Development of Public Health Priorities for End-of-Life Initiatives

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Objective: Recently, end-of-life (EOL) issues have captured the attention of the public health community. This study reports a project to help state health departments better understand their potential role in addressing EOL issues and develop initial priorities for EOL activities.

Methods: The project involved two studies. Study 1 (October 2002 to September 2003) involved a concept mapping process to solicit and organize recommendations from key stakeholders. Concept mapping integrates qualitative group processes with multivariate statistical analysis to represent the ideas of stakeholders visually through maps. A key-informant approach was used to identify stakeholder participants with expertise in aging, cancer, public health, and EOL. In two meetings, stakeholders used the maps to develop short-, intermediate-, and long-term recommendations for EOL initiatives. Study 2 (October 2003 to September 2004) involved a modified Delphi process with three iterations to prioritize recommendations for initial action from among a group of short-term recommendations.

Results: Study 1 resulted in 103 recommendations for EOL initiatives across nine domains. Study 2 resulted in consensus on five initial recommendations from three domains: identifying an EOL point of contact in state health departments, collecting and analyzing data about EOL, incorporating EOL principles into state comprehensive cancer control plans, educating the public about hospice and palliative care, and educating the public about the importance of advance directives.

Conclusions: Diverse perspectives of key public health stakeholders resulted in a series of short- and longer-term recommendations for EOL action. These recommendations can guide future efforts by state health departments and other public health agencies to address EOL issues.

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Introduction

Recent advances in medical care and prevention have expanded the boundaries between life and death and have challenged expectations of how the end of life (EOL) should be. Periodically during the past 30 years, EOL issues have been the focus of societal debate, as providers, medical ethicists, policymakers, and the public considered the important questions about what constitutes quality of life at life's end and withdrawal of life-sustaining treatments.[1–3] Studies indicate that EOL is associated with a substantial burden of suffering among dying individuals[4–7] and health and financial consequences that extend to family members and society.[8–12] Because most deaths occur in hospitals,[13,14] EOL care gained recognition as an important clinical issue warranting improvement.[15–17] Several organizations have focused on improving health system factors and state policies to facilitate quality EOL experiences for patients and families.

Despite its demonstrable importance as a societal health concern, EOL has only recently captured the attention of the public health community. In the October 2002 issue of the *American Journal of Preventive Medicine*, Rao et al.[18] proposed that EOL be recognized as a public health issue and that an agenda be developed that is relevant to the public health community. Such an agenda should consider the work in EOL already performed by other organizations,[19–21] and involve a process of priority setting by public health and its partners.[18]

The public health community consists of federal, state, and local health agencies. State health departments fill a unique link between federal agencies that fund public health activities and local health agencies

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that provide direct services to communities.[22,23] During the past 50 years, state health departments' roles have evolved from collecting health information and maintaining vital records to promoting healthy behaviors and preventing infectious disease outbreaks.[22,23] Present-day state health departments manage many competing issues, including long-standing concerns (e.g., cancer prevention) and current issues (e.g., emergency preparedness).

If state health departments were to begin addressing an emerging public health concern such as EOL, their appropriate role must be better understood. This article describes a project designed to address two specific questions. First, what is the role of public health, particularly state health departments, with respect to EOL issues? Second, what are the critical next steps for state health departments regarding EOL?

Project Overview

The Association of State and Territorial Chronic Disease Directors Program (CDD) is a nonprofit organization that focuses on chronic disease prevention and control at the state and national level. The CDD conducted this project with funding support from the Centers for Disease Control and Prevention (CDC). Representatives of both organizations (JKR, LKJ, JA, LAA, and GAS) formed a steering committee to oversee the project. An external advisory group, comprised of experts in EOL, public health, cancer, or aging issues (see acknowledgments), provided input on project implementation and assisted with inviting stakeholders.

The project involved two sequential and inter-related studies. Study 1 was conducted from October 2002 to September 2003, and involved a concept mapping process. Study 2 was conducted from October 2003 to September 2004, and involved a modified Delphi process.

