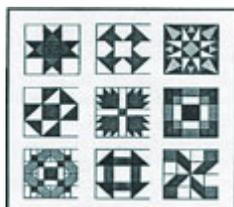


FINAL REPORT

**Assessing the Unmet Needs of Health Care Providers
Using a Web-based Survey**

**Department of Public Health, State of Connecticut
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1. Executive Summary

Introduction. Several influential national reports have identified gaps in knowledge of end-of-life care, recommending improved training of health care professionals. The purpose of this study was to develop and administer a web-based survey to identify the educational needs of health care professionals who provide end-of-life care in Connecticut in order to inform the design of educational initiatives.

Methods. A literature review identified 6 content domains to capture health care professionals' educational needs: Scientific and clinical knowledge/ skills; Communication with patients, family, and clinicians; Spiritual and cultural issues; Ethical, professional and legal principles; Organizational skills; and Attitudes, values and feelings. Twenty instruments were reviewed to identify survey items representative of content domains and disciplines. A survey of 16 items was reviewed by end-of-life experts. Items are rated on a 5-point Likert scale (1=Strongly Disagree; 5= Strongly Agree). Participants included nurses, nurses' aides, physicians, social workers, pharmacists, chaplains, funeral directors, and administrators who were over 21 years of age and spoke English. Participants were recruited by the Internet, at professional meetings and by direct contact. The survey was available on the web and on paper for 9 months. Descriptive and correlational statistics were calculated. Three focus groups with health care professionals were held to gain additional insight into survey results.

Results. Six hundred and fifty-nine surveys were completed, 319 on the web and 340 on paper. Six hundred and two had complete data. Disciplines reported greater agreement on items related to their daily activities. Dealing with cultural and spiritual matters and having supportive resources at work were needs reported by the total sample. Older age and more years in practice were positively correlated with adequate education in both end-of-life communication and overall content of end-of-life care, as well as with adequate knowledge to care for the dying. Focus groups confirmed survey results and highlighted the need for emotional processing of end-of-life issues to enhance personal and professional comfort.

Conclusions. The survey identified gaps in end-of-life education by discipline as well as demographics which can inform educational initiatives. Recommendations for educational initiatives include: 1) increased education for all disciplines in all areas of end-of-life care, with attention to discipline-specific needs; 2) emphasis on knowledge and skills related to cultural and religious/spiritual issues; 3) emphasis on creating opportunities in the workplace for employees to tend to emotional self-care; 4) emphasis on understanding the goals of palliative care; 5) emphasis on exploration of personal experiences and feelings about death and dying and how these can/do affect job performance; and 6) shorter educational sessions, possibly spread over 1-2 days, on-site training.

2. Introduction

A number of influential reports^{1,2} have identified gaps in knowledge about care of individuals at the end of life and the need for attention from the medical, social, and research communities. Numerous studies have detailed patients' needless suffering from physical symptoms and emotional concerns.³⁻⁸ The most recent IOM report on patient needs³ emphasized strategies for overcoming these inadequacies, including the need to ensure sufficient training of health care providers. Previous research has demonstrated that major deficiencies exist in educating health care providers in end-of-life care. A multitude of problems have been identified, including poor physician-patient communication about prognosis and treatment choices⁹⁻¹⁵, inadequate pain medication and symptom control^{16,17}, underutilization of hospice¹⁸⁻²⁰, and limited advanced care planning.²¹⁻²³ The aim of this study was to identify the unmet needs of health care professionals who provide palliative and end-of-life care in Connecticut in order to create educational initiatives to meet identified needs.

3. Work plan: Description of Research Phases

This study was implemented in 2 phases. Phase 1 activities were: 1) to identify and evaluate existing tools for measuring the unmet educational needs of health care professionals who provide palliative and end-of-life care by conducting a systematic review of the literature; 2) to select the optimal survey items for assessing unmet educational needs, and 3) to transfer survey items to a web-based medium and pilot test the web survey with health care professionals. Phase 2 activities were: 1) to conduct a state-wide web-based survey of 800 health care professionals; 2) to conduct focus group sessions based on survey results, and 3) to describe health care professionals' unmet educational needs. The results of the survey and focus groups were analyzed and are presented in this final report.

4. Phase I: Review of the Literature and Survey Development

4.A. Review of the Literature

An extensive review of the literature enabled us to identify scholarly journal articles that discussed or evaluated existing tools for measuring the unmet educational needs of health care professionals who provide palliative and end-of-life care. The MEDLINE, PsychINFO, HealthSTAR, CINAHL, PUBMED, HAPI, and COCHRANE LIBRARY databases were searched in addition to manual reference searches conducted using the Google search engine.

