■ Articles

Disseminating End-of-Life Education to Cancer Centers: Overview of Program and of Evaluation

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Abstract—*Background*. Systematic provision of compassionate end-of-life (EOL) care requires strategic training of health professionals. Disseminating EOL Education to Cancer Centers (DELEtCC) targeted education of interdisciplinary institutional teams. *Methods*. Competitively-selected two-person teams participated in a national three-day EOL conference. Nationally recognized faculty created and presented the curriculum. Project faculty supported teams over 18 months as they implemented EOL goals. Conference evaluations were very positive. *Results*. Independent participant and administrative evaluations reported successful implementation of goals aimed an improving EOL care. *Conclusions*. DELEtCC disseminated education representing best EOL practices, and participants used this knowledge to create and implement goals aimed at improving EOL care. *J Cancer Educ*. 2007; 22:140-148.

Over the next 25 years, the U.S. population age 65 and over is expected to double in size. By 2030, almost 1-out-of-5 Americans-some 72 million people-will be 65 years or older.[1] A large proportion of this population will be cancer patients, since cancer is now the leading cause of death in men and women under the age of 85.[2] In 2006 alone, an estimated 1.4 million new cancer cases will be diagnosed and over 564,000 deaths are expected.[1] Reports indicate, however, that death in the United States is associated with needless suffering for cancer patients and their families.[3-5] An initial requirement to improve the care of the dying is to provide clinicians with the knowledge and skills for quality care.[6]

Recent educational efforts in palliative/EOL care have been supported by national foundations and the government. The Robert Wood Johnson (RWJ) Foundation[7] initially supported the American Medical Association's Education for Physicians on EOL Care (EPEC), a project that provided comprehensive palliative care curricula to individual physicians across the U.S.[5, 7] In another project, physicians from residency programs were able to participate in palliative care teaching programs, developed by Weissman et al.[8, 9]

Another RWJ-supported program, the EOL Nursing Education Consortium (ELNEC), provided EOL education for undergraduate nursing faculty.[10] The ELNEC project continues to target nursing undergraduate and graduate programs, nurses in Oncology, Pediatrics, Critical Care and Geriatrics.[11] In another project the Center to Advance Palliative Care (CAPC), focuses on how to develop hospital-based palliative care programs.[12]

In addition to education initiatives, development of professional guidelines for palliative and EOL care has helped elevate the expectations for appropriate care on a national and international basis. In Canada, an organized approach to improving hospice and palliative care began in the 1970's and included publication in 2002 of National Principle and Norms of Practice established through collaboration among Canadian organizations, providers and consumers.[13] In the United States, national consensus guidelines were developed and published in 2004.[14] These guidelines for care provide the background for education of health professionals in palliative/EOL care.

Disseminating EOL Education to Cancer Centers (DELEtCC) is a project that supported a unique approach to EOL/palliative care education by focusing on interdisciplinary

teams. The overall aim of the DELEtCC project was to provide broad, interdisciplinary education to competitively-selected, two-person teams of health professionals from cancer centers throughout the United States. Resources for this NCI-funded project provided for 18 month post-conference follow up to track institutional EOL/palliative care changes. [15] The purpose of this paper is to provide an overview of the DELEtCC program, and the initial evaluation findings.

The following aims are addressed:

1. Carry out an interdisciplinary-focused EOL curriculum
2. Recruit interdisciplinary teams from cancer centers to attend the conference
3. Assist teams in their refinement of achievable, EOL goals
4. Elicit faculty and participants' evaluation of the conference
5. Analyze teams' initial progress toward improving palliative and EOL care over an 18 month post-conference timeframe

OVERVIEW OF CONFERENCE

Four annual three-day conferences were held between 2002 and 2005. Resources provided through the NCI grant allowed for 400 individuals from 199 institutions to attend across the four conferences. We restricted the number per conference to 100 individuals because in our educational experience larger audiences limit interaction with the speaker in plenary sessions.[10, 16, 17] Processing of human subjects review varied, by institution according to individual policies and procedures on the gathering of data and implementation of training by the conference participants.