Study 1

Methods

Sample. A key informant approach was used to identify stakeholders representing different perspectives regarding EOL. The stakeholders were invited based on their expertise (i.e., aging, cancer, chronic disease, public health, EOL) and organization (e.g., federal health agency, foundation, state health department, etc.). The advisory group and steering committee invited a core group of stakeholders ($n = 48$) who, in turn, asked others to participate. Through this process, 211 stakeholders were invited.

Procedures. Given that there have been no investigations of public health professionals' perspectives regarding EOL, the use of qualitative methods to elicit diverse viewpoints was warranted. Concept mapping, which integrates qualitative processes (brainstorming and sorting) with quantitative methods,[24–26] was selected because it is designed for use with groups and overcomes geographic barriers. This method has been used in several public health projects,[27,28] and is consistent with the CDC's Framework for Program Evaluation in Public Health.[29]

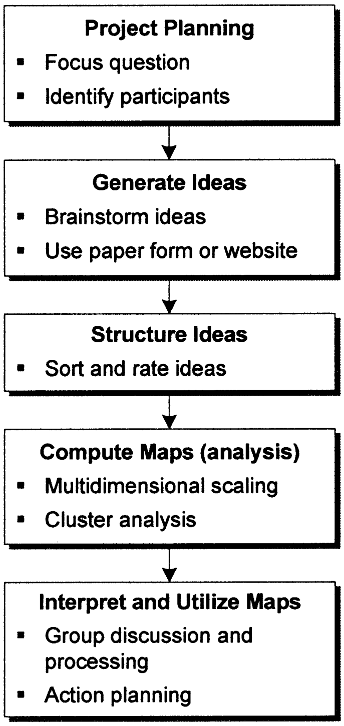

Figure 1. The concept mapping process.

The concept mapping process[25,30] (Figure 1) involves stakeholders in three activities: (1) brainstorming, (2) sorting and rating, and (3) and interpretation of concept maps. The stakeholders used a secure website, mail, or fax to complete the first two activities.

In the brainstorming activity, all 211 stakeholders were invited to provide specific ideas to complete the following statement: "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. . .." Because our goal was to elicit the broadest set of responses, this statement was worded to indicate that death could occur at any age (i.e., "people" rather than "adults") and from various causes (i.e., "seriously ill and injured" rather than "terminally ill"). All ideas were submitted anonymously. The steering committee eliminated statements that were redundant, did not make sense grammatically, or were not directly relevant to the project aims. This process yielded 124 unique statements.

There were two levels of involvement of stakeholders in the sorting and rating activity. The core group of stakeholders sorted the 124 statements into categories or themes. They were instructed to use their own criteria to develop the categories and provide a descriptive label for each category. They also were directed not to sort all 124 statements into one category, not to make a category for each statement (i.e., 124 categories), and not to place one statement in multiple categories. Next, all 211 stakeholders, including those who sorted statements, were invited to rate each statement for importance (1=relatively unimportant to 5=extremely important) and feasibility (1=not at all feasible to implement to 5=extremely feasible or already doing) relative to all other statements. Finally, after completing the ratings, stakeholders provided information on their primary area of expertise (e.g., aging, cancer, chronic disease) and organization (e.g., federal government, state health department). No other identifiers were collected.

Finally, the core group stakeholders attended one of two meetings to interpret the concept maps (see analysis for the development of the maps). They developed recommendations based on these maps.

Analysis. Trochim's method[25] was used to develop the concept maps. First, a similarity matrix was constructed for each core group stakeholder who sorted statements. Each similarity matrix contained 124 rows and 124 columns, one for each statement. If a stakeholder sorted two statements together, the cell for each statement would contain a 1. If the statements were not sorted together, the cell would contain a 0. Next, a group similarity matrix was constructed that combined the sorting data of all stakeholders (i.e., who sorted statements). The group similarity matrix included 124 rows and 124 columns and a summation of the similarity data for all stakeholders.

The group similarity matrix was analyzed using nonmetric multidimensional scaling to create a two-dimensional plot of the 124 statements. This "point map" represents the similarity between each statement as a physical distance. Statements that were most often sorted together are positioned closer together on the map. A hierarchical cluster analysis was performed to partition the 124 statements into groups with similar themes. This analysis incorporated the two-dimensional coordinates (i.e., physical distance between statements) from the multidimensional scaling, and resulted in a series of clusters containing statements with similar themes. Finally, the importance and feasibility ratings were averaged across stakeholders for each statement and cluster to develop three-dimensional maps. These maps displayed the average importance and feasibility ratings for each cluster as vertical columns.

