

"The follow up information [from Survivorship Education for Quality Cancer Care] combined with the six-month telephone calls kept our feet to the fire."

—2006 Conference Participant

Survivorship Education

An NCI-supported educational program at City of Hope in Duarte, Calif.



“It was one of the best conferences that I have attended. We are very excited about starting our [cancer] survivorship work.” —2006 Conference Participant

“I returned to Florida both energized and excited about the future of cancer survivors and the role I may play in their lives.”

—2006 Conference Participant

“The faculty, networking, materials, and resources were immeasurable. I look forward to sharing the information gleaned from the course with our clinical and administrative leaders.”

—2006 Conference Participant

for Quality Cancer Care

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In Brief

While survivorship is a key component of quality cancer care, the healthcare community, as a whole, has not done an exemplary job of addressing the needs of the 10 million plus cancer survivors in this country. In 2005, this lack of follow-up care came under increased scrutiny after the Institute of Medicine (IOM) published its groundbreaking report, *From Cancer Patient to Cancer Survivor: Lost in Transition*.¹ As part of its comprehensive report, IOM offered ten recommendations for improving the healthcare and quality of life of this nation's cancer survivors (see box on page 29). This article highlights one approach to providing survivorship education for interdisciplinary teams from community cancer centers, addressing recommendation seven in the IOM report, “...to provide education opportunities to healthcare providers to equip them to address the healthcare and quality of life issues facing cancer survivors.”



Survivorship Education for Quality Cancer Care

is a National Cancer Institute (NCI) supported educational program (2006 NCI Grant #IR25-CA10710901). The program supports four annual courses for competitively selected interdisciplinary teams from cancer centers across the nation. A key component of the program is 18 months of post-course follow-up evaluation to demonstrate institutional changes in cancer survivorship care that have occurred as a result of the program. *Survivorship Education for Quality Cancer Care* kicked-off in 2006. To date, one conference and one six-month follow-up have been completed. The second conference was held in July 2007. Information about the 2008 course can be found online at: <http://CityofHope.org/cme/Survivorship/Survivorshiphome.htm>.

Program Content

The City of Hope Quality of Life Model for Cancer Survivors (see Figure 1) provided the framework for curriculum development of the *Survivorship Education for Quality Cancer Care* program. Expert faculty from across the United States were selected by the City of Hope project team: Marcia Grant, RN, DNSc, FAAN; Betty Ferrell, PhD, FAAN; and Smita Bhatia, MD, MPH. Faculty were asked to develop content related to four dimensions of cancer survivors' quality of life: physical, psychological, social, and spiritual well-being. These experts presented on available evidence in their specific fields and identified gaps in knowledge that still need to be addressed. Additional experts provided concrete examples of how some community cancer centers have successfully addressed survivorship care. For example, The Living Well After Cancer Program at the University of Pennsylvania Abramson Cancer Center's LIVESTRONG™ Survivorship Center of Excellence established a follow-up clinic for testicular cancer survivors. And, the Palmetto Health South Carolina Cancer Center developed a support group