Framework

The framework for the DELEtCC project draws on three concepts: performance improvement, adult education, and palliative care precepts (Figure 1). The concept of performance improvement included standard information on
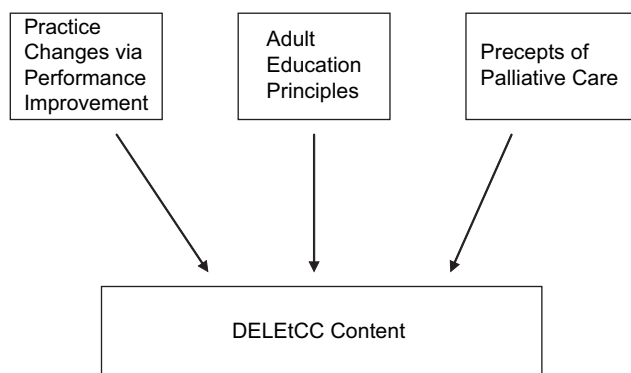

FIGURE 1. DELEtCC Framework.

quality assurance, via a step-wise cyclic approach, and focused on the challenge of institutional change. Each team was expected to anticipate this challenge when implementing EOL goals. DELEtCC introduced the Theory of Diffusion of Innovation as a means to provide the participants with an understanding of what can be expected when new ideas and new approaches to care are presented to members of their institution.[18] DELEtCC also introduced Gladwell's Tipping Point, defined as that magic moment when an idea, trend, or social behavior crosses a threshold, tips, and spreads like wildfire.[19] Institutional change principles were integrated throughout the conference to help teams implement changes in palliative/EOL following the conference.

Adult education principles provided direction in developing teaching materials and methods. Recent research identifies four attributes of the teaching environment needed to optimize learning.[20] First, build on the strengths, interests, and needs of the learner. Second, recognize that teachers need to be proficient in the content being taught, not just skilled in pedagogy. Third, provide learners with an opportunity to test their understanding and receive feedback. Fourth, provide opportunities for post conference continued learning and support. Table 1 applies each of these attributes to the DELETCC course.

The Precepts of Palliative Care[21] informed essential conference content. These precepts highlight the patient and family as the unit of care, the need for an interdisciplinary approach, and an infrastructure that promotes the philosophy and practice of palliative care.

TABLE 1. Application of Teaching Attributes to DELETCC Educational Intervention

Attribute*	Representation of attribute in course design
Learner-Centered	Competitively-selected course participants evaluated on their pre-course description of their qualifications, interests, and goals in applying for the course.
Knowledge-Centered	Selection of nationally known experts in palliation and end-of-life content as course faculty. Inclusion of institutional change experts as faculty.
Assessment-Centered	Participants were involved in small group discussions, individual assignments, and received feedback regarding the development of goals to be achieved in their institutions post course. Individual exercises included helping participants approach systems changes within their individual organization's culture.
Community-centered	Following course completion participants received regular updates with new resources, facts, websites, etc that would continue to aid their growth post course and were contacted 6,12, and 18 months post course for goal evaluation.

*Adapted from Bradford, et al 2000.

Conference Content

The information recommended in the Precepts of Palliative Care was combined with a review of the literature on palliative and EOL care to identify conference content. Expert faculty, from across the United States, were invited to assist in the development and delivery of conference content (Appendix A). Faculty selection was based on several criteria, including expertise in palliative and EOL care and status as principal or co-investigator of nationally-funded research or educational projects on palliative care. In addition we deliberately included faculty from across the United States to decrease potential regional differences in attitudes and beliefs about EOL and to enhance regional faculty available for participants following the conference.

