

**Grant Number:** 1R25CA107109-01A2  
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**PI Title:** PROFESSOR  
**Project Title:** Survivorship Education for Quality Cancer Care

### **Abstract**

The primary aim of this training proposal is to improve quality of care and quality of life for cancer survivors. As of January 2001, there are an estimated 9.8 million cancer survivors representing 3.5% of the population. As cancer survival has increased steadily over the last decades, it is estimated that 60% of adults diagnosed today will be alive five years later. The emerging data on long-term complications of cancer treatment have led to a variety of approaches to increase surveillance and follow-up care for cancer survivors and their family members. Efficient dissemination of successful approaches to assure quality care for cancer survivors is needed. The primary aim of this proposal will be achieved through four annual workshops for two representatives each from 50 cancer treatment centers. Thus a total of 400 participants is planned. Additional dissemination methods and an extensive evaluation will provide a basis for the continuing education of health care professionals beyond the project period. Specific aims to be accomplished are to: (1) Create the cancer survivorship curriculum for training an interdisciplinary professional audience from cancer centers. (2) Implement the survivorship curriculum in national workshops to competitively selected staff from National Cancer Institute-designated clinical and comprehensive cancer centers, and community cancer centers as identified through the Association of Community Cancer Centers (ACCC). (3) Develop a network of course participants to share experiences in dissemination of the survivorship curriculum to the staff of participating cancer centers. (4) Evaluate the impact of the survivorship curriculum on participants' and cancer center staffs' implementation of individual goals for improved care for cancer survivors in respective cancer centers. (5) Describe successes and issues related to dissemination of cancer survivorship care in cancer centers in terms of the characteristics of individual course participants, interdisciplinary teams, and institutions. The project builds on the investigators' previous experience with similar national workshops on pain management, palliative care education for home care nursing staff, a nursing end-of-life (EOL) curriculum developed with the American Association of Colleges of Nursing, the End of Life Nursing Education Consortium (ELNEC) and Dissemination of End-of-Life Education to Cancer Centers (DELEtCC). A national group of leading experts have enthusiastically agreed to be faculty.

**Institution:** CITY OF HOPE/BECKMAN RESEARCH INSTITUTE  
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DUARTE, CA 910103000

**Fiscal Year:** 2005

**Department:**

**Project Start:** 01-SEP-2005

**Project End:** 31-AUG-2010

**ICD:** NATIONAL CANCER INSTITUTE

**IRG:** ZCA1

## 8.0 Research Plan

### A. Specific Aims

The primary aim of this training proposal is to improve quality of care and quality of life for cancer survivors. As of *January 2001*, there are an estimated 9.8 million cancer survivors representing 3.5% of the population.<sup>1</sup> As cancer survival has increased steadily over the last decades, it is estimated that 62% of adults diagnosed today will be alive five years later.<sup>(2, p66)</sup> The emerging data on long-term complications of cancer treatment have led to a variety of approaches to increase surveillance and follow-up care for cancer survivors and their family members. Efficient dissemination of successful approaches to assure quality care for cancer survivors is needed. *One of the objectives and fiscal year 2005 milestones published in the NCI bypass budget request for 2005 is to ensure delivery of best practice guidelines for follow-up care and standards for effective psychosocial and supportive care.*<sup>2</sup> The primary aim of this proposal will be achieved through four annual workshops for two representatives each from 50 cancer treatment centers. Thus a total of 400 participants is planned. Additional dissemination methods and an extensive evaluation will provide a basis for the continuing education of health care professionals beyond the project period.

The project builds on the investigators' previous experience with similar national workshops on pain management, palliative care education for home care nursing staff, a nursing end-of-life (EOL) curriculum developed with the American Association of Colleges of Nursing, the End-of-life Nursing Education Consortium (ELNEC) and Dissemination of End-of-Life Education to Cancer Centers (DELEtCC).

Specific aims to be accomplished are to:

1. Create the cancer survivorship curriculum for training an interdisciplinary professional audience from cancer centers.

Professional audience will include nurses, physicians and administrators as a first tier, and social workers, clergy, pharmacists, psychologists and rehabilitation professionals as a second tier.

2. Implement the survivorship curriculum in national workshops to competitively selected staff from National Cancer Institute-designated clinical and comprehensive cancer centers, and community cancer centers as identified through the Association of Community Cancer Centers (ACCC).

Two representatives from each institute will be selected with a minimum of one from the first tier of professionals (nurses, physicians, and administrators).

3. Develop a network of course participants to share experiences in dissemination of the survivorship curriculum to the staff of participating cancer centers.

4. Evaluate the impact of the survivorship curriculum on participants' and cancer center staffs' implementation of individual goals for improved care for cancer survivors in respective cancer centers.

5. Describe successes and issues related to dissemination of cancer survivorship care in cancer centers in terms of the characteristics of individual course participants, interdisciplinary teams, and institutions.

The evidence available on the need for improved cancer survivorship care is identified in the following background and literature search.

### B. Background and Significance

#### 1. Need for Improved Survivorship Support

In 2004, 1,368,030 new cases of cancer are expected to be diagnosed in the United States.<sup>3</sup> Of these cases, 64% are expected to survive at least 5 years after diagnosis. As of *January 2001* there are an estimated 9.8 million cancer survivors.<sup>1</sup> These numbers reflect a steady increase in survival from cancer, and thus an increase in the number of cancer survivors who need continued access to health care services, and may need a variety of supportive services. Survivors experience long-term physical and psychosocial effects as a result of the cancer and the cancer

treatment.<sup>4-6</sup> Quality cancer care is needed for ongoing surveillance, early diagnosis and treatment of long-term physiological effects, and support for psychosocial challenges.<sup>2</sup>

The definition of a cancer survivor in this proposal will be that defined by the National Coalition for Cancer Survivorship, a patient-led organization founded in 1986 and advocating on the behalf of survivors of all cancers.<sup>7</sup> The charter of this organization states that “from the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor.”<sup>7</sup> This broad definition does not differentiate those patients in active treatment, from those who are “disease-free,” or those who are dying of cancer. This definition, however, matches that of the surveillance databases of the National Cancer Institute (SEER and other tumor registries). This broad definition provides our best approach to identifying the need for survivorship support, until more survivorship phase-specific information is known.

The National Cancer Institute has identified Cancer Survivorship: *Optimizing Health and Quality of Life After Cancer as a broad research priority in the core scientific areas in the Nation’s Investment in Cancer Research, 2005.*<sup>2</sup> *This report identifies need for additional research on the biological, physical, psychological and social mechanisms and their interactions, that affect a cancer patient’s response to disease, treatment, and recovery, and the need . . . to ensure the delivery of new information, interventions, and best practices to relevant audiences.* (2, p.9) *The report also identifies the need to identify optimal follow-up care, how to coordinate such care, and evaluate the effectiveness of such care.* (2, p. 68) *This proposal addresses these issues by convening workshops for cancer center health professionals where leading researchers present the state of the art information of physical, psychological, social and spiritual well being for cancer survivors, as well as examples of current practices for providing follow-up care. This approach addresses the problem of decreasing the time between identification of appropriate study findings on cancer survivorship, and incorporation of such findings into clinical practice. This time period has been defined as up to seventeen years.* (8) *With expert faculty, committed participants, and extensive follow-up, the proposed project anticipates decreasing this long time between knowing research findings, and implementation of improved clinical practices.*

## **2. Development of Organizations to Support Survivorship**

Founded in 1986, the National Coalition for Cancer Survivorship (NCCS) is a patient-led organization advocating on behalf of survivors of all cancers.<sup>7</sup> The mission is “to lead and strengthen the survivorship movement, to empower cancer survivors, and to advocate for policy issues that affect their quality of life.”<sup>9</sup> This organization conducts programs, has policy expertise, and provides publications for cancer patients, family, friends and caregivers. NCCS is the founding organization for THE MARCH, where on September 25, 1998, 200,000 people gathered in Washington DC and hundreds of thousands in communities nationwide to remember those lost to cancer, celebrate survivorship, and hold decision-makers accountable for the goals set forth by the organization. The NCCS is called upon to testify to Congress about survivorship issues, and is also represented on the National Cancer Advisory Board and the National Cancer Policy Board.

The American Cancer Society is the oldest voluntary health agency dedicated to conquering cancer through research, education, advocacy and service.<sup>10</sup> Many of their activities target cancer survivors. They are sponsoring a large nationwide prospective population-based study of cancer survivor needs. The results of this study will provide valuable information to use in identifying support services and follow-up care needed to improve quality of life for survivors. In 1988 they published the Survivor Bill of Rights, and have included caregivers in their development of support services. Reach to Recovery and I Can Cope are examples of well-established ACS programs available across the country through regional and local ACS offices. More recently ACS has developed the Cancer Survivors Network, which is a telephone and Web-based service created by cancer survivors, family and friends to provide a national support system. In addition, ACS continues to provide educational materials for cancer patients and their caregivers.

The Office of Cancer Survivorship in the National Cancer Institute was established in June of 1996 in recognition of the growing number of cancer survivors and their families.<sup>1</sup> The mission of this office is to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize adverse effects experienced during cancer survivorship. The program of research covers the long and short-term physical, psychological, social, and economic effects of cancer and its treatment across ages and including families. Educational needs of cancer survivors are addressed in the Facing Forward series of booklets for survivors and their families. The Web site for Office of Cancer Survivorship provides information about grant funding – who's funded, doing what, additional research needed, and statistics about survivors.