4.B. Identification of Needs Domains

Synthesis of the reviewed articles allowed us to identify 6 domains of need among health care professionals providing palliative and end-of-life care: Scientific and clinical knowledge/technical skills; Communication/interpersonal skills with patients, family members, and other clinicians; Spiritual and cultural issues; Ethical, professional and legal principles; Organizational skills; and Attitudes, values and feelings of health care professionals. A list of the identified Needs Domains can be found in Appendix A.

4.C. Survey Item Development

Items from approximately 20 existing survey instruments were reviewed and matched to identified needs domains to ensure coverage of all domains and that the various areas of need for different professional groups would be addressed on the survey. The research team met to review and refine successive item pools. A core set of survey items was assembled (Appendix B). Items are rated on a 5-point Likert scale where 1=Strongly disagree, 2= Disagree, 3= Neither agree nor disagree, 4= Agree, and 5= Strongly agree.

Copies of the written survey were reviewed individually by experts in end-of-life care, including Marie Bakitas, DNSc, APRN, Thomas Quinn, APRN, Marcia Grant, DnSc, RN, and Ruth McCorkle, PhD, FAAN. The experts were instructed to review the items based on clarity, redundancy, and gaps in conceptual areas covered. Two redundant items were eliminated and 3 additional items were added related to participants' interest in web-based education, participants' county of residence, and supportive resources in the workplace. Although the complete survey included 56 items, only a core number of items (n=16) was administered to all eight professional groups identified for inclusion in the sample.

4.D. Transfer to Web-Based Format

The survey was transferred to an Excel format from which it was then translated to a web-based format for pilot testing. The sampling frame for the web-based survey included a link to the survey on the website of the CT Coalition to Improve End-of-Life Care, announcement of the survey through various state professional organizations, and direct advertisement to individuals using study business cards.

4.E. Pilot Test of Web-Based Survey

The web-based survey was pilot-tested with 2 representatives from each professional group at the Annual Meeting of the CT Coalition to Improve End-of-Life Care, which took place on March 28, 2008. Laptop computers were set up in the reception area of the conference, with 2 research staff members available to assist pilot-testers with any technical issues. Data from completed surveys were compiled into a report which was then reviewed by the research team. Completion time was reported to be 5-10 minutes. In their responses to open-ended questions about the survey, pilot testers generally found the survey comprehensive, clear, and non-redundant. Revisions were made to items reported as confusing. One administrator felt there should be more questions related to this professional group. This individual was contacted to gain additional information about editing or adding items. Additional items were added to the Administrator survey per these suggestions.

5. Phase 2: Survey Implementation and Focus Groups

5.A. Survey Distribution

The survey was available on the web from September 11, 2008 to May 22, 2009. In order to take the survey, participants had to meet the following inclusion criteria: 1) health care professionals who provide palliative and end-of-life care in the State of Connecticut; 2) access to the Internet; 3) ability to communicate in English; and 4) age 21 years or older. All individuals who met the inclusion criteria while the survey was on-line and who were willing to participate were included in the sample. To facilitate

recruitment of participants, we made laptop computer stations available at 6 professional meetings or conferences in Connecticut: The CT Coalition to Improve End-of-Life Care Annual Meeting at the Griswold Inn, Middletown, CT (9.11.08); the New England Pharmacists Convention at the Mohegan Sun Convention Center, Uncasville, CT (9.19.08); the Compassionate Care of the Dying Conference sponsored by the CT Coalition at the Yale School of Nursing (10.24.09); the Cultural Sensitivity Conference at UCONN, West Hartford, CT (1.21.09); the “Addressing the Needs of Adolescent and Pediatric Palliative Care” Conference at Fairfield University, Fairfield, CT (3.28.09); and the 6th Annual Conference of the CT Coalition at the Crown Plaza, Cromwell, CT (4.3.09). We supplemented these recruitment efforts with labor intensive direct contacts with clinical agencies that have high volumes of dying patients. This was accomplished by having a research assistant distribute and then collect paper copies of the surveys by hand. These efforts were undertaken due to participants’ preference and/or not having ready access to a computer.

