

ACE PROJECT—ADVOCATING FOR CLINICAL EXCELLENCE: CREATING CHANGE IN THE DELIVERY OF PALLIATIVE CARE*

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ABSTRACT

Background: Psychologists, social workers, and spiritual care professionals report inadequate preparation to maximize their effectiveness in advocating for institutional reform to meet oncology patients' diverse bio-psychosocial-spiritual and cultural needs. This article provides an overview of the *ACE Project*, a National Cancer Institute, 5 year, R25-funded transdisciplinary palliative care education program designed to enhance the advocacy and leadership skills of 301 competitively selected psycho-oncology professionals. *Methods:* *ACE Project* participants identified an institutional goal, refined their goals during the course and received mentorship and support throughout the subsequent year. Participants were invited to return to a Reunion Conference in year five to report on their activities, network, and share the results of their change efforts. A subset of 28 *ACE Project* participants contributed to this *OMEGA* special issue. *Results:* Participants' goals primarily focused on strategies to improve clinical care through program

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development and improvements in palliative care education within their institutions. *Conclusions:* The results of this transdisciplinary leadership skills-building program for psycho-oncology professionals affirm the feasibility and perceived need for the program. See the *ACE Project* website (<http://www.cityofhope.org/education/health-professional-education/nursing-education/ACE-project/Pages/default.aspx>) for additional program information.

The *ACE Project: Advocating for Clinical Excellence—Transdisciplinary Palliative Care Education*, is a National Cancer Institute R-25 CA 110454 program that sought to fundamentally advance the delivery of palliative, end-of-life, and bereavement care by enhancing the leadership and advocacy skills of system change agents through the development and implementation of a targeted palliative care educational experience for psycho-oncology professionals.

BACKGROUND AND OVERVIEW

Cancer patients continue to report substandard pain and symptom management, poor access to quality services, high caregiver burden, and communication deficits across the continuum of care (Adler, Page, & Institute of Medicine Committees on Psychosocial Services to Cancer Patients/Families in a Community Setting, 2008; The SUPPORT Principal Investigators, 1995; Zabora, Brintzenhofe Szoc, Curbow, Hooker, & Piantadosi, 2001). These concerns become even more magnified when patients face end of life or are members of marginalized populations (Otis-Green & Rutland, 2004).

The National Comprehensive Cancer Network's algorithms for distress management (NCCN, 2012a) and palliative care (NCCN, 2012b) have been adopted in many cancer institutions. Successfully implementing these recommendations depends upon a cadre of skilled practitioners who recognize the tremendous religious, spiritual, ethnic, and cultural diversities in cancer populations and the importance that these variables play in serious illness. The algorithms' ultimate success relies upon an institutional infrastructure with teams of skilled personnel in place to implement the recommended strategies. Specialization as a palliative care psycho-oncology professional, therefore, requires mastery of several critical core competencies.

Quality palliative care is best delivered in a collaborative environment using an integrated bio-psychosocial-spiritual model (Sulmasy, 2002). Skilled teams of medical, nursing and psycho-oncology professionals are needed to address the complex and multi-dimensional concerns common to those facing cancer (McCallin, 2001). Yet too few professionals have been formally prepared to work at this level of integration and too few programs reliably offer this level of comprehensive and collaborative support services (Lickiss, Turner, & Pollock, 2003). And despite the clear need to be engaged in the development of strategies to address these concerns, few clinicians feel confident in leading a change

effort to create the support services necessary to meet patient needs (Lynn, Chaudhry, Simon, Wilkinson, & Schuster, 2007). Social work, psychology and spiritual care professionals share a history of advocacy for the vulnerable and marginalized, yet few have received specific education or support to maximize their responsibility as advocates for institutional change (Kuokkanen, Suominen, Rankinen, Kukkurainen, Savikko, et al., 2007).

The premise for this educational initiative was that psycho-oncology professionals share an ethical responsibility to be the “voice for the voiceless” and, therefore, educational efforts were urgently needed that enhance participant confidence in their leadership and advocacy skills so that they can more effectively address patient and family needs. “Leadership,” in this context, is not based upon a position or job title, but rather on the willingness to take action to improve the delivery of patient care. Clinician change-leaders are needed who can identify gaps in service, educate colleagues, and develop supportive programs and services that make a real difference in patient care.