Figure 1. City of Hope Quality of Life Model for Cancer Survivors



Table 1. Major Agenda Topics for Survivorship Education for Quality Cancer Care

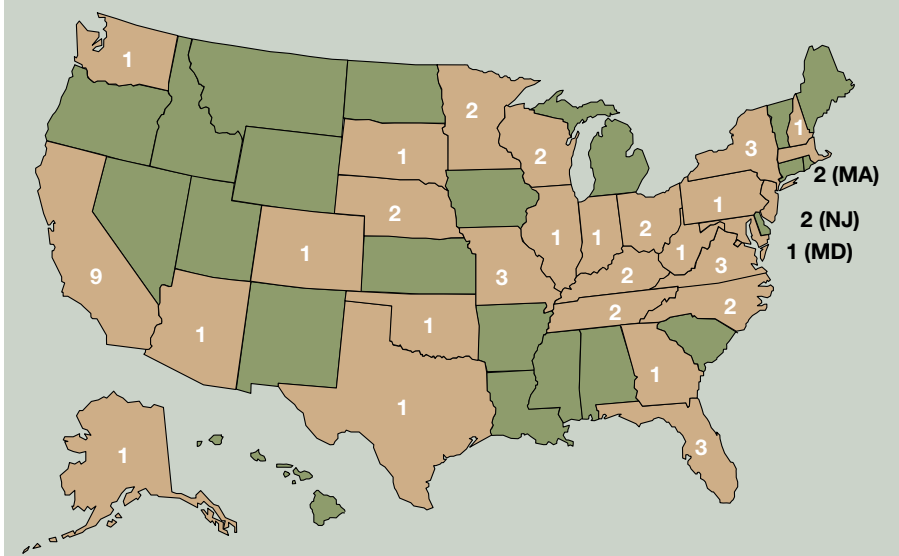
- Introduction to Survival: Strategies for Success
- The National Coalition for Cancer Survivorship (NCCS) and Cancer Survivorship Movement: History and Current Perspectives
- The NCI and the Survivorship Research Agenda
- Health-related Outcomes after Pediatric Cancer: Price of Cure
- State of the Science: Physical Well-Being and Survivorship
- Survivorship Issues for Adolescents and Young Adults
- State of the Science: Psychological Well-Being and Survivorship
- Survivorship Clinics
- Educating for Quality Care: Reaching Diverse Survivorship Communities
- Partnering with Cancer Survivors
- State of the Science: Social Well-Being and Survivorship
- State of the Science Lecture on Spiritual Well-Being and Survivorship

for cancer survivors that includes art therapy, “The Arts and Healing Program.”

Course developers used adult education principles to design plenary sessions, discussion periods, case studies, small group work, and networking opportunities. Because changes in care were expected to occur at each participating institution, course developers also wove principles of institutional change throughout the curriculum.

Today, course content includes the effects of cancer and its treatment on the psychosocial and spiritual needs

Figure 2. Map of 2006 Conference Participants



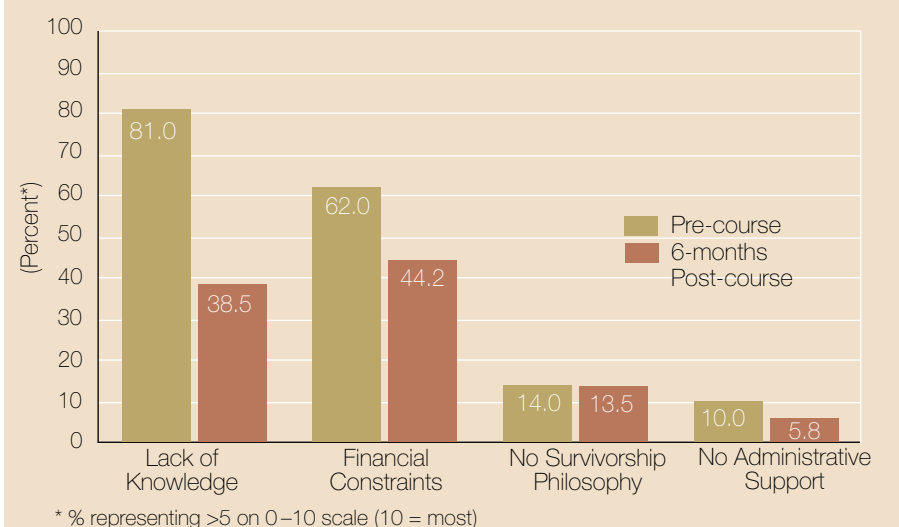
The Application Process

For the first *Survivorship Education for Quality Cancer Care* conference, NCI-designated cancer centers and members of the Association of Community Cancer Centers (ACCC) received information about the upcoming conference that was planned for July 2006. To be eligible to attend this program, cancer centers had to form two-person interdisciplinary teams. A physician, nurse, or administrator had to be one member of this team; the second member could be from one of these three disciplines or from any other profession involved in the care of cancer patients.

The application included demographic and professional information on the applicants, statements of interest, a list of three goals to be implemented by the team following the conference, and letters of support from two institution administrators. Selection was based on eligibility of the applicants, institution commitment as demonstrated in the letters of support, and geographic location. A total of 52 institutions (104 participants) were selected and attended the first conference, representing 28 states (see Figure 2).