5.B. Survey Administration and Results

5.B.1. Sample Description. A total of 659 surveys were completed: 319 participants completed the web-based survey and 340 participants completed the paper version of the survey. This included 288 nurses, 173 nurses’ aides, 97 physicians, 30 pharmacists, 29 chaplains, 22 administrators, 15 social workers and 5 funeral directors. The Nurses category consisted of registered nurses and advanced practice registered nurses. Nurses’ aides included licensed practical nurses, certified nurses’ aides, nurses’ aides, and medical assistants. The Physician category consisted of medical doctors, doctors of osteopathy, and physician assistants. Pharmacists included both pharmacists and pharmacy technicians. Included in the Chaplain category were chaplains, priests, ministers, nuns, rabbis and lay providers. Administrators were from hospitals, nursing homes, and hospices. The Social Worker category included social workers, psychologists and licensed professional counselors.

5.B.2. Statistical Analysis. SAS software for Windows version 9.1 (SAS Institute, Cary, NC) was used to carry out all statistical analyses. Data were cleaned and 57 surveys were thrown out due to technical errors with participants’ data input, yielding the final sample of 602 surveys. Table 1 shows the breakdown of surveys completed by group. Descriptive and correlational statistics were calculated. Data from written surveys were entered into the computer data base by two research assistants. A random 10% sample of participants was double-entered to establish inter-rater reliability. Less than 1% errors were found, and these were limited to the completion of demographic and educational variables.

5.B.3. Demographic Characteristics. Demographic characteristics of the total sample and by discipline are presented in Table 2. Participants had an average age of 44 years. Most of the sample were female (88.6%), White (84.6%), and non-Hispanic (97%). Slightly over half of participants were Catholic (51.4%). Almost 60% had a Bachelor’s degree or higher level of education. Most participants were from New Haven County (42.7%), followed by Hartford (24%), Fairfield (11.7%), Litchfield (7.1%), Middlesex (5.7%), Tolland (4.4%), New London (3.7%) and Windham (.7%) counties. Sixty-five percent of participants reported that they did not have advance directives.

5.B.4. Clinical Characteristics. Clinical characteristics for the total sample are summarized in Table 3. The sample reported an average of 16 years in practice and 7 years in their current position. Areas of practice were Geriatrics (34.5%), Medical/Surgical (11.5%), Oncology (7.1%), Critical Care (5%), Pediatrics (3.2%), and Emergency (2.3%) One-third of the sample (33.3%) reported practicing in another area or a combination of these areas. A few did not indicate a practice area (3.2%). Practice settings included Nursing Home/Rehabilitation (29.6%), Acute Care (21.9%), Home Care (15.6%), Inpatient Hospice (3.8%), Ambulatory Care (3.8%), Emergency (2.9%), and Prison/Correctional facility (0.7%). Twenty-one percent reported another practice setting or a combination of practice settings. A few did not indicate their practice setting. Three quarters of the sample (75%) reported caring for terminally ill patients and using palliative care methods (78.2%).

5.B.5. Data on Education in End-of-Life Care. Data on education in end-of-life care is shown in Table 4. About 66% of participants reported having had training in end-of-life care during their basic education or professional preparation. About the same percentage had received additional training in end-of-life care in the past 5 years. Most (78.6%) had not participated in one of the national end-of-life training programs (e.g. Education for Physicians in End-of-Life Care- EPEC). The most preferred educational format for end-of-life training was a one-day conference (32.3%),

5.B.6. Participants' Responses to Survey Items for the Total Sample and by Discipline. Means and standard deviations for each survey item for the total sample and by discipline are presented in Table 5. Findings appear to be valid because participants reported greater agreement on items related to their daily activities by discipline. For example, social workers reported the most agreement about having adequate education in grief and bereavement and the least agreement in having adequate education in the care of the body after death. For the total sample, on all survey items, the mean response was between 3 "Neither agree nor disagree" and 4 "Agree". These findings illustrate that, overall, participants felt they had average to adequate knowledge and skill in various aspects of end-of-life care; few extreme values (i.e. "Strongly agree" or "Strongly disagree") were reported on any item.

For the total sample, the three items with the highest scores were: "I feel effective in caring for a dying patient" (Item #2, mean score for total sample= 3.95); "I feel knowledgeable about end-of-life care" (Item #1, mean score for total sample= 3.93); and "My education was adequate in grief and bereavement" (Item #11, mean score for total sample= 3.77). The four items with the lowest scores were: "I am knowledgeable about cultural factors influencing end-of-life care" (Item #13, mean score for total sample= 3.34); "I feel that my workplace provides resources to support staff who care for dying patients" (Item #16, mean score for total sample= 3.50); "I am comfortable dealing with patients and families' religious and cultural perspectives" (Item #14, mean score for total sample= 3.64), and "My education was adequate in understanding the goals of palliative care" (Item #3, mean score for total sample= 3.64).