In addition to these three major national organizations, many organizations both national and local have been developed to address a specific cancer, specific treatment, or a specific population. Examples are found in Appendix H. The variety on this list highlights the survivors' need to have information and support specific to their disease. Letters from many of these organizations supporting the current proposal are found in Appendix H.

### **3. Areas of Concern and the Current Status of Research**

Most of what is known about the needs of survivors is based on descriptive studies of various populations at various times since diagnosis and the end of treatment. The goal of survivorship research is to explore the adverse events associated with cancer and cancer treatment, and improve physical, psychosocial and spiritual outcomes for cancer survivors and their families. Many of the studies are limited by the length of follow-up, small sample size, concurrent morbidity, and a narrow focus. Study findings to date can be grouped with the four dimensions of the City of Hope Quality of Life Model, composed of: physical well being and symptoms, psychological well-being, social well-being, and spiritual well-being.<sup>11</sup> An additional topic on health care issues completes this section.

#### Changes in Physical Well Being

Physical problems are abundant following both cancer and cancer treatment and may lead to organ damage. For example, pathology may include cardiomyopathy,<sup>12,13</sup> pulmonary problems,<sup>14,15</sup> urinary and bladder dysfunction especially in patients undergoing prostatectomy,<sup>16,17</sup> cataracts,<sup>18</sup> and cognitive changes.<sup>19-21</sup> Damage to the endocrine system may include thyroid dysfunction,<sup>22</sup> premature menopause,<sup>23</sup> reproductive problems,<sup>24</sup> and sexual dysfunctions.<sup>24</sup> The most common physical symptom experienced by cancer survivors is fatigue.<sup>25,26</sup> The risk for cancer survivors of secondary cancers is greater than the risk for the general population, and occurs across many different cancers.<sup>27,28</sup> Other long-term physical complications include pain syndromes<sup>29</sup> and lymphedema.<sup>30</sup>

#### Changes in Psychological Well Being

Cancer survivors experience psychological effects, not only related to the cancer and the treatment, but to the side effects, and long term changes that occur. Common emotional responses include anxiety and depression.<sup>31-34</sup> Fears occur and include fear of recurrence and fear of a second cancer.<sup>4, 35</sup> Depending on the type of treatment, changes in body image may occur and be accompanied by changes in self concept.<sup>11, 16, 36</sup> Recent studies report that cancer survivors experience symptoms of Post Traumatic Stress Disease (PTSD).<sup>37</sup>

#### Changes in Social Well Being

Adjusting to the social consequences of cancer and cancer treatment presents a challenge for many cancer survivors. Interpersonal relationships within the family and among friends change.<sup>35, 38, 39</sup> Family roles may be impacted.<sup>36,40,41</sup> Survivors may need to either change jobs if working, or stop working.<sup>42</sup> Those who are in school may find it difficult to continue. Financial impact may be great, and the ability to maintain health insurance may be compromised. Discrimination based on the diagnosis may occur.<sup>42</sup>

#### Changes in Spiritual Well Being

The diagnosis of cancer and its treatment may change the “meaning” of life, and result in changes in priorities.<sup>4</sup> Religious and spiritual activities may increase as support for the changed perspective of life becomes apparent to the survivor.<sup>31, 35</sup> A classic explanation of these changes relates to the existential plight faced by the cancer patient.<sup>43</sup> Once the diagnosis of cancer is confirmed, the individual usually feels that life will never be the same – mortality has to be faced.

### Health Care Issues

The cancer survivor faces many challenges with the diagnosis of cancer, especially in navigating the health care system. Who the primary care physician is depends on many factors: the patient, the oncologist, the type of insurance, location, lack of institutional support, among others.<sup>44</sup> No clearly defined system has been identified.<sup>45</sup> Because of the different disciplines involved in the treatment, the primary care physician may be the medical oncologist one week, the surgeon the next, and then the radiation oncology therapist. Survivors need to be well acquainted with their specific cancer and the treatment received. Insurance processes, paperwork, and adequacy of coverage are major issues. In some diagnoses, like lymphoma treated with bone marrow transplant, a care partner needs to be available before the patient is accepted to the program. With changes in health care, patients are discharged earlier, and continuity of care and long term follow-up are difficult.<sup>46</sup> The NCCS addresses many of these problems in their publication on Imperatives for Quality Cancer Care: Access, Advocacy, Action and Accountability.<sup>47</sup> A recent publication by the Institute of Medicine proposes policies to improve the quality of care and quality of life for women with breast cancer and their families. Recommendations include continuing education for health professionals and overcoming barriers to integrating psychosocial services into accessible health care services.<sup>106</sup>

### Significance of the Proposed Project

The overall purpose of this project is to improve the quality of care and quality of life of cancer survivors. The project proposed focuses on cancer centers, both NCI-designated, and community cancer centers. A variety of approaches are currently used to provide follow-up care and support for cancer survivors. Disseminating what is currently being done in model settings can provide participants with information and ideas to take back to their own institutions for implementation. Through the extensive evaluation, resulting applications to improving care can be identified and disseminated for use across many cancer settings.

## **C. Preliminary Activities**

Preliminary work relevant to the proposed project is organized into two sections: research conducted by the investigators on quality of life and long term evaluation of cancer patients, and education and training experience with cancer professionals.

### Overview of QOL Research

City of Hope (COH) studies from 1985 to the present have led to the assessment of quality of life (QOL) as an outcome variable and development of the COH QOL instruments. Dr. Grant is Director of the Department of Nursing Research and has conducted QOL Research in Survivorship populations for more than 20 years. Dr. Ferrell joined Dr. Grant at COH in 1989 and applied the QOL concept to pain research through a study of cancer patients and non-cancer patients (N=150) to test QOL as an outcome for pain research.<sup>48</sup> Other QOL cancer studies from 1989 to the present included numerous studies on pain,<sup>49,50</sup> ovarian cancer,<sup>51</sup> and breast cancer.<sup>29,31,52,53</sup> Studies have included qualitative and quantitative methods. This descriptive QOL research has led to intervention research to address symptoms and improve QOL. The rich cultural diversity in the COH setting has provided between 27% and 43% ethnic minority representation in previous studies. Other QOL studies have focused on BMT,<sup>35,38,54,55</sup> patients with ostomies,<sup>36,56, 107</sup> palliative surgery,<sup>57-62</sup> and numerous other oncology populations.<sup>4,11</sup> The COH investigators have also conducted intervention studies in pain education testing the impact of pain education on QOL outcomes for cancer survivors and their family caregivers.<sup>63</sup>

Dr. Bhatia's program of research is in childhood cancer and survivorship.<sup>64-69</sup> Dr. Bhatia, (Co-Investigator) is currently conducting a study of 2000 pediatric and adult patients who have undergone HCT at two institutions (City of Hope National Medical Center, and the University of Minnesota Cancer Center) and have survived for two years or more. The comprehensive evaluation includes long-term effects and QOL, with the ultimate goal of improving the transplant process by reducing transplant-related morbidity. Dr. Bhatia's studies have examined issues such as ethnicity and survivorship,<sup>64</sup> second malignancy,<sup>65</sup> and QOL assessment in pediatrics.<sup>66</sup> Several related papers have been published.<sup>64-69</sup> This sustained program of research by the COH investigators creates a foundation for QOL as a model of addressing cancer survivorship.

### **QOL Survivorship Studies**

#### **1. Quality of Life in Patients with Ostomies**

Several studies have focused on the quality of life of patients with ostomies. Our recent endeavors have involved revising a previously used quality of life instrument specific to ostomy patients. To develop reliability and validity, in-depth interviews with cancer patients having ostomies were conducted. A panel of researchers, nurses, and physicians analyzed the qualitative data, and used results to revise the original ostomy tool. The tool was then tested in a large population of members of the California Ostomy Association. The mailed survey was analyzed, using psychometric techniques, and testing hypotheses about which groups would have the best quality of life. Results indicated a psychometrically sound instrument that is now being implemented in 2 multisite studies spearheaded by Dr. Robert Krouse at the University of Arizona Veterans Hospital, and involving the VA institutions at Indianapolis and Los Angeles *and Kaiser Permanente families in Northern California and in the Northwest.*<sup>107</sup>

#### **2. Quality of Life in Breast Cancer Survivors**

In this descriptive survey, Dow, Ferrell, et al<sup>70</sup> evaluated QOL in 297 breast cancer survivors using 2 standard QOL tools (i.e., QOL-Cancer Survivors and FACT-G) and an open-ended QOL questionnaire. Results showed that specific changes in physical well-being (fatigue and pain); psychological well-being (fear of recurrence); social well-being (sexuality concerns); and spiritual well-being (meaning from illness) were major problems affecting breast cancer survivors. This study identified high incidence QOL problems affecting a large proportion of cancer survivors and further identified the need to design interventions to maintain or improve QOL from a comprehensive, multidimensional perspective. The investigators then used qualitative methods including interviews and focus groups to define the QOL issues of breast cancer survivors, to validate the conceptual model for this population, and to develop the Breast version of the COH-QOL instrument.<sup>29,31,52,53</sup> A convenience sample of 21 breast cancer survivors stratified by three age groups (<40, 41-60, and >60) was selected to explore and describe how survivorship varies with age. Subjects were at least three months beyond initial treatment completion and at least one year since diagnosis. Data analysis led to the revision of the QOL model for breast cancer and identification of the needs across the four domains. The revised tool was validated in a cross-sectional, age stratified sample from the COH cancer registry and resulted in 298 subjects completing the QOL instrument, the Brief Pain Inventory and the FACT-G Tool.<sup>71</sup>

#### **3. Quality of Life in Thyroid Cancer Survivors**

The COH investigators evaluated the impact of thyroid hormone withdrawal on patients' perceived changes in QOL. The sample included 34 subjects (mean age 40 years, 85% female, 74% Caucasian) with thyroid cancer who were undergoing thyroid hormone withdrawal in preparation for follow-up thyroid scanning.<sup>72,73</sup> Study findings contributed to our understanding of the heightened fear of recurrence, metastasis, and second cancers related to follow-up testing after initial treatment.