The *ACE Project* developed a transdisciplinary leadership-skills building curriculum focusing upon the unique needs of oncology psychologists, social workers, and spiritual care professionals. Although an integrated approach to care offers clear benefits to patients (Otis-Green & Fineberg, 2010; Stark, 2011), professionals continue to receive the majority of their training within their own discipline (McCallin, 2001). Few interdisciplinary palliative care education opportunities exist (Fineberg, Wenger, & Forrow, 2004; Gelfand, Baker, & Cooney, 2003; Koffman & Higginson, 2005) and there is an urgent need to address the educational deficits of those currently in practice (American Psychosocial Oncology Society, n.d.; Otis-Green, Lucas, Spolum, Ferrell, & Grant, 2008). The design of the *ACE Project* was based upon the premise that a transdisciplinary perspective would lead to more effective team functioning and more skillful integration of the delivery of palliative care.

The transdisciplinary model emerged from hospice where there is an expectation that all clinical staff have shared areas of core competencies (Larson, 1993). For example, in a hospice setting, all clinicians may be expected to have collaborative communication skills, an ability to assess for pain and distress, and an appreciation of the diverse concerns that might impact care delivery. Although there is significant role-overlap, each discipline’s scope of practice is valued and seen as vital to the goal of providing truly comprehensive patient and family care. Despite a background of shared values that exist between the three disciplines targeted by the *ACE Project*, participants found that there were many misconceptions regarding role function between the disciplines.

METHODS

A comprehensive quality-of-life model guided curriculum development. Previous publications provide initial course evaluation results and more in-depth

information on the *ACE Project* curriculum design and course framework (Otis-Green & Ferrell, 2010; Otis-Green, Ferrell, Spolum, Uman, Mullan, Baird, et al., 2009). Curriculum content drew upon an extensive literature review with input from project advisors, consultants, and professional peer review. Palliative, end-of-life, and bereavement care core competencies for psychologists (Haley, Larson, Kasl-Godley, Neimeyer, & Kwilosz, 2003), spiritual care professionals (VandeCreek & Burton, 2001), and social workers (Gwyther, Altilio, Blacker, Christ, Csikai, Hooyman, et al., 2005; Wesley, Tunney, & Duncan, 2004) were identified and integrated throughout the curriculum materials.

The *ACE Project* curriculum supported participants in reclaiming their role and responsibility as system advocates for improved palliative and end-of-life care within their network of influence. Expert faculty presented didactic information, facilitated small group interactions, and provided mentorship and coaching. Faculty integrated examples of their own change efforts to illustrate successful examples of policy and institutional change.

The *ACE Project* curriculum included a wide variety of educational strategies to facilitate adult learning. Didactic presentations and experiential exercises were designed to promote a personal commitment to change. Personal death-awareness exercises and legacy-building strategies provided practitioners with an opportunity to personalize their commitment to improve the delivery of palliative care. In recognition that working with the dying reminds us of the importance of living an authentic life, there were multiple opportunities for participants to reflect upon their career choices (Palmer, 2000, 2004) and give consideration to their life purpose and the creation of a personal legacy.

A unique element of this transdisciplinary educational program was the integration of the expressive arts into the interactive learning sessions. Faculty included a professional harpist who provided inspirational music for reflection and ritual activities, as well as served as a role model through the sharing of her change efforts (see Box, page 13: *Hands-on-Harps: Integrating Music in Palliative Care*).

The National Consensus Project's *Guidelines for Quality Palliative Care* (National Consensus Project for Quality Palliative Care, 2009) provided the foundation for the *ACE Project* course curriculum. Nine major topic areas were selected that reflected key shared constructs among the disciplines (see Table 1). Principles of transformational learning theory (Jellison, 2006; Spitzer, 2004) provided the basis for the faculty to create an environment that inspired participants to reach personal and professional goals. Course participants received a text focused upon creating institutional change in palliative care (Lynn et al., 2007) and a binder that contained nearly 1,000 pages of resources, references, slide content, patient narratives, and educational exercises.