By discipline, nurses reported higher scores (mean score of between 4 and 5, indicating "Agree" to "Strongly Agree") on items pertaining to feeling knowledgeable about end-of-life care (Item #1, mean score= 4.07) and feeling effective in caring for a dying patient 8

(Item #2, mean score= 4.09). Social workers also reported higher scores for these items (mean scores of 4.47 and 4.27, respectively) as well as on Item #11 on adequate education in grief and bereavement (mean score= 4.47), Item #14 on comfort dealing with religious and cultural perspectives (mean score= 4.13), and Item #15 on having adequate knowledge to care for people at the end of life (mean score= 4.13). Aides reported scores of greater than 4 on 3 items: effectiveness in caring for a dying patient, adequate education in the care of patients at the time of death, and care of the body after death (Item #s 2,8 &9, mean scores of 4.01, 4.10 & 4.02 , respectively). Chaplains reported scores of greater than 4 on 50% of the items (Item #s 1,2,6,8,10,11,12 & 14, mean scores 4.00-4.32). Funeral directors reported a mean score of 4.00 on only one item, #9, which pertains to care of the body after death. Administrators reported higher scores on Item #2, effectiveness in caring for a dying patient (mean score= 4.33), and #15, adequate knowledge to care for people at the end of life (mean score=4.00). Physicians and pharmacists did not report mean score of greater than 4 on any item.

5.B.7. Correlations of Participants' Demographic Characteristics to Survey Items. Correlation statistics were performed to analyze relationships between participants' demographic information and 4 of the survey items, including: "My education was adequate in communication with patients/families at the end-of-life" (Item #6); "My education was adequate in overall content of end-of-life care" (Item #12); "I am knowledgeable about cultural factors influencing end-of-life care" (Item #13); and "I feel that I have adequate knowledge to care for people at the end-of-life" (Item #15). Several of these correlations were statistically significant. Older age and more years of practice were both positively correlated with having adequate education in end-of-life communication, overall content of end-of-life care, and having adequate knowledge to care for people at the end of life. Being Black was negatively correlated with having adequate knowledge to care for people at the end-of-life. Having less education was negatively correlated with having adequate education in end-of- life communication and adequate education in overall content in end-of-life care.

5.C. Focus Groups

5.C.1. Design. Three hour-long focus groups were held to confirm and expand upon survey data. A convenience sample of health care professionals was used. All disciplines except funeral directors were represented. Two separate discussion guides (Appendices C & D) were created to elicit discussion on topics of interest based on the survey data, including if participants agreed with the survey results, facilitators and barriers to caring for patients at the end of life, and preferences for future training in end-of-life care. The first discussion guide was tailored for a group comprised primarily of nurses' aides, while the second version of the discussion guide was constructed for more multidisciplinary groups. Participants also had the opportunity to bring up other concerns not included in the topic list. Demographic information, including the participants' age, education, specialty training in end-of-life care, gender, race/ethnicity and years of experience was collected using an original demographic data collection form. All groups were digitally recorded.

5.C.2. Sample. A total of 30 professionals participated in the focus groups, which took place in August and September. The first group (n= 9) was held at the VNA of South Central Connecticut. The second group was held the Southington Care Center (n= 8), 9

which has a well developed end-of-life training program. These participants were able to serve as key informants about the survey results and implications for end-of-life education in the State. The third group was held at St. Raphael's Hospital (n= 13). Of the total sample (n=30), 40% were nurses' aides and the remainder included a social worker, a physician, a chaplain, and an administrator. Table 6 provides a detailed description of the sample as a whole and by individual group.

5.C.3. Analysis and Findings. Focus group data were analyzed by the research team using the constant comparative method of qualitative data analysis.^{24,25} Participants in both focus groups generally confirmed the survey findings. Themes emerging from the groups were:

- lack of knowledge about cultural issues and differences in talking about and dealing with death and grieving

"It was really hard to deal with [a patient] because she was so matter of fact [that she was dying] so business-like. It's hard to understand those types of people and [to know] how to react..."

"A few weeks ago we had someone who was here who was Muslim, and I didn't know about it... and I felt so bad about it afterwards and we could have supported him."

- concern about helping patients emotionally/fear of doing something "wrong"

"I have a greater fear of a dying person than a dead person..... You're afraid of messing up. They're only in this state once in life and you're afraid of doing something wrong...It's emotional... I may cause [a patient] pain or discomfort, and that's what bothers me more than not knowing what to do."

- difficulty dealing with divisiveness within families

"It can be so intense... because one [family] member can feel one way, and another another way."

- difficulty dealing with conflicts among health care professionals about what is the best care

"It may not be the way [the staff] want [patient care] to happen, and it's an institution, so you're never going to have a perfect relationship."