#### **4. Quality of Life in Women with Ovarian Cancer**

This study, which contained both descriptive and quantitative elements, was conducted by Ersek, Ferrell, et al. in 1997<sup>51</sup>. The investigators evaluated QOL in 152 ovarian cancer survivors using the QOL-Cancer Survivors tool and an open-ended questionnaire. Results pertaining to physical aspects of QOL indicated that the ovarian cancer survivors experienced considerable fatigue, pain, and difficulty sleeping, while nausea, appetite, and constipation were of less concern. Psychologically, the women experienced significant distress related to their initial diagnoses and treatments, as well as fear of recurrence, and degradation of self-concept. Despite this, they maintained a sense of happiness, satisfaction with life, and usefulness. In the social domain, women described family distress, sexuality, and financial burden as negatively impacting their QOL, while support from others and personal relationships were described positively. Finally, regarding spiritual concerns, the ovarian cancer survivors experienced significant uncertainty, but they were encouraged by a strong sense of purpose in life and hopefulness.<sup>51</sup>

### **5. Quality of Life Issues in Ovarian Cancer: CONVERSATIONS! with 21,806 Women**

In 2001–2002 Drs. Ferrell and colleagues conducted this qualitative study to describe QOL concerns and experiences in women with ovarian cancer in order to advance future care. The data were received from women with ovarian cancer who corresponded through an ovarian support newsletter, “Conversations!” The correspondence (n=21,806 letters) occurred from 1993-2000. Analysis procedures included data reduction and content analysis using the QOL model as a guiding framework. A panel of experts in ovarian cancer and QOL as well as an ovarian cancer survivor validated the coding. Findings, based on major themes derived from the analysis, include presence of numerous physical symptoms.<sup>74</sup> In the psychological domain, fears of recurrence and distress over treatments were coupled with profoundly candid explanations of methods to cope and maintain hope.<sup>75</sup> Socially, the overwhelming support that these women received from their families and friends was not successful in alleviating feelings of isolation and the need to confide in other survivors who identified with their personal battles. Distress regarding the potential genetic nature of the disease also comprised a large theme in the social domain.<sup>76</sup> Comments related to spiritual well-being revealed that faith for comfort and healing was strong, as was the meaning found in illness and its ability to enact positive changes in the lives of ovarian cancer survivors.<sup>77</sup> This study provided a rare opportunity for an ethnographic exploration of QOL from the natural correspondence between women with ovarian cancer. The findings of this study contribute to our understanding of survivorship concerns.

### **6. Survey of Quality of Life in Ovarian Cancer (OVCA) Survivors**

In 2002, the investigators (Ferrell and colleagues) collaborated with the national newsletter for ovarian cancer survivors (“Conversations”) to obtain quantitative data regarding QOL issues. The analysis from the above qualitative study was used to refine the QOL – ovarian tool which was then completed by 1,383 OVCA survivors. The QOL – OVCA tool included 45 items scored from 0=poor to 10=best QOL outcome. Mean scores for the QOL domains were 7.17 (Physical), 5.37 (Psychological), 6.23 (Social), and 6.52 (Spiritual). Mean total QOL score was 6.12. Most significant QOL concerns by subscale included fatigue (5.85), sleep (6.23), pain (6.50) for Physical Well Being; distress of initial diagnosis (1.48) distress of treatment (2.58), and fear of recurrence (3.08) for Psychological Well Being; family distress (2.91), concern that relatives will be diagnosed with cancer (3.82), and sexuality (4.56) in Social Well Being; and uncertainty (3.69), spiritual activity (5.79) and positive effects (6.58) in Spiritual Well Being. ANOVA comparisons demonstrated best QOL outcomes for those over 60 years of age and in the over five-year survivor category. Results of this study were presented at ASCO in May 2003.

### **7. QOL-HCT Studies**

A series of studies have been conducted since 1991 to develop a valid and reliable instrument for measuring QOL in HCT patients and identify areas for nursing intervention. Content validity for the hematological cell transplant (HCT) population involved a panel of HCT physicians

and nurses, and interviews with 119 HCT survivors. Findings confirmed the QOL model and identified survivorship issues not seen in previous studies.<sup>38,55</sup> A quantitative QOL-HCT instrument containing 30 items was tested with 194 HCT survivors.<sup>35</sup> Multiple regression analysis identified variables ( $p < 0.05$ ) influencing QOL identifying life satisfaction, enjoyment, control, and visual disturbance as the strongest predictors of QOL status. Factor analysis confirmed the four major domains of the conceptual model including physical, psychological, social and spiritual well-being. Revisions to the questionnaire increased the QOL section to 58 items based on survivorship questionnaire analysis in related populations, added 4 dimension scores and 2 items related to reactions to filling out the questionnaire. QOL was next measured in 450 HCT survivors at time points ranging from 100 days post-HCT to over 15 years post-HCT. Results of overall and dimension subscale scores showed moderate to poor QOL that remained fairly stable across time since transplant. A retrospective chart review of 100 discharged transplant patients was conducted to describe discharge and readmission patterns and identify implications for nursing interventions to improve patient quality of life and other outcomes.<sup>108</sup> Findings were used to develop a pilot study teaching and coaching program testing an advanced practice nurses intervention which replicates McCorkle's work using a Standardized Nursing Intervention Protocol.<sup>109</sup>

### **8. NCI/IOM Survivorship**

In 2002, Ferrell et al. were asked by the Institute of Medicine and National Cancer Policy Board to prepare a report of the status of nursing care related to cancer survivorship. This included analysis of the roles of oncology nurses in improving the quality of care for cancer survivors through several research activities. A content analysis of textbooks, journals, and key documents, surveys of graduate oncology nursing programs and the Oncology Nursing Society's Survivor Special Interest Group; review of the nursing licensure exam and oncology nursing certification, review of undergraduate and graduate nursing standards and review of currently funded nursing research was conducted. Ten critical content areas of cancer survivorship were used for the analysis: description of the population of cancer survivors, primary care, short- and long term complications, prevention of secondary cancer, detecting recurrent and secondary cancer, quality of life issues, rehabilitative services, palliative care and end-of-life care, and quality of care. The key content of the five texts was reviewed. The most prevalent survivorship content areas present in all the books were primary care and quality of care. Each of the texts contained information regarding QOL issues, stressing the important role of the nurse in caring for patients across the physical, psychological, social and spiritual domains. A total of 148 articles in the 2001 volumes of three leading journals were also reviewed. The most common themes discussed were primary care and QOL issues, demonstrating the unique link between nursing care and QOL issues after diagnosis and primary treatment. The results of the journal review reflect the similar strengths and deficits apparent in the text review. Although findings with each source indicated significant information related to the roles of nurses in caring for cancer survivors, deficits were also identified. Review of key literature and resources suggests significant contribution by oncology nursing over two decades to the area of cancer survivorship.<sup>78</sup> This project documents the need for developing model interventions to begin addressing gaps in usual care.

#### **Education and Training Experience**

The COH investigators have an extensive record of education and training in areas of pain, quality of life, and end-of-life (EOL) care. Following is a brief summary of their related experience:

1. The Department of Nursing Research and Education, under the direction of Dr. Grant, has a long history of conducting community-based programs for cancer nursing.<sup>79</sup> Community-based education began in the late 1980s as the department received multiple requests for education on cancer nursing care from nurses in community hospitals where skilled oncology nurses were unavailable. Classes such as Basic Oncology, Chemotherapy, and Vascular Access Devices were

developed from materials original created for City of Hope nurses. In 1989 instructors from the department provided one to two hour classes at twenty-one institutions over a nine-month period of time, with 1,175 nurses attending (with 113 more than once). The department was established as a resource for cancer nursing classes and nurses from the community became willing to come to City of Hope to attend classes. By 1993, over 700 nurses from other institutions attended cancer nursing classes at City of Hope.<sup>79</sup>

2. The demand for pain management courses of increased depth and length was recognized and led to the development of multi-day courses for nurses. The Pain Resource Nurse (PRN) Training Program was implemented in 1992 by Drs. Ferrell and Grant and involved a structured educational program on pain content to prepare one COH staff nurse on every unit and on every shift to function as a resource and role model for nursing assessment and intervention in pain management. Because of the success of the program, it has been extended to include nurses from COH and the community and repeated annually since 1992 with an average attendance of 150 nurses per course. Results of the first year of the PRN program were published in the *Journal of Pain and Symptom Management*.<sup>80</sup> The program has been replicated in more than 80 institutions across the country and the 13<sup>th</sup> course was held at COH in September, 2004.

