into which the points were sorted. Ideas within a cluster are related conceptually, and clusters that are close together may represent similar themes.

The Cluster Map (Figure 2) shows the nine clusters without the points (i.e. groups of individual); the labels summarize the ideas within each cluster: patient, family and caregiver education; public education; professional education; policy and planning; quality of services; Access to support services; research, epidemiology, and evaluation; funding and financial issues; and help for patients, families and caregivers.

Other analyses examined whether the ideas received different ratings of emphasis (i.e., importance, feasibility). The Cluster Rating Map (Figure 3, on page 7) highlights the relative importance of each topic (cluster), as rated by the participants. The number of layers in a cluster indicates the average importance rating for the topic (more layers denote more importance). For example, “Help for Patients, Families, and Caregivers” has only one layer, and thus was considered less important than “Professional Education,” which has five layers. Note that these ratings refer to relative importance. Because key stakeholders generated all of these ideas, all ideas were considered important.



*Figure 4:
Cluster
Pattern Match
of Importance
and
Feasibility:
End-of-Life
Recommendations for State
Health
Departments*

Participants also completed a feasibility rating. Figure 4, Pattern Match of Importance vs. Feasibility, shows the correlation between the average importance rating and the average feasibility rating for each topic. The greater the slope of the line between the importance and the feasibility ratings, the less the ratings were correlated. For example, the average importance rating for “Funding and Financial Issues” was considerably higher than its feasibility rating, indicating that the participants perceived this topic to be quite important but relatively difficult to address.

In regional meetings, core group members explored these results, focusing on ideas that ranked relatively high in both feasibility and importance. They generated short-term recommendations and longer-term recommendations for each cluster.

PHASE II: MODIFIED DELPHI PROCESS

In Phase II, a modified Delphi process³ was used to reach a consensus on a set of short-term priorities generated in Phase I. A subgroup of 23 participants from Phase I participated in this phase. The Delphi process is a structured method that allows the development of a consensus among experts who have diverse opinions. Four features to the Delphi process are particularly suited to this project: anonymity, iteration, controlled feedback, and statistical aggregation of a group response.

MODIFIED DELPHI METHOD

A subset of 29 statements⁴ reflecting short-term priorities from the five most feasible topics were selected for the Delphi process:

- **Public Education:** Actions that provide information and increase awareness regarding end-of-life issues to people who may not yet be affected by such issues.
- **Patient, Family & Caregiver Education:** Actions that provide information and support for people dealing with end-of-life issues in their personal lives, such as living wills, organ donation, spirituality, grief, and caregiving.
- **Research, Epidemiology & Evaluation:** Actions that assess and improve understanding of the impact of end of life, barriers to care, and program efficacy.
- **Professional Education:** Actions that build skills, knowledge, and awareness among service providers and public health professionals of issues related to end of life.
- **Policy & Planning:** Actions that focus decision-makers on the integration, regulation, and implementation of programs and services related to end-of-life.

The modified Delphi process included three iterations. In the first round, participants ranked the top five overall priorities for the next two years. The participants' rankings in Round 1 were collated, and this information was provided on the Round 2 form. In Round 2, the participants were again asked to rank the top five priorities. These results were also collated, and the Round 3 form included information on the Round 1 and Round 2 rankings. In Round 3, participants once again ranked the top five priorities. In Round 3, five recommendations were ranked most frequently (receiving from 78% to 48% of the votes); the others received five or fewer votes.

FINDINGS

The top five priority recommendations for state health department action in the short term are:

1. Identify a chronic disease point person within the state health department to coordinate/liaison end-of-life activities with relevant issues (e.g., aging, cancer).
2. Collect, analyze, and share data about end of life through state surveys such as the Behavioral Risk Factor Surveillance System (BRFSS).
3. Incorporate end-of-life care into state comprehensive cancer control plans.
4. Educate the public about the availability of hospice and palliative care.
5. Educate the public about the importance of advance directives and health care proxies.

DISCUSSION

End of life is a relatively new area for public health. The project reported here was successful in bringing a diverse and distinguished group of experts together to develop a set of recommendations for public health action regarding End-of-Life issues. In addition to fostering relationships between the different stakeholders and organizations involved with this work, this project resulted in a framework and a set of recommendations that will be useful to state health departments and other public health agencies over a period of time.

The findings of this project will be compared with other consensus-based recommendations (e.g., Institute of Medicine reports) and will be disseminated through manuscripts and presentations. Future work will focus and build on the initial priority recommendations identified in this project, and will include an environmental scan of current state health department efforts and comprehensive cancer plans.

ACKNOWLEDGEMENTS

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Finally, we thank Mary Kane and Jill Helmle of Concept Systems, Inc., for managing the concept mapping process in Phase I of the project.

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