- moral distress

"...their mother told them years ago that she would suffer at the end of her life, and her family let her."

"How can you prepare someone for that process if you're not even willing to tell them what they're having . . . instead we wait, and then all of a sudden they go to the acute side and they're dying, and the family says 'what happened?'"

- self-care/concerns over reacting emotionally well to patients

“When I got myself into the healthcare field, ever since then, I said I had to overcome this thing, and I didn’t want to live in fear of death...”

- preferred format of on-site/small group/in-service with an experiential component

“I would find it very helpful if you had a series of two presentations and came two months back to back. This is when aides are expected to come. It’s on-duty time and its paid time... That would be a wonderful opportunity for us to learn more.”

“I think we need a lot more education . . . and experiential is so important.”

“On-site would definitely be the best way, and maybe not even a whole day, but two half-days. What we do for in-servicing is twice in a row half and half because not everyone can leave the floor.”

6. Discussion

6.A. Results. As a whole, participants reported average to adequate knowledge on all survey items. This result is important given the finding that over 78% of participants reported that they use palliative care techniques. In other words, although most are using palliative care techniques, they do not feel strongly about their ability to do so. By discipline, although there were some higher ratings on certain discipline-specific activities, (e.g., funeral directors agreeing with having had adequate education on care of the body), participants reported low mean scores on other activities that are routine and important to satisfactory job performance. For example, chaplains were the only group who agreed or strongly agreed that they had adequate education in communication with patients and families at the end of life (Item #6). This finding indicates the need for additional education in basic, discipline-specific activities related to palliative and end-of-life care. These lower than expected ratings combined with the reported desire for further education indicate that the health care professionals feel there is room for improvement and that they are willing to spend the time to address reported deficiencies.

A main theme in the focus groups was coping with personal feelings about death and dying and how these feelings affect job performance. This suggests that even while caring for patients at the end of life routinely, health care professionals still struggle to process issues of death and dying in their professional and personal lives. The result that only 35% report having an advance directive themselves supports this thought.

6.B. Limitations. A few limitations to this study must be noted. We used a convenience sample rather than a random sample to gather survey data, which can bias results. Health care professionals in private practice or in high volume practices may not have been represented due to lack of time to take the survey. In addition, some individuals or groups of potential participants, e.g. nurses’ aides, do not have access to computers. We had to find alternative ways of recruiting these populations to complete the survey. Cooperation in facilitating completion of the survey among professional groups was

mixed. Therefore, we consider the survey results to be conservative because potential participants with the greatest need for end-of-life education may have been underrepresented. Another limitation is that focus groups participation was somewhat biased as participants were predominantly White female nurses or nurses' aides. Finally, we were unable to carry out our original plan of using web-based survey services out of the Yale Information Technology Department. Due to delays in the state contract, we had to use an alternate, less sophisticated survey mechanism, which resulted in the loss of data. Nevertheless, this study identified important areas of need among a statewide sample of health care professionals.

6.C. Recommendations. The purpose of this study was gather survey data to inform the design of educational initiatives in end-of-life care for health care professionals in Connecticut. Based on the survey results and focus group data, we recommend the following in the design of end-of-life educational programs:

- Increased education for all disciplines in all areas of end-of-life care, with attention to discipline-specific needs
- Emphasis on knowledge and skills related to cultural and religious/spiritual issues
- Emphasis on creating opportunities in the workplace for employees to tend to emotional self-care
- Emphasis on understanding the goals of palliative care
- Emphasis on exploration of personal experiences and feelings about death and dying and how these can/do affect job performance
- Shorter educational sessions, possibly spread over 1-2 days, on-site training

6.D. Deliverables. We have begun to disseminate and build upon the results of this research. In addition to the presentation of work-in-progress at 6 conferences as reported, a summary of the results was presented to the Executive Board of the CT Coalition at the Annual Meeting on November 12. To share these important survey findings with a statewide audience, we will present the survey findings at a plenary session at the Annual Conference of the Coalition to be held in April, 2010. To begin to address the identified need regarding understanding patients' religious values and practices at the end of life, a breakout session will focus on the approach of different religions to the end of life. We have 2 manuscripts in progress related to this grant: "Assessing the unmet end-of-life needs of healthcare providers using a web-based survey," to be submitted to *Palliative and Supportive Care* and "A survey instrument to assess health care professionals' needs in palliative and end-of-life care," to be submitted to *Journal of Palliative Care*. Finally, this research was selected from among 50 entries to win the Center for Disease Control Success Story Award. Our "success story" will be published in the 2010 CDC Success Story publication.

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