3. A completed study by Drs. Grant and Ferrell supported by NCI was "Cancer Pain Management Course for Nurse Educators" (R-25CA 57882, conducted from 1992-1996). The purpose of this course was to provide pain management knowledge and related teaching approaches to undergraduate nursing school faculty. Programs were held for 86 competitively selected nurse educators from 86 different undergraduate nursing schools representing 42 states. Pre-course requirements included faculty demographics, pain management audits, pain curriculum evaluation, faculty knowledge and attitudes related to pain (K&A), and student K&A. A total of 1,635 undergraduate nursing students participated. Students' scores revealed major deficits in pain knowledge and attitudes. Curriculum surveys revealed a need for increased pain management content in the curricula of participating schools. Comparison of participants' pre- and post-program goals illustrated that participants moved from increasing their own knowledge (pre-course) to implementing curriculum changes in their individual institutions (post-course). Analysis of four and nine-month follow-up of goals revealed similar trends. Participants' pre- and post- K&A revealed improved scores following the program.<sup>81-84</sup>

4. Dr. Grant's study funded by the National Cancer Institute (NCI) titled "Improving Clinical Practice in Cancer Pain Management" provided three-day courses conducted by nationally recognized experts in pain management within a framework of Continuous Quality Improvement. Competitively selected participants were drawn from hospitals, ambulatory care, physicians offices, and home care settings across the country. A total of 144 nurses from 144 institutions representing 40 states attended the courses. Institutional commitment was fostered through required letters from the chief nurse, chief physician, and the CEO. Pre-course requirements included pain K&A surveys from participants and a minimum of 20 staff from their institutions, chart audits from each institution, and a description of the institution's current pain program. Post-course requirements included immediate post-course K&A by participants, 12 month-post-course K&A from both participants and their staff, and 12-month evaluation of participants' goal implementation and changes in the institution's pain program. Improvement in participants' pre- and post K&A surveys revealed significant increases in knowledge. Goal refinement during the course revealed a change in focus from improvement of participants' own knowledge to the need to improve knowledge and skills of those in their institutions. Goals achieved within the first 12 months post-course focused on improving assessment of pain management, education of professional staff, and developing ways to evaluate the success of implementing pain standards. Results have been published and presented at a number of conferences.<sup>85-87</sup>

5. Dr. Ferrell directed a training program funded by NCI for “Patient and Public Education in Cancer Pain Management” (R-25-CA77189, 1999-2002). This program included 3 national conferences to assist institutions with improving patient/public pain education. Originally intended for only 50 participants per course, the first course announcement resulted in 180 applicants from 40 states. A supplemental grant was received which provided 148 individuals opportunity to attend the first course in January, 2000. The second course held in October, 2000 filled to capacity without a mailing or course announcement from those on the waiting list or who have heard about the course from the first participants. Follow-up evaluation from the program rated the overall course effectiveness at mean = 4.84 on a scale of 0 = low to 5 = high. The third and final course was held in October, 2001. A paper based on this project was published in the *Journal of Pain and Symptom Management*.<sup>88</sup> Patient teaching materials from this project are widely disseminated through our Pain/Palliative Care Resource Center.

6. Parallel to the pain management courses were a series of courses focused on end-of-life care. The first project, HOPE: Home care Outreach for Palliative care Education, began with a one-year pilot project from 1996 to 1997 funded by the Project on Death in America which developed and tested a curriculum to improve end of life (EOL) care in home care.<sup>89</sup> This program was then extended for the time period of 1998-2002 through a training grant funded by NCI with Dr. Ferrell as P.I. which provided further implementation of the HOPE curriculum and a national trainers conference. The content of the HOPE curriculum covers five modules of general palliative care principles, pain management, symptom management, family/communication and care at the actual time of death. Through the NCI funded project, the HOPE curriculum was extensively revised and implemented in 5 additional agencies with 153 participants completing the training. The HOPE curriculum was further disseminated through a national conference attended by 50 home care agencies held in March, 2001. This project concluded in March, 2002.<sup>90</sup>

7. A major EOL care project involved a grant funded by the Robert Wood Johnson Foundation from 1997-2000. This project, “Strengthening Nursing Education in End-of-life Care”, involved several strategies for improved nursing education. A major activity of this project involved review of more than 45,000 pages in 50 major nursing textbooks for content across nine EOL topics.<sup>91</sup> The final analysis revealed that only 2% of textbook content was related to EOL care. A parallel project done by medical investigators in collaboration with the COH found almost identical results in medical texts.<sup>92</sup> This project also involved working with the National Council of State Boards of Nursing to improve EOL content in the nurse licensure examination, collaboration with several national nursing organizations and surveys of nurse educators and clinicians regarding EOL care.<sup>93,94</sup> This project led to the development of the ELNEC project described below. This project has resulted in several publications.<sup>110-112</sup>

8. The next project, the End-of-life Nursing Education Consortium (ELNEC) is a comprehensive national effort led by Drs. Ferrell and Grant to improve EOL care by nurses. This 3½-year effort, which began February 2000 and concluded in July 2003, entails the partnership of the American Association of Colleges of Nursing and COH to coordinate national nursing efforts related to EOL issues. The ELNEC project is also supported by an Advisory Board including multiple nursing and health care organizations. Faculty attending the five undergraduate courses totaled 550 from 543 schools teaching undergraduate nursing students and represented all 50 states plus Washington DC, Virgin Islands and Puerto Rico. Eight courses were also conducted targeting continuing education for practice nurses. Follow-up evaluation averaged over these five courses rated the overall course effectiveness as 4.9 on a scale of 0 = low to 5 = high. Numerous papers have been published from the ELNEC project.<sup>95-97</sup>

9. The final project, Dissemination of End-of-life Education to Cancer Centers (DELEtCC) is a comprehensive, interdisciplinary project aimed at improving EOL care in cancer centers. Led by Dr. Grant, the primary objective of this proposal is being achieved through annual workshops for

two representatives each from 75 cancer treatment centers. Funded by the NCI in June, 2001, the first course was held in June, 2002 *followed by courses in April 2003 and 2004*. A total of 279 participants representing 140 institutions have attended. Content includes topics identified through the ELNEC project expanded to include aspects of change related to institutional commitment, and a framework of continuous quality improvement.<sup>98</sup> Participants are selected from two tiers of staff at cancer centers: Tier 1 consists of nurses, social workers, administrators, and physicians, and tier 2 consists of clergy, pharmacists, psychologists, rehabilitation professionals, and unlicensed personnel. An extensive evaluation provides analysis of goals achieved and barriers experienced by participants and forms a basis for the continuing education of health care professionals beyond the project period.<sup>99</sup> *Findings to date have been presented at several national conferences.* (113-117)

In summary, the above studies illustrate the investigators' wide range of experiences related to this proposal. The investigators have a well-established record of educational research including topics of pain management, knowledge and attitudes regarding pain, institutional barriers related to changing practice as well as pain and quality of life issues. Drs. Grant and Ferrell have worked together for 11 years and have benefited from these and numerous other experiences in conducting national oncology training programs. These previous studies will contribute to the proposed content of the program and will build on the investigators' experiences in conducting and evaluating educational programs. The proposed collaboration with the multidisciplinary faculty compliment this record of education and research. For patients with cancer, professional staff in cancer centers need access to this education and should be the leaders in their communities for further dissemination of the education.

#### **D. Cancer Education Program Plan**

The overall purpose of this Cancer Education program is to develop, implement, evaluate and disseminate a cancer survivorship curriculum aimed at improving the quality of care and the quality of life of a cancer patients. The background for this project is found in the Background and Significance (B) and the specific objectives of the course are found in Appendix A. Components within the following framework shaped the development if this proposal.

**1. Program Direction** The PI and program leader, Marcia Grant, RN, DNSc, has an extensive record of education and training in the areas of pain, quality of life, end-of-life care and survivorship. She had directed the Department of Nursing Research and Education at the City of Hope National Medical Center since 1986 and is Co-Director of the Cancer Center Program, along with the Cancer Center Director Ted Krontiris, MD, PhD, entitled Clinical, Genetic, and Psychosocial Determinants of Cancer Risk and Outcomes. She has worked with the Co-Investigator, Betty Ferrell, RN, PhD for over 15 years. Multiple courses, local and national, have been conducted with dissemination of results through publications, monographs, websites, curriculum distribution, and presentations. Previous courses following a similar format on pain management, end-of-life and palliative care, have been consistently over-subscribed and successful in relation to changes implemented in participants' settings. Dr. Grant's educational leadership and management is illustrated in her receipt of the 2003 Oncology Nursing Society Mary Nowotny Excellence in Cancer Nursing Education Award.

#### **2. Proposed Cancer Education Program**

##### **a. Framework**

The need for this training program is based on the recommended objectives of the National Cancer Institute 2004 Plan and Budget Proposal. Cancer Survivorship is identified as one of the areas of Extraordinary Opportunity.<sup>2</sup> Within the 6 proposed objectives, is one that focuses on the need to develop and disseminate new interventions and best practices. Health care professionals taking care of cancer patients need the information on the best practice guidelines currently available for follow-up care, surveillance, monitoring cancer survivors and providing effective

psychosocial and supportive care.<sup>101</sup> Without the initial step, knowledge of what is currently known about cancer survivors, their long-term health care needs, and the resources currently available, application to individual cancer centers cannot occur.

The call for increased research on cancer survivorship will produce increased scientific knowledge that will stimulate changes in health care service and build new programs. Meanwhile, dissemination of what is currently known is essential and is proposed to be accomplished through the current proposal for continuing education workshops for interdisciplinary teams from cancer centers.

Armed with this new information, participants next face the challenge of introducing change in their institutions. Their responsibility will include providing education to their colleagues, disseminating information to administrators, and implementing new ways to deliver quality cancer care to survivors. Our proposal includes experts in the field, using appropriate teaching methodologies and addressing methods for changing practice to provide such information.