Teaching strategies were predicated upon change concepts (Dent, 1999; Fullan, 2008; Hayes, 2010; Periyakoil, 2009) taken from psychology (Oreg, 2003; Rogers, 2003; Sullivan, Lakoma, Billings, Peters, Black, 2006) and

Table 1. *ACE Project* Course Curriculum

| | |
|----------|--|
| Module 1 | Moral Imperative |
| Module 2 | Advocacy and Change |
| Module 3 | Personal Death Awareness |
| Module 4 | Ethical Obligations of Psycho-Oncology Professionals in Palliative Care |
| Module 5 | Transdisciplinary Team Work & Team Building/Introduction to Goal Refinement |
| Module 6 | Physical Aspects of Palliative Care |
| Module 7 | Psychosocial Aspects of Palliative Care |
| Module 8 | Spiritual Aspects of Palliative Care |
| Module 9 | Applying our Heart, Head & Hands: Bringing Together Passion, Knowledge & Action for Quality Palliative, End-of-Life and Bereavement Care |
| Optional | Labyrinth Exercise |

business (Gladwell, 2002, 2008; Shapiro, 2003) and established adult learning theories (Holton, Swanson, & Naquin, 2001; Knowles, 1973; Mezirow & Associates, 2000) that indicate adult learners are self-directed, possess rich life experiences, and are concerned with solving relevant life-problems. These concepts were explicitly integrated through the course. For example, the requirement that participants complete an institutional review and identify a meaningful change goal was intended to serve the dual purpose of improving care and creating a personal motivation for learning.

Throughout the course, participants were encouraged to see themselves as accountable for creating meaningful change on behalf of the vulnerable populations that they served (Otis-Green, 2011). The S.M.A.R.T. goal paradigm (Conzemius & O'Neill, 2002) was used to provide a common structure to aid the participants in refining their institutional change activities. Goals that are "S.M.A.R.T." are: Specific, Measurable, Achievable, Realistic, and Time-framed. Participants were encouraged to refine their institutional change projects throughout the course and supported in their efforts to identify concrete and practical steps that would lead to the success of their change project. Attention in several facilitated small groups throughout the course was devoted to assisting the participants in considering how they might implement S.M.A.R.T. strategies to achieve their desired goals.

Competitively selected participants ($n = 301$) attended one of four national training sessions. An innovative aspect of this educational initiative was the

invitation for *ACE Project* participants to return to a Reunion Conference in year five to reinforce and celebrate their achievements as system change agents. Participants from across the nation returned to present abstracts and posters highlighting their on-going activities to improve palliative care with the goal to reinforce change efforts, share lessons learned, and disseminate findings. Thirty of these emerging leaders were recognized with monetary awards for their outstanding leadership efforts.

ACE Project Results

There was active interest from throughout the United States, with nearly twice as many applicants as available spaces. Participants were 89% Caucasian with a balance from African-American and Latino backgrounds; they came from institutions serving 55% Caucasians, 20% African Americans, 15% Latinos, 5% Asians, and 5% American Indian, Native Hawaiians and others. More than 300 psychologists, social workers, and spiritual care professionals from 216 institutions in 45 states attended the four courses. The *ACE Project* participants were 51% social workers, 35% spiritual care professionals, and 14% psychologists, reflecting the approximate proportions of the disciplines working within palliative care, and represented 216 institutions.

ACE participants' work settings included: hospital 45%; cancer center 17%; hospice 16%; and other 23%. Many psychologists, social workers, and spiritual care professionals reported that they work in settings with few if any other psycho-oncology colleagues and under the supervision of managers from another discipline. The networking aspect of this transdisciplinary approach was encouraged to build a sense of community among like-minded psycho-oncology professionals. This sense of community was seen by participants as a particularly valuable component to the *ACE Project*. At the time of application, participants expressed that the focus of their goals were: education 32%; clinical care 29%; organizational change 21%; quality improvement 14%; and research 4%.