An outline of content was identified and a three-day curriculum developed. Faculty were assigned to specific modules for the development of objectives, outlines, resource materials, references, and slides. These materials were reviewed by the project team for accuracy, inclusiveness, redundancy, and appropriateness of slide material. Recommendations for additions and revisions were made and materials were returned to faculty for changes. A syllabus of approximately 1000 pages was created. Each participant received a syllabus and a CD of all the conference presentations. Participants also received a packet with assessment tools, a current copy of the Journal of Cancer Education, and a report consisting of examples of institutions with differing approaches to palliative care programs.

Application Process

Conference participants were competitively selected using an application process. Marketing to potential applicants included mailing information to Directors of the NCI-Designated Comprehensive Cancer Centers and to administrators of institutions within the Association of Community Cancer Centers. Additional marketing included announcements in journals, national meetings, and electronic newsletters.[22]

Two-person institutional teams applied. The first member was required to be a physician, nurse, or social worker. These disciplines were identified as those involved in patient care and likely to be in positions where needed changes in care could be recognized and initiated. The second member of the team could be another nurse, physician, social worker, or any other discipline involved in caring for patients with advanced disease. The ethnic status of the population served by the team's institution as well as the ethnic status of each team member was requested. Additional criteria included: the provision of two letters of support from a medical, hospital, or nursing administrator; statements of interest from each team member; and identification of goals the team planned to implement in their institutions following the conference.

Evaluation Process

Evaluation began pre-conference and continued immediate post-conference, 6, 12, and 18 months later. An extensive evaluation process focused on each of the aims and applied a number of measures/forms. Evaluation started with the application, which included characteristics of the team members, the institution, and the patients cared for in the institution. The DELEtCC Project Team, selected participants based on their interest and leadership experience; discipline; geographic location; and the commitment of the institution as illustrated by the recommendation letters from the institution administrators. Administrators were evaluated on the basis of their leadership positions within the institution and their presumed authority to initiate institutional change. Once selected, participants were notified and required to submit additional institutional information. This included: an institutional assessment of palliative and EOL care services; a chart audit of a recent patient death; a case analysis of a recent patient death; and a brief institutional survey of interest and readiness for change in palliative and EOL care. These forms were completed pre, 6, 12, and 18 months following the conference.

Evaluation of the conference content occurred at the completion of each conference day and included 5-point scale ratings of the speakers, content, and environment. In addition, participants rated the overall conference on content, the thought-provoking nature of the material, and whether individual expectations of the conference were met. Space for optional qualitative comments was included. Results of the faculty and conference evaluations were used to revise each subsequent conference. For example, participants wanted more time for questions and answers, and more time for small group work. These recommendations were implemented in subsequent conferences.

During the conference participants worked in small groups to discuss and refine their team goals. Project staff and faculty met with these groups, helping identify feasible goals. Each goal could focus on any aspect of change in structure, process, or outcomes needed to improve palliative and EOL care at their institutions.[23] Participants wrote final goals on duplicate paper, with participants keeping one copy and the investigators keeping the other copy to use in evaluating achievement at 6, 12, and 18 months post-conference. This procedure for goal development, revision, and follow-up has been used successfully in other dissemination conferences conducted by the investigators.[10] Follow-up consisted of a mailed report by the team identifying goal achievement and team telephone interviews by the project director at 6, 12, and 18 months post conference, to discuss barriers and support systems encountered by participants as they implemented goals. Additional or alternate goals were identified as well during this interview.

Administrators, who submitted pre-conference letters of support, were mailed a survey at 12 and 18 months post-conference. The first question asked administrators

whether or not they had discussed their team's goals. The remaining questions addressed institutional changes initiated by the participants.

Evaluation Results

Results are presented in relation to each of the aims.

Aim 1 - Carry out an interdisciplinary-focused EOL curriculum

A pre-conference evening reception served to introduce participants and faculty. The conference began the following morning with a motivational keynote presentation on *Making the Case for Palliative Care*. Conference content addressed Pain and Symptom Management; Setting up a Palliative Care Service/Financial Aspects of EOL Care; Creating a Palliative Care Culture using Performance Improvement Approaches; Grief, Loss, and Bereavement; Communication Issues with Cancer Patients; Cultural Aspects; Care During the Last Hours of Life; and Maintaining Quality of Care at the EOL.