The framework selected for meeting this educational need has three components: changes in practice, principles of adult education and selection of the education content for quality care for cancer survivors. Each of these components provides direction in the development and implementation of this project.

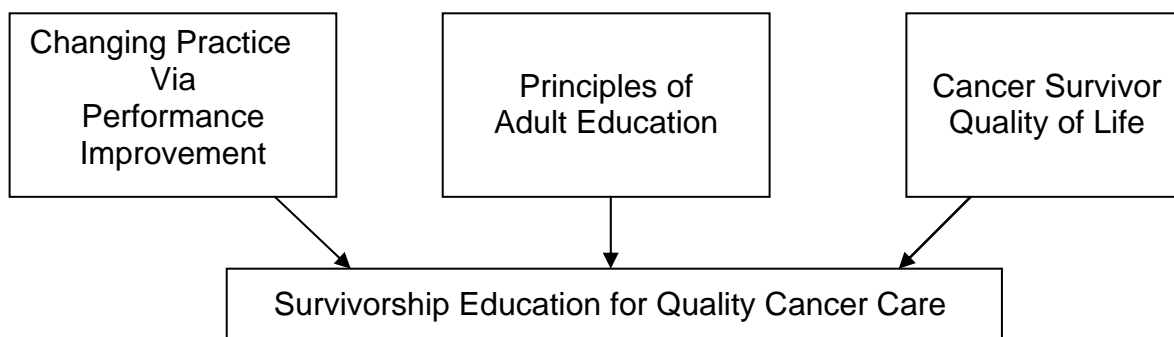


Figure 1 - Framework

### **Changing Practice Via Performance Improvement**

Changing care in clinical settings is a major challenge. Our previous efforts in conducting courses and workshops to educate professionals to change pain management practices have identified several approaches that we feel are essential.<sup>87,102,103</sup> Commitment by the participants and the institutional are needed. For participants, several activities are have assisted in this commitment. Participants were required to submit precourse data, describing their institution's program and identify written goals for changing clinical practice in their individual institutions. Continued commitment of participants following course completion was fostered by follow-up evaluations of goal achievement at periodic intervals, and completion of interviews. Institutional commitment was obtained by requiring letters of support *as well as follow-up evaluation* from the participant's administrator, chief of staff, and the nursing executive. For the proposed project these same methods will be applied and related to providing quality care for cancer survivors.

To further assist participants in changing cancer survivors' care, a performance improvement (PI) approach will be used. PI is used in the health care setting as a strategy for evaluating, changing, and improving systems of care. This approach is derived from the work of W. Edwards Deming, a leader in transforming organizations.<sup>104</sup> PI is advocated by the Joint Commission on Accreditation of Health Care Organizations, and will be familiar to the administrators at participants' institutions. PI provides a mechanism for improving cancer survivors' care that is advantageous for patients as well as the institution.

PI involves a cyclic approach to improving clinical practice by assessing the problem, planning an approach, implementing the approach, and reassessing the problem. The PI aspect of

the framework directs the need to assess current institutional practice and activities for survivors, plan activities to improve care, implement the approaches and evaluate the impact of the change. This assessment and reassessment can include changes in the care patients receive. The PI approach will be referred to throughout the course to assist participants in identifying and refining their post-course goals. *Specific presentations addressing PI application to the current project are identified in the agenda and presented by Dr. Marilyn Bookbinder.* The PI approach will be used in participant follow-up to demonstrate goal achievement in the participants' institutions. *Evaluation of PI activities by participants will include both qualitative and quantitative approaches described below under the Cancer Education Evaluation Plan.*

### **Principles of Adult Education**

The education component of the framework will provide guidance to the selection of course content and methods. Assumptions about adult learning are based largely on the works of Knowles.<sup>105</sup> He views adult learners as self-directed, having a resource of life experience, being ready to learn, and concerned with solving problems. The adult learner needs immediate application of knowledge rather than delayed application. These principles of adult learning will be emphasized in faculty preparation and used to plan appropriate education methods for the overall courses and for the curriculum dissemination during the final year. Teaching methods planned will vary dependent upon the content and include lectures for new information, discussion sessions for sharing and clarification, case studies and use of the case method, as well as demonstration and role playing. It is anticipated that participants will implement educational activities at their own institutions. Therefore, participants will be provided with multiple learning resources including lecture notes, slides, and other educational tools. Course content will include providing participants with the principles of adult education so that they can apply them as a foundation for facilitating, planning, and developing educational projects at their specific institutions.

### **Cancer Survivor Quality of Life**

The background material condensed for this proposal organized what is currently known about health issues for survivors into four dimensions: physical well-being, psychological well-being, social well-being, and spiritual well-being. Content in the agenda is organized around these four dimensions, with expert faculty presenting the state of the science lecture on each dimension. This will be accompanied by descriptions of models of excellence currently available across the country.

Because the quality of care for cancer survivors is an emerging area of concern for both health care providers and patients, each speaker and each participant will be provided with the statement by the National Coalition for Cancer Survivors statement of Quality Cancer Care – Declaration of Principles. These are identified in Table 1.

**Table 1**  
**Quality Cancer Care - Declaration of Principles**

1 <sup>st</sup> Principle	People with cancer have the right to a system of universal health care.
2 <sup>nd</sup> Principle	Quality cancer care should be available in a health care system whose standards and guidelines are developed in consideration of treating the whole person with cancer.
3 <sup>rd</sup> Principle	Standards of cancer care should be driven by the quality of care, not only by the cost of care.
4 <sup>th</sup> Principle	All people diagnosed with cancer should have access to and coverage for services provided by a multidisciplinary team of care providers across the full continuum of care.
5 <sup>th</sup> Principle	People with cancer should be provided a range of benefits by all health care plans.

6 <sup>th</sup> Principle	People with histories of cancer have the right to continued medical follow-up with basic standards of care.
7 <sup>th</sup> Principle	Long-term survivors should have access to specialized follow-up clinics.
8 <sup>th</sup> Principle	Systematic long-term follow-up should generate data that contribute to improvements in cancer therapies and decreases in morbidity.
9 <sup>th</sup> Principle	The responsibility for appropriate long-term medical care must be shared by cancer survivors, their families, the oncology team, and primary care providers.
10 <sup>th</sup> Principle	The provision of psychosocial services must be safeguarded and promoted.
11 <sup>th</sup> Principle	Psychosocial research is integral to comprehensive cancer care and, as such, psychosocial outcome measures should be included in all future clinical trials.
12 <sup>th</sup> Principle	Cancer survivors, health care providers and other key constituency groups must work together.

Clark, E.J., Stovall, E.L., Leigh, S., Siu, A.L., Austin, D.K., Rowland, J.H. Imperatives for Quality Cancer Care: Access, Advocacy, Action, and Accountability. 1996 National Coalition of Cancer Survivors, pg 7-8.

In summary, the framework provides directions for change (PI), guidance for teaching (adult learning principles) and an approach for selection of content (Cancer Survivor Quality of Life).

#### **b. Content and Scope of Educational Activities**

The objectives for this course on quality cancer care for cancer survivorship are found in Appendix A. These objectives have been derived from current literature in cancer survivorship and the numerous documents included in the background section. The content and scope of the education addresses the key issues that have been identified by major cancer organizations in recent years in establishing future needs for cancer survivors. They are consistent with the perspective of the National Coalition of Cancer Survivorship as a consumer body as well as the leading professional organizations in cancer care.

The proposed agenda for the course is included in Appendix B. The agenda includes an intensive three-day training course. The course is organized around the four dimensions of quality of life for cancer survivors including physical, psychological social and spiritual well-being which has been described above in the Background and in the Framework sections. The agenda addresses both adults and pediatric cancer survivors. Each of the major dimensions of quality of life is presented by first presenting a "State of the Science Lecture" on the QOL domain by a national leader. The lecture is followed by a session titled "Models of Excellence" to provide participants with role models of cancer researchers and clinicians who are already providing quality care for cancer survivors. Great attention has been given to providing current knowledge and state of the art science in the field while also providing clinically relevant, practical information to assist the participants in their implementation of goals when they return to their settings.

**Table 2**

#### **Comparison of Goals Before and After Implementing Content on Goal Refinement and Quantification**

<b>Before Sessions</b>	<b>After Sessions</b>
<p><i>To increase the level of comfort of health care providers in providing effective pain management</i></p> <p><i>In conjunction with the Ethics Committee, assist in promoting the patients' right to self-determination regarding end-of-life choices</i></p>	<p><i>In 6 months a smoother transition to hospice will be achieved as evidenced by the increase in referrals by 20%</i></p> <p><i>In 12 months, 50% of all patients will have an up-to-date advanced directive in the patient's chart.</i></p>

Across the three days of the course, networking is encouraged in a variety of ways to facilitate learning by the participants from each other. With permission from the participants, a list of names, address, emails etc. will be assembled and distributed. The participants will also be invited to bring poster exhibits or hand out materials from their own facilities to share with the other participants. All the faculty will be encouraged to attend the entire course so that they will also be available on an individual basis with participants.