One hundred and thirty-two participants attended the *ACE Project* Reunion Conference reflecting all four cohort groups and in proportion to the numbers of each of the three disciplines of the study. Given that nearly 4 years had passed from Cohort One's initial *ACE* course attendance, and the subsequent national economic downturn, the attendance for the conference was robust. The Reunion Conference curriculum reflected the investigative team's intention to provide content (see Table 2) to further reinforce and enhance leadership and advocacy through an expectation of accountability. The *ACE Project* asked participants to identify a goal and work toward making an improvement in care that they would be accountable to the larger *ACE* community to report on through their attendance at the Reunion Conference in year five of the study. Participants were queried through an electronic survey to identify a range of practical skills that they would find of interest. Participants voiced an eagerness to explore further

Table 2. *ACE Project* Reunion Conference Curriculum

| | |
|------------------------|--|
| Module 1 | Developing Leadership Strategies |
| Module 2 | How to Get Published in a Journal |
| Module 3 | Teamwork: Additional Constructs & Concepts |
| Module 4 | Research as an Essential Skill to Advocate for Clinical Excellence |
| Module 5 | Mentorship and Supervision |
| Participant activities | Panel (Participant Success Stories); Participant Poster Sessions |

strategies to share their work and it was from their interest in publishing that this special issue was born.

In reflection of the ongoing commitment to integrate adult learning, an expectation for the conference was that all participants were required to submit formal abstracts describing their change efforts. Participants were also invited to present their work in a series of poster sessions as well as through participant panels. Thirty outstanding institutional change efforts were acknowledged with monetary awards to support them in further dissemination of their work. All participants were encouraged to consider opportunities to apply these skills following the conference. Anecdotal reports indicate that many of the participants have submitted their *ACE* abstracts for presentations at professional meetings, used their posters as teaching tools in their home environment, and have published their work following their *ACE* experience (in addition to this special issue).

Overview of *OMEGA* Authors

This special issue of the *OMEGA: Journal of Death and Dying* specifically highlights the change efforts of 28 *ACE* participants, representing 18 states and the District of Columbia. Sixteen of these authors had received awards and recognition for their accomplishments at the Reunion Conference (see Table 3). Following submission of their manuscript to this special issue, participants were asked to complete an electronic survey to learn more about the barriers and motivations that clinicians experienced regarding the publication process.

OMEGA authors represented all four *ACE* cohort groups. The primary work setting for the 28 authors were: cancer clinic (2); community hospital (3); National Cancer Institute designated cancer center (3); academic medical center (5); hospice/home healthcare (6); and other (9). Although 75% of the authors reported that they have worked in palliative care for 6 or more years, more than one-third had never published their work prior to this experience. The authors reported that they were motivated to submit from a desire to share their *ACE*

Table 3. *OMEGA* Authors' *ACE Project* Background

| Poster Award Winners | |
|----------------------|----|
| Advocacy Honors | 5 |
| Awards of Merit | 11 |
| Authors' Cohorts | |
| 1 | 4 |
| 2 | 7 |
| 3 | 8 |
| 4 | 9 |



accomplishments and the majority indicated that their confidence in disseminating their work has increased. The authors reported barriers to writing that included time constraints, competing work priorities and lack of support from colleagues.

The authors expressed that participating in the *ACE Project* had been a positive experience overall and reported feeling encouraged and empowered by the support they had received from other palliative care professionals who shared the same commitment to excellence as they did. All of the authors indicated that the mentorship and materials had been useful in their efforts to strengthen the palliative care programs at their institutions. Each of these authors have shared

Hands-on-Harps: Integrating Music in Palliative Care

I started out as a rock musician. It was not until I was an adult professional that I discovered the Celtic Harp. The harp's clear tones and lovely sounds led me to take it everywhere I went, and soon I was encouraging others to play. I would take my harp to the most unexpected places and found that the soothing sounds affected everyone I encountered.

In 1999, the news of the Columbine tragedy shocked our nation. I was glued to the television feeling helpless and sad. One day I received an unexpected call from one of the Columbine families directly affected by the tragedy. Their high school daughter, Ann Marie, had been paralyzed from the waist down from three gunshot wounds and was in intensive care. She had difficulty sleeping but her family wanted me to know that one of my CDs soothed her. Coincidentally, I was scheduled to perform soon in Colorado, so I offered to visit Ann Marie at the hospital with my harp.