Results

Because the brainstorming was performed anonymously, a response rate could not be calculated among the 211 stakeholders invited to participate in that activity. Of the 48 core group members who were invited to sort statements, 38 (79%) completed that task. For the rating activity, 113 (54%) of the 211 stakeholders responded, including 38 core group members. Stakeholders who rated statements identified EOL (29%), aging (26%), and cancer (22%) as their primary areas of expertise. Of the 48 core group members invited to the meetings, 27 (56%) attended. The distribution of expertise among the attendees was relatively similar to the stakeholders who rated statements.

The analysis identified nine clusters (Figure 2) that best fit the 124 statements regarding EOL issues. The 124 statements are available on the Concept Systems, Inc. website (www.conceptsystems.com). At the meetings, the core group members selected the appropriate labels for each cluster. The clusters were named as follows: (1) public education, (2) patient education, (3) professional education, (4) help for patients, (5) access to support services, (6) quality of services, (7) funding, (8) policy, and (9) research. Notably, many statements in the research cluster (e.g., "develop quality assurance indicators for hospice services") related to the other clusters.

The five clusters (Table 1) considered most feasible relative to other clusters were public education, patient education, research, professional education, and policy. Notably, although stakeholders rated the funding cluster as the least feasible, they also rated it as most important. Relative to the other clusters, the research cluster was rated as least important.

In the meetings, core group stakeholders also developed recommendations for EOL-related activities that state health departments could perform or enable others to perform. They considered the overall importance and feasibility ratings for each cluster and the average importance and feasibility rating of each statement within a cluster when developing these recommendations. The stakeholders prioritized the recommendations as short term, intermediate term, and long term. Short-term recommendations were considered to be activities that could be implemented within 2 years. Intermediate-term recommendations were those that could be implemented within 5 to 7 years, and long-term recommendations could be implemented within 10 years. The stakeholders developed 103 recommendations and prioritized them as follows: short term (n =45), intermediate term (n =39), and long term (n =19). The short-term recommendations are presented in Table 2 and in the Appendix.

Study 2

Methods

Sample. Twenty-seven stakeholders, most of whom participated in Study 1, were invited to participate in Study