Teaching methods included large group lectures, discussions, small group case presentations, and individual team work. Faculty were available throughout the conference to help participants apply the concepts being presented, to identify approaches to overcome individual institutional barriers, and to develop appropriate goals.

Aim 2 - Recruit interdisciplinary teams from cancer centers to attend the conference

Participants included 199 teams over the four conferences, with representation from forty-two states (Figure 2). Two international requests to attend the conference came from Australia and Russia. Guest status was provided and their data are not included in the evaluation.

Most participating institutions identified themselves as non-profit, community cancer centers. Representation from NCI-designated cancer centers varied from 6 to 29% across the conferences. The majority of participants were women, with nursing representing 60% of the disciplines (Table 2). The second most common discipline represented was social workers, followed by physicians. This distribution was as expected since one member from each institution was required to be a nurse, social worker, or physician. Other team members came from a variety of disciplines, ranging from administrators to chaplains.

Minority status was examined from two perspectives, – the distribution of patients seen at the institutions which averaged 29% minorities, and representation of participants across conferences which averaged 11% minorities.

Teams were also described in relation to the disciplines represented in each team. The most frequent combination was a nurse:nurse team, occurring in 33% of all the teams. The next two most common combinations were social worker:nurse (24%) and physician:nurse (16%). A variety
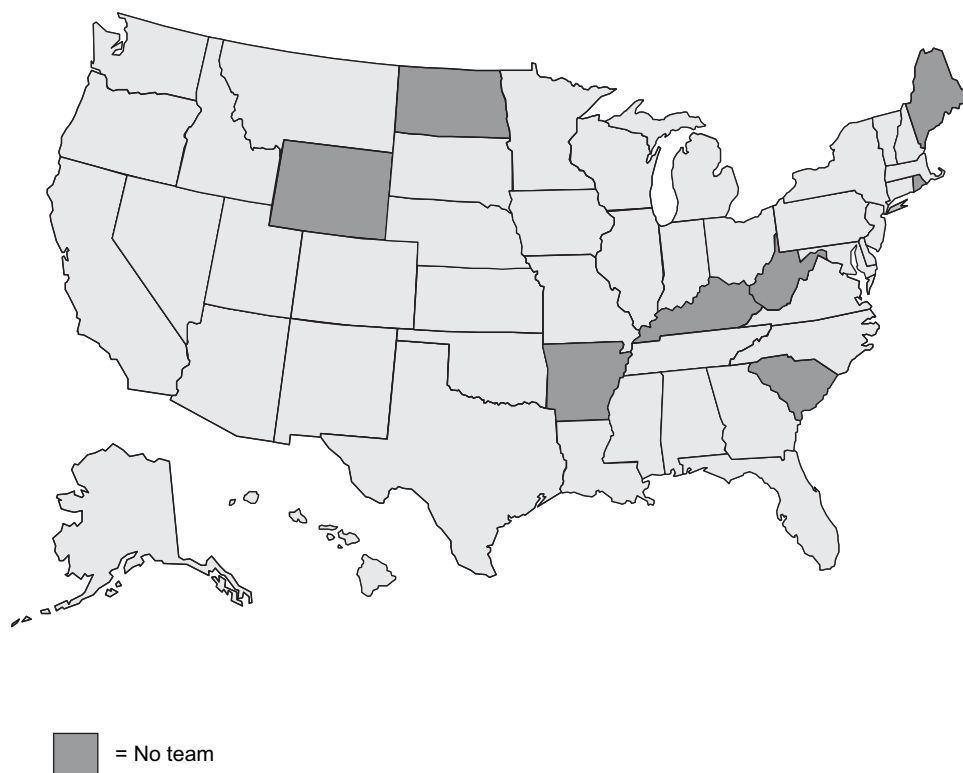

□ = No team

FIGURE 2. Institutional Teams Geographical Distribution.