An additional method of reinforcement for all participants after completing the course will be the creation and mailing of a newsletter on a quarterly basis for one year following the course. The purpose of the newsletter is to continue to share new resources, keep participants aware of the activities of their colleagues and to assist them with their goal implementation. This newsletter reinforcement has been extremely successful in previous City of Hope educational programs. A website will be created to provide information about *upcoming* courses and provide access to the application. Following each course, participants will have access to protected areas of the website where they can download speaker slides for dissemination of information they can utilize in their institution, pose questions for other participants, faculty and investigators to respond to, and have access to additional resources as they become available. This method has been very successful in the implementation and follow-up for the DELEtCC courses. Participants will also be encouraged to access the City of Hope Pain/Palliative Care Resource Center website (<http://lprc.coh.org>) which is a national clearinghouse for pain and palliative care information and also has many resources relevant to cancer survivorship. The PRC has more than 400 materials of which 300 are available *free of charge* on the website. Examples of websites and newsletters from our current courses are found in Appendix G.

### **c. Proposed participants**

Participants will be recruited from NCI-designated cancer centers and community cancer centers from across the United States. Mailings will include marketing materials to NCI-designated cancer centers and community cancer centers. Currently, there are 53 clinical and comprehensive cancer centers funded through the NCI Center mechanism. The mailing list for community cancer centers will be obtained from the Association of Community Cancer Centers (ACCC). This organization was founded in 1974 and is a national interdisciplinary organization that focuses on defining quality care for patients with cancer and continually improving oncology care. Membership is by organization, with *more than 650* institutions in 2004. ACCC estimates that members of their organization see approximately 40% of all new cancer patients. Membership includes all members of the cancer care team: physicians, program administrators, nurses, social workers, and data managers. We have used their mailing list in previous pain management course and end-of-life courses. Participants from these organizations have been eager to attend, and successful in implementing goals for changing care of patients. The ACCC journal, *Oncology Issues*, published 6 times per year, as well as their annual meeting will provide avenues for advertising the course as well as disseminating results of this project.

A total of 100 participants from 50 institutions will be selected for each three-day course. Participants from NCI-designated cancer centers will be given priority each course, with additional spots coming from the ACCC membership. The availability of the audience can be assured from our past records of course applicants. For our previous pain courses which focused on clinical settings, a total of 244 applications were received, for a total of 144 positions (44 in year 01, 58 in year 02, and 42 in year 03. The project budget had provided for only 40 positions per year. Additional resources were needed for additional participants). In the project on Patient and Community Education in Pain Management, first year applications equaled 180 from 40 states. Because only 50 positions were available, supplemental funding was sought, and 148 applicants were accepted. Equal or increased enthusiasm is expected for the course on cancer survivorship. The enthusiasm of our potential speakers is reflected in their letters of support (Appendix D).

When contacted, many commented on the timeliness of this course and how well it fits with the current focus on cancer survivorship. All previous courses have been consistently filled to capacity. We have designed the course for 100 participants with two attendees present from each institution. We feel this is the maximum we can accommodate and still implement the principles of adult education, and provide follow-up evaluations from 50 institutions per course.

The applicants may be nurses, physicians, and administrators as tier 1 and social workers, pharmacists, psychologists, rehabilitation specialists, clergy and unlicensed personnel as tier 2. Each institution can apply with one or two members from tier one, and a maximum of one member from Tier 2. The rationale for this selection process is to provide access for personnel involved in leadership roles of the institution and who may be influential in producing changes in patient care. Our previous experience with pain management education has demonstrated the value of two people from one institution.<sup>103</sup> The application form will include information on the experience of the applicants in caring for patients with cancer and their participation in the institution's PI process.

#### **d. Recruitment and Retention of Participants**

A total of 400 participants, representing 200 institutions (100 participants from 50 institutions for each of four courses), will be competitively selected from submitted applications. Prior to each course, announcements will be mailed using lists obtained from the National Cancer Institute (NCI) and the ACCC. Announcements will also be made regarding the application process in various journals (Oncology Nursing Forum, Oncology Issues, Cancer Nursing, Cancer Practice, Cancer, Journal of Clinical Oncology, Journal of Pain and Symptom Management, and Oncology Management). The application will include information on both applicants as well as the institution. The packet will also require two letters of support from the cancer center medical director, the nursing administrator, or the institution's administrator (or a comparable position). These letters will assist with institutional commitment which is needed if successful changes to clinical care are to be made. The letter will also identify who to contact for evaluation at 6, 12, and 18 months. Institutional commitment has been effective in assisting participants in our previous courses – the Mayday funded Institutional Commitment to Pain Management, our NCI funded faculty educator courses on pain management, our courses on pain management for clinical institutions, *and our current courses on end-of-life care*. This commitment has enabled the participants to implement their goals to improve care in their institutions. The application packet also identifies the participants' role in providing pre-course data. These requirements have been effective in our other courses to identify participants who will be active, committed, and effective in changing clinical practice in their own settings. Applications will be reviewed by the investigators using the Application Evaluation Checklist (Appendix E). These review criteria will provide priority for participants in NCI-designated cancer centers, minority candidates, geographic distribution, access to minority populations, and representation from each of the multidisciplinary professionals identified in Tiers 1 and 2.

Plans have also been developed to recruit and train ethnic minority participants or those who work in minority institutions. A minimum of 30% of the participant spots will be reserved for minority participants or those from minority serving institutions. The application form in Appendix E includes data for these decisions. Additionally, the investigators will promote the application by individuals representing minority-serving institutions through the marketing efforts of the course including mailing to minority professional organizations (such as the African American Nurses and Hispanic Nurses Associations), hospitals and agencies in predominant minority settings, and announcements to other groups such as previous participants in the Oncology Nursing Society (ONS) education courses and the multicultural special interest group of ONS. All participants will be encouraged to develop goals which target minority populations through several means including the program session on minority issues, asking all speakers for all sessions to address minority

issues, and reinforcements with special content on this topic through the website and the reinforcement newsletters.

Prior to attending the course, selected participants will be required to complete and submit the pre-course evaluation materials as described in the evaluation section below. A candidate's failure to complete pre-assessment materials will result in his/her replacement by an alternate. Participants will be required to bring three institutional goals with them.

Retention will be fostered through 1) website notification to past participants providing additional resources 2) regular follow-up contacts with participants 3) regular contacts with administrators from each institution, and 4) networking among participants.

#### **e. Potential Benefits to Cancer Patients**

The project is designed to improve the care of cancer survivors. It is intended to provide up-to-date information on quality of life issues facing cancer survivors, and present examples of approaches cancer centers have used to support cancer survivors. Issues of health care access and follow-up care will also be addressed. Participants will be drawn from the interdisciplinary teams involved in the care of cancer patients, and include administrators, physicians, nurses, social workers, pharmacists, psychologists, rehabilitation professionals and unlicensed personnel. The challenges involved in caring for cancer survivors are imbedded in issues of health care costs. To address this important problem, presentations will address reimbursement procedures, using institutional resources already in place, and becoming familiar with the many community resources already established.

This innovative program focuses on personnel in cancer centers, whose position in their communities includes modeling the best care available for patients. A total of 400 participants from 200 cancer centers will participate in one of four courses. The targeted cancer centers, 53 NCI designated clinical and comprehensive cancer centers, and the *more than 650* institutions that are members of ACCC, provide care to a substantial number of cancer patients, with the 650 seeing approximately 40% of all new cancer patients. Combined with the NCI cancer centers, our training could reach institutions which provide care to over 50% of all cancer patients. Additional broad dissemination methods will be used to provide for nationwide distribution to other settings.

Course content will include the framework (PI) for changing clinical practice and using adult education principles. Course content will be shaped by the model of quality of life for cancer survivors where patient and family needs are easily evident.

A strong evaluation plan and opportunities for dissemination following completion of the project further strengthen the potential benefits to cancer survivors. Each institution will be implementing goals once participants have completed the course. Their leadership in their communities for survivorship care will benefit theirs as well as other institutions caring for cancer patients.

#### **4. Cancer Education Evaluation Plan**

To evaluate the success of this Survivorship Education for Quality Cancer Care, an extensive evaluation plan has been developed based on the experience of the investigators in educational programs as well as from their research. This plan is described below in relation to 1) the components of the educational plan (curriculum, individual participants, participant teams' institutions) 2) the evaluation instruments and when data are collected, and 3) and by the overall project aims. Data used for evaluation are derived from pre-course materials starting with the participants' applications and continuing through the 18 months following each course (except for the 4<sup>th</sup> course, when follow-up ends at 12 months). The components of the evaluation focus on the curriculum content initially, and include the development of the content as well as the evaluations received at the end of the course by participants (course evaluations) and by faculty (Faculty Debriefing forms). Another component of the evaluation of the curriculum will be the evaluation of website activity by participants following the course, as well as requests for the PPRC for any

reprints, standards, and other materials. The second focus of the evaluation is on the individual participant. This evaluation will involve descriptions of the participants using application information, letters of support, goals (pre-post and follow-up and achievements). Goal analysis is described below where the goal evaluation tool is described. The third focus of evaluation is on the team and the agency. Descriptive data from the application will be used to categorize participating institutions. In addition, an institutional assessment and an institutional survey will be completed before the course, 12 and 18 months post course. Analysis will evaluate institutional changes in relation to survivorship resources, services, and access. A number of evaluation tools have been created specifically for this project. Some of the evaluation tools have been used in other courses. All tools will be pilot tested while the curriculum revisions are occurring (month 5). The evaluation includes the process, outcome and impact of the program. In addition, the focus of the evaluation is on the participant, the nature of the team from each institution and the changes that have resulted. *Table 3* identifies the evaluation plan by type and target of the evaluation. Each tool is described next. *Table 4* identifies the time evaluation is conducted for each course.