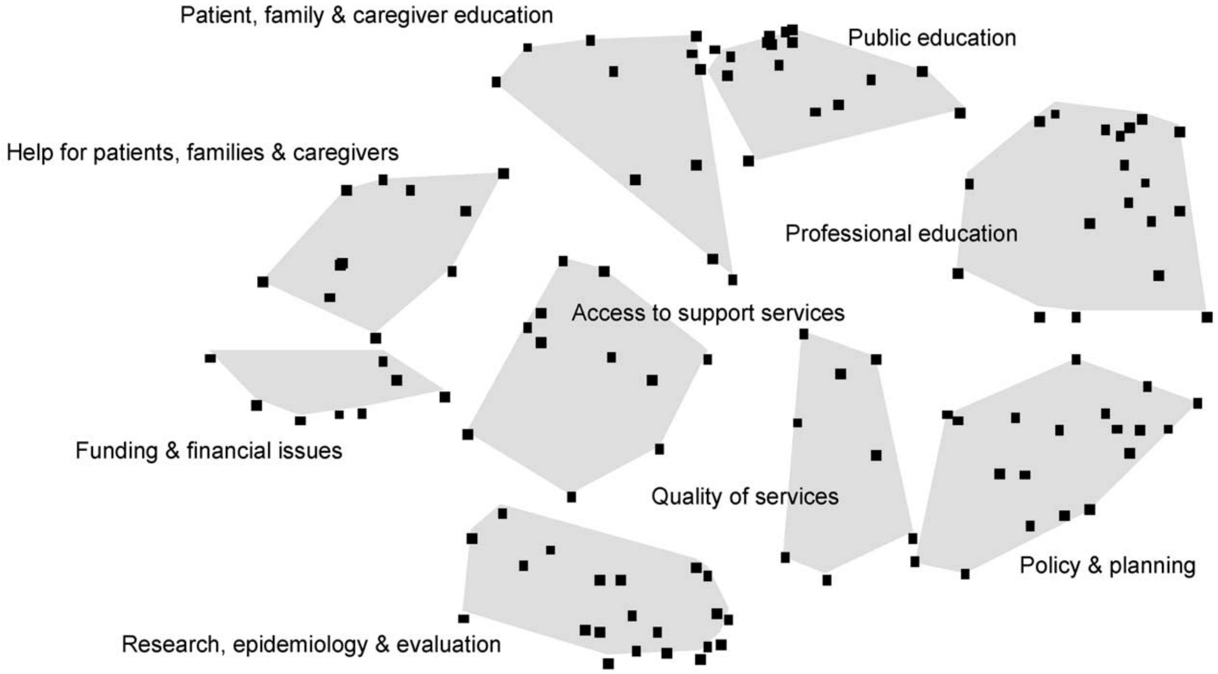

Figure 2. Point map displaying the arrangement of the 124 brainstormed statements into nine clusters of end-of-life activities.

2. The distribution of expertise and organizational type among this group was relatively similar to that of the participants in Study 1.

Procedures. The modified Delphi process is a structured method that facilitates the development of consensus among experts with diverse opinions.[31–34] Two steering committee members (JA, LAA) managed this process.

The short-term recommendations from the five most feasible clusters (Table 2) were included in the modified Delphi process. These clusters were (1) public education, (2) patient education, (3) professional education, (4) policy, and (5) research. The modified Delphi process consisted of three rounds of rankings. Stakeholders were given 2 weeks to respond to each round and a 2-week break between rounds. Individuals who did not respond were not permitted to participate in subsequent rounds.

Stakeholders received a worksheet that provided the project background, definitions for the five clusters, and the short-term recommendations within each cluster. In each round, they identified their top five public health priorities for the next 2 years. That is, among the recommendations, stakeholders chose five statements that they believed should serve as the initial priorities, and ranked them from 1 (highest ranking) to 5 (lowest ranking). The Round 2 worksheet contained the frequency of top five rankings (1 to 5) that each statement received in Round 1. The Round 3 worksheet included the following information for each statement: the total number of top five rankings in Round 1 and frequencies of individual rankings (1 to 5) in Round 2.

Table 1. Importance and feasibility ratings for the nine clusters identified in the concept mapping process

	Importance rating		Feasibility rating	
Cluster name	**Mean rating**[a]	**Rank relative to other clusters**	**Mean rating**[b]	**Rank relative to other clusters**
Funding and financial issues	3.80	1	2.86	9
Professional education	3.78	2	3.35	4
Public education	3.70	3	3.61	1
Quality of services	3.69	4	3.29	6
Patient, family, and caregiver education	3.65	5	3.42	2
Policy and planning	3.65	6	3.33	5
Access to support services	3.63	7	3.24	7
Help for patients, families, and caregivers	3.52	8	3.09	8
Research, epidemiology, and evaluation	3.46	9	3.38	3

[a] Importance was rated on a 1 to 5 scale, with higher scores reflecting greater importance relative to other clusters.
[b] Feasibility was rated on a 1 to 5 scale, with higher scores reflecting greater feasibility relative to other clusters.

Table 2. Five most feasible clusters and short-term recommendations included in modified Delphi process