When I arrived at the hospital, I met Anne Marie's family and spent the day with them. I played for Anne Marie's family, talked with them, rested, and played more music. I left that day with my heart filled and a different person. I started thinking about the purpose of music in my life and how it can be used to serve. I realized that perhaps I could make a small difference to those who were suffering—physically and emotionally. Thinking of Anne Marie and my experience with her family, I wanted to do more music therapy for patients. I was profoundly moved by the power of music and discovered that I could share the harp in a new way.

I reached out to the City of Hope to create a live music program for their cancer patients. We were able to obtain grant support and created the *Hands-on-Harps* program. The objectives for our music program included:

1. evening concerts in the waiting room with professional musicians who were touring through Los Angeles; concerts were followed by *Hands-on-Harps* workshops, where patients, families, and staff have an opportunity to play harps themselves;
2. live music in the hospital and clinic hallways and waiting areas;
3. private music for hospitalized patients (typically requested for those nearing end of life); and
4. development of a music library, where patients can check out small harps, music CDs, instructional videos, and books.

Developing the program was very exciting and grew to be much more than I ever expected. We took every possible opportunity to spread the word on City of Hope's campus, and the concerts were a resounding success. We learned to alert patients of the concerts by placing invitations on meal trays. World-class musicians, touring through Los Angeles, made stops at City of Hope to perform exquisite music. The music in the hallways offered a very relaxing ambience to what sometimes was a stressful environment. Our *Hands-on-Harps* program was such a success that soon some newspapers were interested in covering the story of patients and staff playing harps together. While playing in the hallways of City of Hope, I wrote a record (*Hopes & Dreams*) for the patients and the families that was both soothing to the soul and relaxing to the body. More interest in the program led to invitations to tell story on various network news channels. Surprisingly, my record *Hopes and Dreams* went to number six on the Billboard New Age charts! Our program at City of Hope is now approaching its 10-year anniversary. Concerts and music in the halls have become a normal sight and sound. Since beginning this journey, I have been invited to present and speak at various medical conferences and to other hospitals. We have received various grants to pay modest honorariums to the performers as well as the hallway musicians. Our harps have now visited many hospitals, rehabilitation centers, convalescent homes, and elementary schools. I've started working at Children's Hospital in Los Angeles, where kids who are waiting for or receiving treatment have a chance to participate in making music. Other hospitals have arranged for music in their hallways and intensive care units, and even given my CDs to parents of newborns. Meeting Ann Marie changed me forever. Inspiring hospitals to implement music in their settings is what I will be doing for the rest of my life. (For more information on *Hands-on-Harps*: <http://www.lisalynne.com/presskits/workshops.html>; to learn more about Lisa Lynn and her work: (<http://www.lisalynne.com/>). See Table 4 for listing of additional resources useful to guide the integration of the creative arts into the delivery of palliative care. See Table 4 for listing of additional resources useful to guide the integration of the creative sets into the delivery of palliative care.

Table 4. Integrated Arts Resources

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Table 4. (Cont'd.)

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their *ACE* activities through other means (with several reporting that they have written other publications expanding upon their change efforts).

DISCUSSION

The *ACE Project* sought to encourage exploration of role function, improve clinical judgment, integrate advocacy and ethics, enhance professionalism, increase collaboration and systems thinking, embed cultural sensitivity, facilitate accountability, and develop improved inter-professional communication skills. The *ACE Project* was unique in its transdisciplinary approach, and by its specific focus upon the targeted needs of psycho-oncology professionals. Although the program was limited in its attention to only three disciplines involved in palliative care, these three were selected as the major disciplines responsible for attending to the psychosocial-spiritual concerns of cancer patients. Further studies that integrate a wider range of disciplines would be beneficial. Advocacy and leadership skills were highlighted with the explicit intent to “change the change agents” and increase their confidence in their competence.

This initiative demonstrated the feasibility of a transdisciplinary palliative care education program for oncology social workers, psychologists, and spiritual care professionals. Supporting oncology patients and families requires competent and compassionate leaders willing to advocate for improved care. Our hope is that the *ACE Project* proved a source of support for

those involved in this important work and will be a model for future educational programs.

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