**Table 3 - Evaluation Plan**

	<b>Process*</b>	<b>Outcome**</b>	<b>Impact***</b>
<b>Curriculum Content</b>	Module Evaluation Form	Faculty Debriefing Form	
	Course Evaluations	Administrative Evaluation	Website Activity PRRMC I Requests
<b>Individual</b>	Agency Application		
	Pre-course Goals	Post-course Goals	Goal Follow-up and Evaluation
	Letters of Support	Administrative Evaluation	Administrative Evaluation
			Participant Goal Achievement Interview
<b>Team from Each Individual Institution</b>	Agency Application	Post-course Goals	Administrative Evaluation
	Agency Application	Administrative Evaluation	Administrative Evaluation
	Pre-course Goals	Post-course Goals	Goal Follow-up and Evaluation
	Institutional Assessment		Institutional Assessment
	Institutional Survey		Institutional Survey

\*Process = Pre or during course;\*\* Outcome = Immediately post-course;\*\*\*Impact = 6, 12, and 18 months after course

**Agency Application:** (Appendix E)

This tool provides descriptive data about the agency and an assessment of interest and current status care for cancer survivors. It is modified from our HOPE and DELEtCC projects. It is completed by a Cancer Center administrator in collaboration with the two institution applicants. The application provides data on the discipline of the applicant, experience of the participants, and characteristics of the institution. Two letters of support are included in the application from the Director of Nursing/Patient Care Services, Chief of Staff/Medical Director, or an Institution Administration representative. These letters of support are used to capture commitment and support from the institution and will be used as a baseline of enthusiasm for institutional change. Data will be used for individual and team process and for institution outcome evaluation. It will be

used to characterize participants and institutions and allow for comparison (type of discipline involved, large vs. small institutions, etc.).

**Application Evaluation Checklist:** (Appendix E)

This checklist is used by the City of Hope team of co-investigators to evaluate the applications received. It addresses geographic location, ethnicity of the cancer population, leadership experience of the applicants, and several other aspects. It is used to screen those not eligible and provide data for prioritizing applications for invitation to the course. We are currently using a parallel form for processing DELEtCC applications.

**Module Evaluation Form:** (Appendix F)

This form is used by the investigators and by the Faculty in evaluating the content for each presentation. It provides for expert content review. The form provides for an accounting of all the required components of the module (case studies, resource list, etc). Data are used to evaluate the curriculum content for process. It will be used along with the Faculty Debriefing Form to evaluate curriculum content prior to and after each course. Revisions for curriculum content will be made for each course based on information from this instrument, consultation between the faculty and the investigators and an updated literature search before implementation of the next course. This module content evaluation includes checking module content to make sure minority and ethical/legal issues are included.

**Institutional Assessment Tool:** (Appendix F)

This tool is a self-rating instrument for providing organizations with information about the possible survivor services and resources available at an institution. Data are used to evaluate institutions for process and impact and will be carried out pre-course and at 12 months.

**Institutional Survey:** (Appendix F)

This tool is used to identify participants' evaluation of their own interest in making institutional changes as well as their view of the institutions readiness for change. It is submitted with the agency application and at 6, 12, and 18 months. A parallel form is currently being used with our current courses.

**Course Evaluation:** (Appendix F)

This evaluation form has been used extensively by the COH Education Department. It provides evaluation from the participants on the actual course for each day. Data are used to revise subsequent courses and in determining the content most valuable to the participants. Data are used to evaluate curriculum content for process and teaching methods.

**Final Goal Form:** (Appendix F)

The investigators have learned the value of training programs which are based on the establishment of individual goals submitted and committed to by participants. The use of participants' goals pre-course and evaluation of the goals following the course is consistent with adult learning principles. Participants will be asked to work as an institutional team of two to establish goals prior to coming to the course. During the three-day course, goals will be refined and revised as ideas from discussion and networking lead to more specific ideas and strategies for implementation. Participants will be asked to include the target audience in the goal (which health professionals at the institution), method of education if applicable, and connection with the institution's quality improvement program.

**Administrative Evaluation:** (Appendix F)

This tool will be mailed to one of the designated administrators (Director of Nursing/Patient Care Services, Chief of Staff/Medical Director, or an Institution Administration representative). The selection of the administrator to contact will be made by each agency. Questions focus on whether or not the administrator perceives the course content and local implementation appropriate. Information will also include the leadership skills and change agent abilities of the course participants and their fit with the agency. Questions also provide data on institutional changes that

may affect survivorship issues. Data are used to evaluate the individual and the institution for outcome and impact, and the curriculum content for outcome.

**Faculty Debriefing Form:** (Appendix F)

This form will be completed by faculty following the course. It will provide data on the course materials for ease in use, completeness, etc. It will ask for comments regarding teaching methods used.

**Goal Follow-up:** (Appendix F)

This tool will be used by the investigators at 6, 12 and 18 months post-course to evaluate goal achievement by participants. Goal analysis will be conducted allowing for differences across institutions. Some institutions may have no identified services for survivors, others may have some services, and still others may have established programs. Participants will be submitting and refining throughout the course, 3 goals per team. Achievement of these goals, as well as others identified and implemented will be done 6, 12, and 18 months post course. *Goal analysis will include both qualitative and quantitative approaches. Qualitative analysis will involve content and categorization into structure, process, and outcome components of performance improvement.*

**Goal Evaluation Tool** *Quantitative analysis will involve analysis goal achievement in terms of percentage achievement on patient outcome goals. Each goal will be evaluated at 6, 12, and 18 months post course. A percentage achievement will be calculated based on what change was identified in the goal over what time period. Each goal will be scored separately, and a mean score of percentage achievement across all three goals will also be calculated. Aggregated data across institutions will reflect an average percentage achievement across all institutions. Quantitative analysis will identify which goals are implemented most commonly across institutions, and which goals meet the most resistance to implement. Data will be used for individual, team, and institutional assessment for process, outcome and impact.*

**Patient Satisfaction** (Appendix F) *Participants will be expected to conduct patient satisfaction surveys on a limited and specified group of patients that are expected to benefit from the implementation of goals at individual institutions. Participants will be expected to survey a minimum of 30 patients before and after goal implementation (30 is the minimum number recommended by JCAHO for PI studies). The survey used can be adapted from the generic patient satisfaction tool (Appendix F) or a similar patient satisfaction tool used at their institution. Analysis will involve a comparison of pre and post satisfaction scores for each institution. Scores will be converted to percentages so that aggregated findings across institutions may be analyzed.*

**Table 4 - Evaluation Components by Time Period**

Instrument	Pre-Course	Course Day 1, 2, & 3	Immed . Post-Course	6 Months	12 Months	18 Months	Prior to Goal Implemen tation	6, 12, 18 months After Goal Implemen tation
Agency application	X							
Letters of Support	X							
Pre-course goals	X							
Institution Assessment	X				X			
Daily course evaluation		X						
Post-course goals			X					
Administrative Evaluation				X	X	X		
Faculty Debriefing			X					
Goal Follow-up				X	X	X		
<i>Goal Evaluation Tool</i>				X	X	X		

Institutional Survey	X			X	X	X		
Patient Satisfaction							X	X

Data from all forms will be coded and entered at the City of Hope. Each institution will receive a report of their own agency data and results from the total group. *Table 5* organizes evaluation instruments by aim.

**Table 5 - Evaluation by Aim**

Aims	Instruments
Create the cancer survivorship curriculum for training an interdisciplinary professional audience from cancer centers.	Module evaluation tool
Implement the survivorship curriculum in national workshops to be competitively selected staff from National Cancer Institute-designated clinical and comprehensive cancer centers, and community cancer centers as identified through the Association of Community Centers (ACCC).	Agency application Course evaluation Faculty debriefing Application Evaluation Checklist
Develop a network of course participants to share experiences in dissemination of the survivorship curriculum to the staff of participating cancer centers.	Website information Newsletter articles Newsletter responses
Evaluate the impact of the survivorship curriculum on participants' and cancer center staffs' implementation of individual goals for improved care for cancer survivors in respective cancer centers.	Institutional Survey Institution Evaluation Goal Evaluation Tool Patient Satisfaction
Describe successes and issues related to dissemination of cancer survivorship care in cancer centers in terms of the characteristics of individual course participants, interdisciplinary teams, and institutions.	Administrative Evaluation Goal Evaluation Tool Patient Satisfaction

### Timeline

The first six months of the project will be used to develop the cancer survivorship curriculum. This will be done through written communication to all faculty, requesting initial submission of course materials. These will then be distributed to all faculty to identify content additions, overlaps, and other suggestions. Curriculum will include a detailed outline of content, references, case studies or examples, policies, standards, and other related material and/or resources. The investigative team (PI, CoIs, and Project Director) will review and finalize all materials, and assist each faculty in preparing slides. The announcements of the course will be sent in month 3, with application forms emailed and mailed as requested. Selection of participants will occur in Month 8 and precourse data due in month 9. The first course will be held in month 10. During the course the participant goals will be finalized. Course evaluation and faculty post-course debriefing will occur at the end of the course. Then 6 months goal follow-up will occur in month 17 and 12 month goal follow-up in month 22. The data collected will be entered throughout. This pattern will continue for all four courses. At the end of the first course, the investigators will develop abstracts, and begin outlining the list of publications. After each course, the curriculum materials will be reviewed and revised as necessary. During the last year, methods for curriculum dissemination will be finalized, as the last evaluations are being carried out. Curriculum materials are anticipated to be disseminated through publications, website materials, and mailings to cancer centers.

### Innovation

This project builds on the investigators background in national courses in pain management and end-of-life care. It is innovative in that it focuses on cancer survivor quality of care and targets cancer centers as models for this care and focuses on the interdisciplinary team.