Cluster and short-term recommendations	Final top five ranking: Rank	Final top five ranking: Percent
Public education		
Educate public about availability of hospice and palliative care.		
Educate public about importance of advance directives and healthcare proxies.	4	57
Establish an information clearinghouse on EOL issues for healthcare providers and general public.	5	52
Facilitate the dissemination and distribution of educational materials and messages through different channels (e.g., media, library, etc.).		
Integrate EOL into existing chronic disease educational materials.		
Partner with palliative care/EOL organizations to identify culturally appropriate educational materials relevant to the population served and services available within the state.		
Patient, family, and caregiver education		
Encourage people to talk about EOL issues with their family and providers.		
Make informational resources on EOL available in all physicians offices, clinics, and home care agencies		
Provide culturally appropriate materials to families.		
Provide educational training across chronic disease programs for family members and persons dealing with EOL.		
Support the use of living wills, healthcare agents, family consent procedures, and organ donation.		
Research, epidemiology, and evaluation		
Assess supply of healthcare workers who can provide quality EOL care.		
Collect, analyze, and share data about EOL through state surveys, such as the Behavioral Risk Factor Surveillance System.	2	76
Identify the most important EOL services and assess the community's ability to deliver these services.		
Perform an assessment of current status of EOL in the state (e.g., state report cards).		
Study barriers to EOL care (reimbursement, eligibility, quality, access).		
Professional education		
Educate physicians and healthcare workers on EOL issues.		
Identify palliative care/EOL experts within the state, region, or nation to serve as educational resources.		
Include workshops on EOL issues in conferences.		
Integrate palliative care principles into chronic disease management.		
Provide EOL and grief education/training for state public health staff.		
Policy and planning		
Assess state statutes regarding the EOL.		
Create a state-level expert panel on pain management and palliative care.		
Encourage pain assessment policies and practices for all nursing homes, foster homes, and board/care homes.		
Identify a chronic disease point person within the state health department to coordinate/liaison EOL efforts with relevant activities (aging, cancer, etc.).	1	86
Identify legislative barriers to care.		
Incorporate EOL care into state comprehensive cancer control plans.	3	62
Inform the legislature about things that could be done to improve EOL care in the state.		
Request that the state medical licensure board review guidelines on pain management.		

EOL, end of life.

Analysis

For each round, the stakeholders' rankings were collated, and the individual frequencies of 1 to 5 rankings were calculated for each statement. Any statement that was not ranked in the top five by any stakeholder was excluded from subsequent rounds. After Round 3, recommendations that had the highest levels of agreement were identified.

Results

Twenty-three of 27 invited stakeholders agreed to participate in the modified Delphi process. Twenty-one stakeholders (91%) completed all three rounds of rankings, with two members completing Rounds 1 and 2 only.

In Round 1, 13 of 29 recommendations received 1 or 2 votes in the top five; nine received ≥6 votes (range 6 to 11). Because all 29 recommendations received ≥1 vote, none were excluded. In Round 2, eight recommendations received 1 or 2 votes, and five received ≥6 votes. Six recommendations received no votes and were excluded. In Round 3, a total of eight recommendations received 1 or 2 votes, and five received ≥11 votes (range 11 to 18). Thus, the following five priorities were identified (Table 2): (1) identifying an EOL point of contact in state health departments, (2) collecting and analyzing data about EOL, (3) incorporating EOL principles into state comprehensive cancer control plans, (4) educating the public about hospice and palliative care, and (5) educating the public about the importance of advance directives and healthcare proxies. All were ranked in the top five by >50% of the stakeholders (range 52% to 86%). There were no differences in rankings of these five priorities by public health professionals compared to non–public health professionals.

Discussion

This article describes the perceptions of public health stakeholders on the role that state health departments might play in addressing EOL issues. State health department actions best fit within nine clusters, and the roles for addressing EOL issues were considered feasible and important by stakeholders. A summary[35] of the findings was shared with the project participants, state chronic disease directors, and others, was also presented at several national conferences, and is posted on the CDD website (www.chronicdisease.org).

Relative to the other clusters, it is interesting that the funding cluster was rated the most important, but was also considered least feasible by stakeholders. The importance ratings likely reflect the attitude (and reality) that funding is an important driver for implementing new initiatives in state health departments. On the other hand, the feasibility ratings may also reflect budgetary constraints at the state and federal levels that state health departments have encountered in administering existing programs. The steering committee chose to include the most feasible clusters in the Delphi process to develop priorities that potentially could be implemented within existing resources and allow state health departments to demonstrate some early success in this area.

Notably, the nine clusters identified in Study 1 are consistent with the core public health functions[23] as outlined by the Institute of Medicine in 1988. For instance, the research, public education, and patient education clusters are consistent with the assessment functions of monitoring population health and providing health information. The professional education, help for patients, quality of services, and access to support services clusters are consistent with the assurance functions that link people to necessary personal health services. Similarly, the funding and policy clusters are compatible with the policy functions of promoting partnerships and policies to solve health problems.