Two quantitative surveys provided additional information on

Figure 3. Institutional Barriers of 2006 Conference Participants



of survivors as well as lingering and disabling physical symptoms, such as pain and fatigue. Adult, adolescent, and pediatric content are all part of the final program agenda, which provides topics and content for a two-and-a-half-day conference (see Table 1). The course syllabus includes an overview, objectives, a course outline, slides, references, and other resources for each agenda topic. The curriculum features a CD-Rom of all course material that participants can use to educate professional staff at their home institutions. Participants also receive additional resources including:

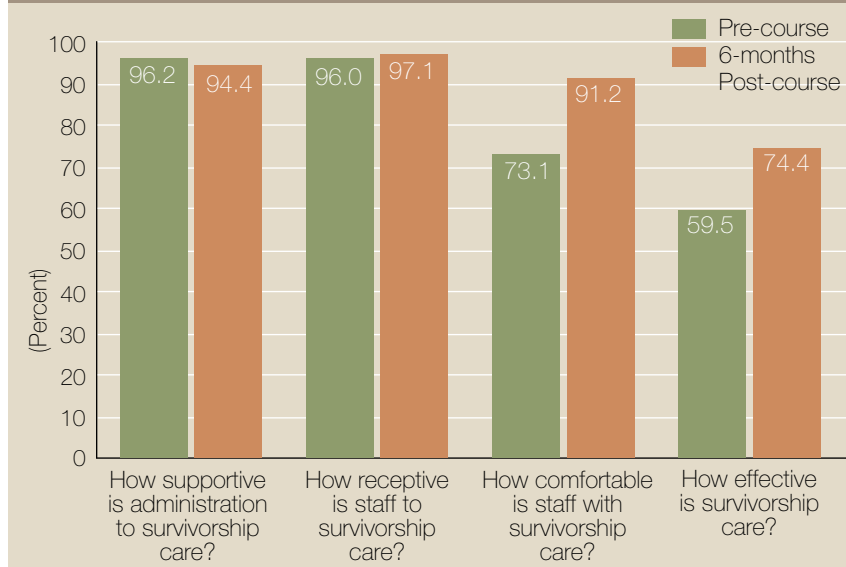
- A copy of the IOM report, *From Cancer Patient to Cancer Survivor: Lost in Transition*
- The *American Journal of Nursing* issue on cancer survivorship (March 2006/Supplement Vol. 106, No. 3)
- The 2006 book by Feuerstein and Findley, *The Cancer Survivor's Guide: The Essential Handbook to Life after Cancer*.

characteristics of the participants' settings (Figures 3 and 4). Both surveys were administered pre-conference and at six months post-conference. The pre-conference institutional surveys completed by the each of the participating teams addressed such questions as:

- How supportive is administration to changes in survivorship care?
- How receptive is staff to survivorship care?
- How comfortable is staff with survivorship care?
- What is the current effectiveness of survivorship care at your institution?

Prior to the conference, average survey scores indicated areas for improvement. Barriers to the improvement of survivorship care prior to the conference were identified in forced-choice (i.e., Yes or No) questions. The most frequent barriers identified pre-course were lack of survivorship knowledge and financial constraints. Only a small

Figure 4. Institutional Survey of 2006 Conference Participants



percentage of participants identified “no survivorship philosophy” and “administrative support” as barriers (see Figure 3).

Teamwork

A major activity throughout the conference involved teamwork on revising and refining goals to be achieved following the conference. Each institution’s two-person team was asked to identify and develop goals to be achieved at their home institution following completion of the course. Because participating institutions varied tremendously in terms of the current status of care for cancer survivors, so too did these goals. Some institutions focused on raising awareness of survivorship issues through education of the staff, others began development of a business plan for survivorship clinics, while others refined methods to be used to expand their already-existing survivorship clinics. Faculty and project staff assisted participants in refining these goals, emphasizing achievable goals defined as steps toward improving survivorship care.

Conference participants were also encouraged to look at current patient support activities in their institutions and consider how these could be repackaged to address survivorship issues. For example, most institutions had support groups for patients early in treatment. Expanding these support groups to focus on patients at the end of treatment was one recommended approach. At the end of the conference, participants gave a copy of their goals to project staff to be used in the follow-up evaluation at 6, 12, and 18 months post-course.