## 5. Dissemination Plan

Dissemination of this educational endeavor will begin with the completion of the first training program. The investigators will analyze the pre and post-course evaluation data and determine what areas of significant change occur. Results of this evaluation will be used to a) identify materials and approaches to improved cancer survivor care that appear to have a major impact and b) identify teaching methods that appear to be associated with positive changes. These results will be disseminated in several ways. Publications will be prepared for submission to interdisciplinary journals; results will be incorporated into presentations that the investigators carry out at local, state, and national meetings. Previous educational efforts by the City of Hope investigators have resulted in numerous peer reviewed publications and presentations.

Participants who successfully carry out their institutional goals will be encouraged to prepare their results for presentation and publication. *This is occurring now with participants in our ELNEC and DELEtCC courses.* The annual meeting of the ACCC is expected to be an excellent program for these presentations, and ACCC has encouraged us to promote this vehicle for dissemination. We will also use the ACCC website to disseminate results of the courses. Continued dissemination of the positive aspects of this program will occur in the courses taught by the investigators and faculty that are a part of this project. The long-term follow-up after completion of the project is appreciated by the investigators and will be pursued. All course materials will be submitted to Pain Resource Center at the City of Hope for distribution to others.

In recent years, advances in the treatment of cancer pain have resulted in a number of guidelines, standards, and various other resources to improve pain management. In 1995, Dr. Ferrell received support from the Mayday Foundation to establish the Mayday Pain Resource Center (MPRC) to serve as a dissemination point linking resources derived from research, education, and clinical practice to settings where the quality of pain management could be improved. Within the first three years, the MPRC's distribution of resources totaled 41,525 items provided to 19,612 individuals which included reprints of COH pain publications, standards of pain management, patient teaching materials, research instruments, documentation forms, policies and procedures. Materials were mailed to individuals in 35 countries and all 50 states. In 1999, the resource center name was changed to the City of Hope Pain/Palliative Care Resource Center (PRC) to include palliative care resources. Participants of this proposed project will have access to the PRC and these resources will assist participants to improve EOL care in their institutions. An initial evaluation of the PRC project was completed and published in the *Journal of Pharmaceutical Care in Pain and Symptom Management*.<sup>100</sup> The PRC became available on the Web effective January 1, 1998 (Appendix G). Website visits have increased from 36,670 in 1999 to over 440,000 in 2003. More than 495 materials or links are listed on the website (<http://prc.coh.org>) which is updated monthly. The PRC serves as a dissemination vehicle for all COH education programs.

An additional website was built for DELEtCC and provides resources to foster communication among course participants, provide updated information, and disseminate PowerPoint presentations from course speakers (Appendix G). Since the website opened in 2002 we have had many past participants access speaker slides, other resources and pose questions to other participants and staff. Future participants use the website to obtain information about upcoming classes and obtain directions and forms for applying to a course. *A similar website will be created for the Survivorship project participants.*

*In summary, the investigators have planned to implement four courses for 2 participants from each of 50 cancer centers, for a total of 200 institutions and 400 participants. Dissemination will occur not only in the cancer centers participating, but in the communities in which the centers are located, as expertise in cancer survivor care is demonstrated and shared. The strong team of investigators and faculty provide a foundation for successful implementation of this program in cancer centers for improving survivor care for cancer patients nationwide.*

#### **6. Statement of Institutional Commitment**

Institutional Commitment and plans to continue implementation of educational content will be evident in the City of Hope National Medical Center as well as tracked through every institution attending the education courses and implementing institutional changes in quality care for cancer survivors. This will be indirect through the analysis of goals at 6-months, 12-months, and 18-months following the course. Analysis of goals will include what services, community partnerships, and other mechanisms are implemented across participating institutions for improving support. It is anticipated that educational goals at institutions will continue to be implemented after the end of life grant support. At City of Hope, our commitment to this educational program includes 1) *a minimum of three additional annual courses* sponsored by COH on survivorship issues, and 2) continued follow-up of participating institutions on what educational endeavors, within the institution and for their communities are continuing.

#### **E. Human Subject Research**

IRB review by the Director of Research Subjects Protection at the City of Hope is complete. We have received Exemption 1. Processing of human consent at participating institutions will vary according to the individual institution policies and procedures.

#### **Women and Minority Inclusion in Clinical Research**

##### **Inclusion of women**

We expect at least half if not more participants will be women since our population consists of administrators, nurses, physicians, social workers, psychologists, clergy, rehabilitation staff etc. In our current courses more than half are women.

##### **Inclusion of minorities**

We will recruit from minority institutions, and gather information about the minority distribution of patients in each institution. We will advertise in minority journals and target that population. The minority recruitment plan includes mailing to minority professional organizations (such as the Black Nurses and Hispanic Nurses Associations) hospitals and agencies in predominantly minority settings and announcements to other target groups such as previous participants in the Oncology Nursing Society (ONS) education courses focused on minority issues and the Multi Cultural Special Interest Group of ONS. All participants will be encouraged to develop goals that target minority populations throughout the course. Dr. Underwood will conduct a program session on minority issues. We will also ask all speakers to address minority issues. Reinforcements with special content on this topic will continue through the website and the reinforcement newsletter.

##### **Inclusion of children**

No one eligible to attend the course would be classified as a child, since only professional staff will be attending the course.

#### **F. Vertebrate Animals = N/A**

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114. *Hanson, J. 2002, Disseminating End-of-Life Education to Cancer Centers, City of Hope Interdisciplinary Grand Rounds, Duarte, CA (presentation)*
115. *Hanson, J., & Grant, M. 2003, DELEtCC: Disseminating End-of-Life Education to Cancer Centers, Oncology Nursing Society 28th Congress, Denver, CO (presentation)*
116. *Grant, M. 2004, Status of Supportive Care in Cancer Centers, 1<sup>st</sup> Annual Meeting of the American Psychosocial Oncology Society, Orlando, FL (presentation)*
117. *Hanson, J. 2004, Evaluating A Minority Recruitment Plan for Interdisciplinary End-of-Life Education for Cancer Centers, American Association for Cancer Education 38<sup>th</sup> Annual Meeting, Baltimore, MD (presentation)*

## H. Consortium/Contractual Arrangements = N/A

### I. Consultants and Letters of Support

Dr. Linda Jacobs is Clinical Assistant Professor at the University of Pennsylvania School of Nursing. In her current position, she was responsible for creating and implementing the long-term care clinics at the University of Pennsylvania for cancer survivors. She has, as a result, developed many relationships with members of the Cancer Center at the University of Pennsylvania, and is collaborating on many projects related to cancer survivor follow-up. She will be responsible for reviewing, along with Drs. Grant, Ferrell and Bhatia, all materials submitted by faculty for the curriculum. She is budgeted for 6 days for the first year, when the curriculum is being created. For years two through four, she is budgeted for 2 days per year, to assist in evaluating the course presentations for revisions, additions, etc. and assisting with interpretation of participant evaluation materials (goals and goal achievement, institutional survey results, and institutional assessment results). For year five, she is budgeted for 3 days to assist with final evaluations, interpretation of overall results, and assistance with dissemination via manuscripts and presentations. Her letter of support for her consultant status is attached.

Dr. Marilyn Bookbinder is Director of Nursing in the Pain and Palliative Care Department at Beth Israel Hospital in New York City. Her background includes extensive work in quality improvement and institutional change. She is currently working with the PI on her project on Disseminating End-of-Life Education to Cancer Centers leading discussion, development, and quantification of participants individual institutional goals. She will conduct a parallel approach in the Survivorship Education via daily presentations and interactive group sessions. In addition, she will work with the investigation team after each course, refining this content based on the evaluations received from course participants and faculty. She will consult with the PI on analyzing the goal follow-up data and the goal evaluation tool. She is scheduled for 3 days in years 01 and 05, and 2 days in years 02-04.

Dr. Gwen Uman, head of the firm, Vital Research, will provide biostatistical support for the project, working with the investigators on the data coding, entry, database design, and analysis. She will provide support before and after each course, and will guide combining data across courses in year 05, assisting with data interpretation and manuscript preparation. Her letter of support is attached.

We have decided not to have any additional consultants, as our faculty are nationwide experts. We will enlist their participation prior to the courses for reviewing of the content of the curriculum, to ensure inclusion of appropriate material, decrease overlap between speakers, and assist in providing a cohesive and comprehensive curriculum. Biosketches and other support from consultants follows.

### Faculty

Marilyn Bookbinder, RN, PhD  
 Katherine Brown-Saltzman, RN, MA  
 Patricia Ganz, MD  
 Sue Heiney, PhD, RN, CS, FAAN  
 Jimmie Holland, MD  
 Melissa Hudson, MD  
 Linda Jacobs, PhD, RN  
 Paul Jacobsen, PhD  
 Diana Jeffery, PhD  
 Judi Johnson, PhD, RN, FAAN  
 Mary McCabe, RN, MA

Sandra Millon-Underwood, PhD, RN, FAAN  
Ida Moore, RN, DNS, FAAN  
Shirley Otis-Green, LCSW  
Margaret Riley, MN, RN  
Leslie Robison, PhD  
Sheila Judge Santacroce, PhD, ARPN  
Linda Sarna, RN, DNSc, FAAN  
David Spiegel, MD  
Ellen Stovan  
Rodger Winn, MD  
James Zabora, ScD  
Brad Zebrack, PhD, MSW, MPH  
Theodore Krontiris, MD, PhD