TABLE 2. Demographic Characteristics of
DELEtCC Participants

	N = 400 (%)
Gender	
Female	346 (86)
Male	54 (14)
Discipline	
Nurse	239 (60)
Social Worker	77 (19)
Physician	45 (12)
Chaplain	14 (4)
Psychologist	10 (3)
Pharmacist	6 (2)
Therapist	4 (1)
Administrator	3 (1)
Other	2 (1)
Ethnicity	
Caucasian	348 (87)
Asian/Pacific Islander	15 (4)
African-America	11 (3)
Hispanic/Latino	8 (2)
Am Indian or AK Native	0 (0)
Other/Unknown	7 (2)
Non-Responders	11 (3)

of other combinations ranging from nurse:chaplain to social worker:medical bioethicist teams were also included.

As the teams were followed over 18 months, we were able to identify if the team was still configured as it had been at the beginning of the conference. At six months, the percentage of teams maintaining their original status averaged 83% across all conferences. These numbers decreased for the 12 and 18 month periods with 64% of the teams maintaining their original status at the end of the follow up period. Teams whose status changed either reported that one or two members were no longer part of the team, or simply did not respond to multiple attempts to contact them. A variety of reasons led to changes in the team status. For example, participants reported that their fellow team members became ill, were on maternity leave, left the institution, were reassigned to a different area, or were promoted. Future analysis will include on the impact of team stability on goal achievement and other institutional improvements in palliative/EOL care.

Aim 3 - Assist teams in their refinement of achievable EOL goals.

Each team, at the completion of the conferences, had revised goals to improve palliative and/or EOL care at their institutions. Some goals focused on structure changes for the institution, such as creating a new position for a palliative care medical director and/or a palliative care nurse. Others had larger aspirations of creating a palliative care unit in their organization. Most of the goals were process oriented and focused on education of their colleagues. Participants proposed using grand rounds and continuing medical and nursing education conferences to present palliative and EOL content. A focus on patient education included creating educational materials to be distributed to each new patient at the institution. Other teams focused on public education, using community forums that were part of their current institutional outreach. Outcome goals included better pain and symptom management of patients and increasing the number of patients with advance directives.

*Aim 4 - Elicit faculty and participants' evaluation of the conference*

The evaluations included ratings on three aspects of the conference. Scores on the 1 - 5 point scale (5 = highest) were high, revealing that the participants were very satisfied with the curriculum (4.8); their conference expectations were met (4.7); and overall opinion of the conference was high (4.8). In addition participants' evaluation of the faculty averaged from 4.2 to 4.9 illustrating positive support for faculty.

Aim 5 - Analyze teams' initial progress toward improving palliative and EOL care over an 18 month post-course timeframe.

The 18-month post course evaluation included an institutional survey, an administrative survey, and participants' reports on goal achievement. The institutional survey questions included the effectiveness of EOL care for all patients at their institution, the comfort of the staff in caring for EOL patients, the receptivity of staff in improving EOL care for patients, and the support provided by administration. Ratings were obtained prior to the conference, and completed again at 6, 12, and 18 months post-conference (Figure 3). Results revealed that effectiveness of care increased significantly from before the course to 18 months. In addition, significant improvements occurred in ratings of the degree of comfort staff had in caring for EOL patients. Receptiveness of the institutions' staff to improvements in EOL care improved significantly from pre-conference estimates to 12 and 18 months. Perceived administrative support was recorded as high pre-conference, perhaps reflecting the requirement that administration include letters of support in the application process. Following the conference, this administrative support significantly decreased at 6, 12, and 18 months. However the score of eight and above on a ten point scale show that participants did perceive that administration was essentially supporting palliative/EOL care activities.