Evaluation and Follow-up

Participants evaluated and rated the content of the course and faculty at the conclusion of the conference. The quality of the agenda was rated at a mean score of 4.6 (scale=1-5 with 5 as the highest score). Faculty scores included:

- Clarity of Presentation: avg. 4.6
- Quality of Content: avg. 4.6
- Value to you as a clinician and/or practitioner: avg. 4.4.

Following the conference, project faculty continued to provide resources for participants to help them stay focused, to maintain their commitment to implementing their goals, and to provide additional information on new resources. Contacts with participants included a tri-annual newsletter that provided information on new resources, tips for participants implementing survivorship programs, and highlights of successes at participating institutions. As new information on survivorship became available, it was emailed directly to

conference participants. For example, participants received the November 2006, Vol. 24, No 32, *Journal of Clinical Oncology* that focused on survivorship issues.

Follow-up evaluation by project staff included contacting the participants by telephone to determine the extent to which they had succeeded in carrying out the goals they established at the conference. These contacts are planned for 6, 12, and 18 months post-course. To date, only the six-month follow-up for the first 2006 course has been completed.


Six Month Post-Conferences Results

Successful telephone conferences occurred with 90 percent of the 2006 conference participants. Evaluation of progress of goals revealed that 68 percent of the institutions had achieved more than 50 percent of their goals. Three per cent of the teams actually completed 100 percent of their goals. For these teams, project staff helped identify additional goals.

Comparison of scores on the pre- and six-month post course surveys showed that administration remained supportive of survivorship care and staff maintained their receptiveness to survivorship care (Figure 4). Improvements were seen in staff comfort with survivorship care and the effectiveness of the care provided (Figure 4). With regards to barriers, the six-month survey showed that “knowledge” as a barrier dropped, “financial constraints” decreased somewhat, and “survivorship philosophy” and “administrative support” remained fairly stable (see Figure 3).

Most exciting were the survivorship goals that many institutions were able to achieve six months post-conference. For example, Vanderbilt Ingram Cancer Center at Vanderbilt University in Nashville, Tennessee, started a multidisciplinary clinic for childhood cancer survivors one-half day per month with plans to expand to two full days per month by the end of 2007. Hoag Cancer Center in Newport Beach, California, began a fertility preservation program, developing a brochure to share with its patients who are seeking fertility preservation and conducting professional education on fertility preservation for its physicians and staff. As a result of the presentations and


IOM's **10** Recommendations for Improving the Health Care and Quality of Life of Cancer Survivors¹

1. Healthcare providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.
2. Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "Survivorship Care Plan" should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payers of healthcare.
3. Healthcare providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts.
4. Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.
5. CMS, NCI, the Agency for Healthcare Research and Quality (AHRQ), the Department of Veterans Affairs (VA), and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.
6. Congress should support the CDC, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.
7. The NCI, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to healthcare providers to equip them to address the healthcare and quality of life issues facing cancer survivors.
8. Employers, legal advocates, healthcare providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.
9. Federal and state policymakers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payers of healthcare should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.
10. The NCI, CDC, AHRQ, CMS, VA, private voluntary organizations such as the American Cancer Society (ACS), and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care. 

research-based information received at the *Survivorship Education for Quality Cancer Care* conference, this institution also gained the support of key stakeholders from the hospital, cancer center, and community to establish a formal survivorship program. Community philanthropic support will likely meet the needs of this new survivorship program.

The Future is Bright

Changing care in institutions is a challenge that cannot even begin without an informed and motivated staff. *Survivorship Education for Quality Cancer Care* participants appeared highly motivated at the end of the course; 92 percent continued to be interested and active in changing survivorship activities at their own institutions six months post-course. Administrative support—another essential component to successfully changing the delivery of care and the provision of supportive activities—also remained high. As the two-person teams move toward 12 and 18

months post-conference, project faculty anticipate a continued increase in survivorship activities across all participating institutions. 

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References

¹ Hewitt M, Greenfield S, Stovall E. (Eds.) The National Cancer Policy Board's Committee on Cancer. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, D.C.: The National Academies Press, 2005.