Given these consistencies, it is not surprising that these recommendations within the clusters are also compatible with the core public health functions. For example, "collecting and analyzing data on EOL issues" is consistent with the assessment function. Similarly, "encouraging pain assessment policies and practices in facilities" is compatible with the regulatory functions that support individual and statewide health efforts. Interestingly, many recommendations, particularly those that focus on educational efforts or ameliorating financial barriers to EOL care, are also consistent with other consensus-based recommendations.[15,19,36–38] These consistencies are likely related to the diverse expertise and organizational affiliations among the stakeholders who submitted ideas and developed recommendations.

Several factors should be considered when reviewing our findings. These results should not be interpreted as representing all views of those who work and focus on EOL issues. The stakeholder group also included individuals involved with state-level funding and policy implementation as well as others who focus on other health concerns. Although nearly 30% of the participants were EOL experts, the remainder had expertise in other relevant fields, such as aging, cancer, or public health. This balance of participants was chosen because state health departments and other public health agencies were the intended audience for our results.

Another consideration is that a single focused question was used to determine the role of states in addressing EOL issues. The question did not specify a particular state of health (e.g., terminally ill), form of response (e.g., hospice care), or responsibility. The lack of specificity resulted in a set of general recommendations that warrant further refinement and elaboration within public health programs that have an interest in addressing EOL issues. Further work focusing on people with a specific health condition or in a particular situation (e.g., in the intensive care unit) could generate recommendations that are more specific for those circumstances.

Finally, the dynamics of participating over the Internet asynchronously is a qualitatively different experience than participating in a typical mailed survey. An anonymous web-based brainstorming activity provides little control over who actually participates, and this may have affected participation rates and the content of submitted ideas in Study 1. On the other hand, participants reported that the web-based system was easy to use, particularly for the brainstorming activity. Those uncomfortable with the computer interface had the option of submitting suggestions by mail or fax.

The findings direct us toward several initial priorities for state health departments and other public health agencies in addressing EOL issues. One benefit of the meetings convened for Study 1 was the identification of relationships between EOL experts and stakeholders with expertise in cancer, aging, and public health issues. These relationships should be explored in the context of the EOL priorities identified in this project. For example, the debate regarding the Schiavo case suggests that a "teachable moment" exists regarding the importance of advance directives. Public health agencies might play a role in helping to inform the public on this issue. Such initiatives, which were identified as important by stakeholders, may be best achieved through partnerships with groups external to state health departments. Another benefit of this work is that public health programs can begin implementing the initial recommendations and address the longer-range recommendations later, as appropriate. Furthermore, because they were developed by stakeholders with diverse perspectives, the recommendations are expected to provide guidance to various groups interested in ensuring a more inclusive approach to EOL by all sectors of health care.

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Appendix

Clusters and short-term recommendations not included in modified Delphi process

Funding and financial issues

Identify existing funding sources that could be expanded to include EOL issues (e.g., in cancer, heart disease, diabetes grants, etc.).

Collaborate with other public and private organizations/agencies to seek and use funds.

Partner with other private/public organizations that have dedicated staff (i.e., to leverage funds and avoid state hiring freezes).

Inventory services provided to people who will die in the next year.

Identify appropriate EOL partners for funding.

Identify or develop tools to help providers integrate hospice patients into Medicaid program.

Help for patients, families, and caregivers

Integrate EOL into family caregiver networks.

Identify and promote approaches to increase EOL services utilization.

Designate a social services contact or EOL navigator to link patients, families, and caregivers to hospice, home healthcare, financial services, etc.

Link state health department activities and programs such as healthy aging, or cancer with state and local caregiver programs.

Quality of services

Convene training workshops on EOL quality measures.

Identify and define quality measures and standards of services for EOL.

Identify or develop tools to help providers screen for hospice eligibility.

Partner with health resources and services administration to implement palliative care in quality improvement efforts across all diseases in community health centers.

Access to support services

Develop a strategic plan with critical partners to address the following topics: access to care, coordination of care, children and adolescent issues, and symptom management.

Include children's issues in EOL priorities.

EOL, end of life.