The administrative survey, mailed to administrators at 12 and 18 months post conference had one forced choice question and one open-ended question on institutional changes. In response to the question "Has the DELEtCC team discussed their goals with you?" 95% of the administrators said yes. Responses to open-ended questions were also positive as illustrated below:

"The program has been extremely successful consulting over 200 patients in the last six months."
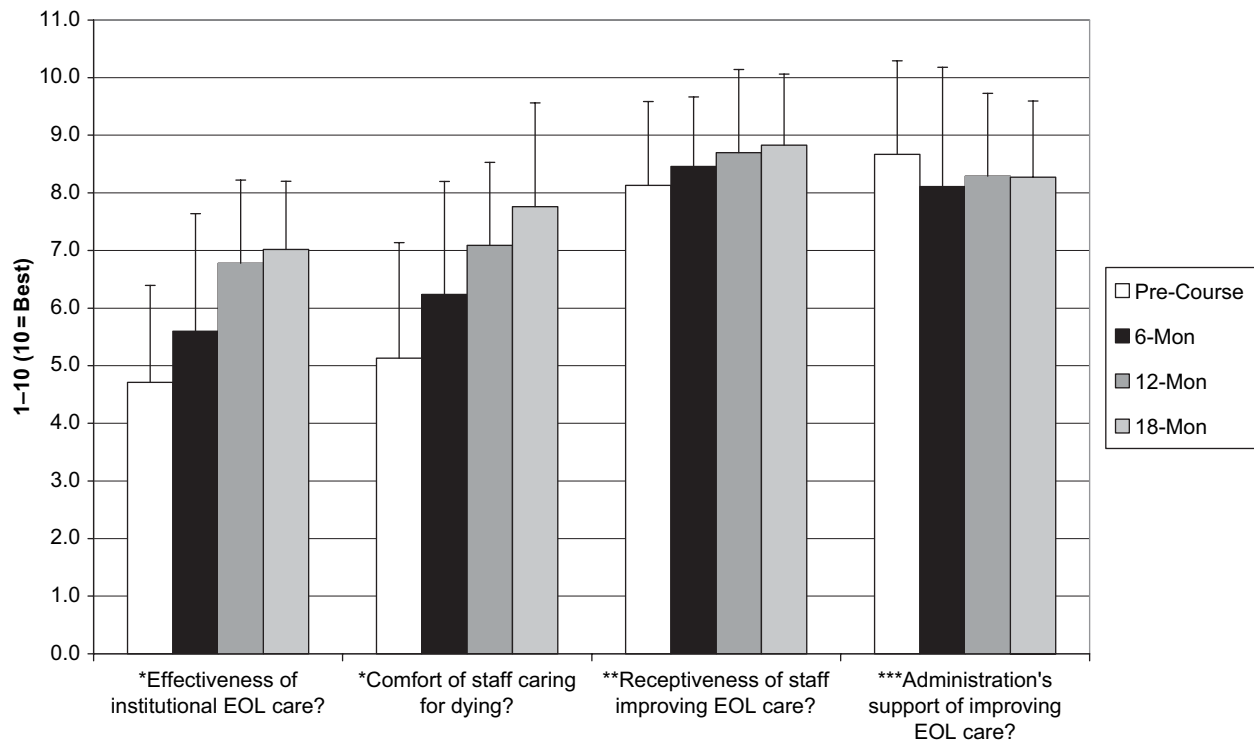
*Pre-Course score significantly lower from all subsequent scores. p < .001
**Pre-course scores significantly lower than scores at 12 & 18 months. p < .001
***Pre-course administration support was significantly higher than at 6, 12, & 18 months. p < .001

FIGURE 3. Cancer Centers' Rating EOL Capabilities.

"Our institution is committed to treating the whole person: mind, body and spirit. Honoring this commitment, we have hired a physician specializing in EOL/palliative care."

Initial analysis of EOL/palliative care goals achieved by participants following the conference showed that over 50% of the institutions implemented goals defined during the DELEtCC conference. Also, over 35% of the institutions implemented additional goals and palliative care activities. Further evidence for institutional changes following the DELEtCC conferences is illustrated by specific goals reported by the participating institutions. Table 3 provides examples of these goals within Donabedian's Institutional Changes Framework of structure, process, and outcomes.[24] Future analysis of all participants' goals will include a comparison of goals achieved by the kind of institution and the composition of the interdisciplinary team.

DISCUSSION

Initial efforts in the American Association for Cancer Education helped to focus and define professional palliative

TABLE 3. Application of Donabedian's Institution Change to Goal Analysis

Category	Definition	Example
Structure	Characteristics of the setting	Development of a Business Plan for Pain and Symptom Management Department
		Implementation of a new position for a Palliative Care Physician
Process	Actual practice or delivery of care	Creation of a Palliative Care Advocacy Team
		Implement Interdisciplinary Palliative Care Rounds
Outcomes	Effect of structure and/or process on the patient's health status	Provide classes in the Patient Care Center on Management of symptoms
		Improved pain management inpatients admitted to the comfort care suites

care training competencies.[25] Support from the NCI and national foundations encouraged the development of training programs, which focused on health care professionals. Our efforts to build on that legacy took the form of identifying interdisciplinary teams which would work with their cancer centers to promote and disseminate palliative care education. Our findings extend successes previously reported on single discipline educational projects.[7,9,10]

To develop a comprehensive and interdisciplinary focused EOL curriculum, we drew on established adult learning principles, palliative care precepts, and institutional change paradigms that focus on performance assessment. Our efforts in developing an interdisciplinary curriculum were aided through the selection of faculty known for their teaching excellence, as well as their research and content expertise. Our curriculum development process, which required faculty to submit their modules in response to a standardized protocol, may also have helped to elicit the perceptions of our participants that the curriculum met the goals and objectives of providing interdisciplinary focused curriculum. With many disciplines represented, socialization into interdisciplinary care occurred. For example, content on pain management with EOL may have been too complex for the social worker and not in enough depth for others; however, such content provided participant with an understanding of each discipline's role and an appreciation for overlap.

The marketing approach we used to recruit interdisciplinary teams emphasized the congruence of our methods and content with the cancer centers' mission. As our results indicate, we were able to attract participation of interdisciplinary teams. The largest percentage of participants came from nurses, physicians, and social workers. Our marketing approach also resulted in cancer centers serving substantial proportions of underrepresented minorities. Only 64% of the teams were still functional at 18 months post course, illustrating the movement of people in and out of specific positions in cancer centers. Attracting interdisciplinary teams that have longevity remains a challenge.

In terms of short-term evaluation of the program, our findings indicate that the majority of participants perceived the conference as meeting their expectations. For goal achievement, data indicate over 50% of the participating institutions were successful by the 18 month follow-up. Goal achievement by these institutions may have contributed to the growth of palliative care programs reported by Morrison et al.[26]

Our findings are limited by use of a descriptive design which does not allow for comparisons to institutions not participating in the conferences. In addition, our follow up ended at 18 months post course, so we are unable to explore whether or not the changes that occurred lasted beyond 18 months. Many participant goals included institutional changes to improve palliative/EOL care. However, other factors occurring within an institution could account for some or even all of that change and we did not collect this information. In addition, the composition of the participating

teams changed over time, with only 64% having the same two members at 18 month post conference. Evaluation does include perspectives of institutional change in EOL/palliative care from both the institutional administrators as well as the conference participants.

CONCLUSIONS

The DELEtCC project shows initial success in creating a well-defined curriculum in EOL education. The project selected interdisciplinary teams focused on institutional change. Our large sample of 400 health professionals representing 199 institutions, and the use of multiple measures of evaluation, helped fill an identified gap in the palliative care education research.[27] This model may inform others developing similar programs. DELEtCC disseminated content and approaches that encouraged effective learning and provided 18-month follow-up evaluation of improvements in EOL care in cancer centers.

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APPENDIX A

DELEtCC Teaching Faculty

Name	Position/Institution
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Margaret Riley, MN, RN, CNAA	Director of Specialty Center for Cancer Care and Research Saint Joseph's Hospital Atlanta, GA

(Continued)

Name	Position/Institution	Name	Position/Institution
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