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An Overview and Evaluation of the Oncology Family Caregiver Project: Improving Quality of Life and Quality of Care for Oncology Family Caregivers

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Introduction

Rarely do people go through the cancer experience alone. In fact, cancer is referred to as a disease affecting the family who travel the cancer journey together [1,2,3]. Across the cancer care trajectory, family caregivers (FC) provide the vast majority of home care [4,5,6,7,8]. With over 1.5 million new cancer diagnoses each year and more than 12 million cancer survivors [9], it is estimated that two of every three American families will at some time have at least one family member diagnosed with cancer. With the current trends of earlier discharge from acute care hospitals and the increase in home care, more adult children are becoming involved in caring for a physically dependent parent. Additionally, advances in cancer treatment have led to increased survivorship, which in turn has led to caregiving demands that may exist for several months to years. These trends along with the ongoing change in reimbursement, have contributed to a shift in the burden of care from the health care professionals to the patients and their FC [10,11].

It is important to recognize that FC typically put the needs of their loved one before their own needs [12,13]; and when providing complex care for an extended period of time, they are at increased health risk, due to the limited time to rest, engage in self-care activities, or to seek medical help when they need it [14,15]. Furthermore, many in the aging FC population have chronic health problems such as arthritis, diabetes, or hypertension which can be made worse by the stress of caregiving [5,16]. Between the years, 2005 and 2030 the number of older adults in the United States will almost double, making up 20% of the population. Over half of all cancers occur in those 65 and older [9]. The average age of FC caring for adults is 49 years old [17].

Although intensely affected by a loved one's cancer diagnosis, FC have received negligible attention [2]. The "Improving the Quality of Life and Quality of Care of Oncology Family Caregivers" training program is a NCI supported project (R25CA132664) which educates oncology professionals to improve support and resources for FC. The purpose of this article is to provide an overview of the project and present an evaluation of the first 3 courses training healthcare professionals.

Background

Family caregivers are those who provide uncompensated care in the home and who have a pre-existing relationship (either through friendship or kinship) to the person for whom care

is being provided [16,17,18,19,20]. This care may be in any of the quality-of-life (QOL) domains including physical, social, psychological and spiritual care. Like cancer patients, FC themselves have diverse needs and health concerns [21].

Caregiver needs vary based upon the trajectory of illness from diagnosis through treatment, survivorship, and end-of-life care [3,8,22]. Cancer caregivers are distinguished from other FC due to the unique nature of the disease and its treatment [23]. As the primary setting for care has shifted from the hospital to home, cancer FC are particularly challenged to integrate complex and multiple responsibilities into their lives [24]. To better prepare them for their caregiving responsibilities, FC require education and support from the professional health care providers [2].

Caring for a loved one with cancer at home entails inherent physical, psychological, and financial burdens [25]. Complex symptom management presents a challenge for FC who are often unskilled and uneducated about the care they need to provide [2]. Family caregivers report feelings of anxiety, depression, fear, helplessness, anger, guilt, and uncertainty, yet often do not seek care for themselves [16,26]. Although these needs have been recognized, there are few model programs to address these needs. Furthermore, FC have needs ranging from informational, personal, household, to patient care issues that are not fully acknowledged by health care providers, with consequent impact upon adherence and delays in medical decision-making [5,15,27].

Caregiver needs and access to resources vary based on many factors, including gender, age, culture, education, economics, and geographic setting (rural vs. urban) [22,28]. Those caring for an especially vulnerable loved one with cognitive impairments or one who is physically or emotionally dependent and who requires substitutive decision-making are at risk for increased guilt and complicated bereavement [29,30]. Patients and FC may vary regarding preferred coping styles, which can further stress a relationship already challenged by illness [31,32].

At the time of diagnosis the FC, like the patients themselves, may be overwhelmed with the need to adapt to the myriad of new information, decision-making, and adjustments to the impact of the illness upon their lives [14]. Many with cancer find themselves facing their illness as a chronic disease requiring months or even years of active treatment resulting in long-term impact upon FC [33]. Although the survivorship phase may last for decades, patients are often left with an illness or treatment legacy that continues to require ongoing attention from FC [33]. For those facing end of life, caregiving needs typically escalate as FC attempt to cope with the increasing burden of illness upon their loved one [12,34]. There is growing attention to the impact of home deaths upon FC coping and bereavement needs [30,35,36]. However, developing and standardizing appropriate bereavement support services for differing caregiver groups remains problematic [37].

Despite these differing needs, caregivers have many concerns in common. Family caregivers consistently express a desire for increased communication with their healthcare team [12,38,39]. They are especially challenged with communication needs when their loved one is in a critical care unit [40,41,42,43,44]. Communication patterns are particularly distressing surrounding the concept of delivery of “bad news” to patients and FC. Issues surrounding advance care planning, not just with patients but with FC, benefit from skilled communication by healthcare providers regarding their understanding and readiness for transitions in prognosis [40].

Because FC may assume their caregiving role under unexpected and emotionally difficult circumstances, anticipatory guidance and education regarding effective coping strategies are often desperately needed [16,31,45]. Sophisticated assessment and intervention skills are

needed by the entire oncology team to maximize health outcomes. Failure to address these complex needs impacts adherence to healthcare treatment, satisfaction with care, and is a factor increasing risk for complicated bereavement [43].

Family conferencing strategies have been studied as a high-impact intervention for FC [46]. There has been growing recognition that despite the many challenges and burdens of caregiving, it is an activity that many caregivers find to be deeply rewarding and meaningful [47]. Supporting FC as they navigate their role to increase the propensity of benefit-finding is an underdeveloped area of professional attention [30,37,48].

The growing recognition that the family is the unit of care, underscores the importance of support and resources for caregivers. Yet, the majority of health care providers lack information and training regarding these multidimensional complex needs. While many professional education programs in oncology in areas such as survivorship, palliative care, or those newly diagnosed have included some content on family caregivers, we are not aware of any previous professional training programs with a sole focus on family caregivers. The literature cited above has documented a need to create an educational program; thus the “Improving Quality of Life and Quality of Care for Oncology Family Caregivers” project was developed.

Improving Quality of Life and Quality of Care for Oncology Family Caregivers Project

This project builds on over 20 years of research by the investigators in cancer family caregiving [49,50,51] and brings together a national faculty of leaders in family caregiving. This project provided an opportunity for translational research as the knowledge gained from these studies is shared with oncology clinicians through this project in which the knowledge is then applied to changes in the clinical setting. It is innovative in that it focuses on the quality of care for FC; targets cancer settings as models for this care; and focuses on the interdisciplinary team.

Prior to the study, IRB approval was obtained. Two-person institutional teams, made up of over 400 competitively selected interdisciplinary oncology professionals from 200 nationwide cancer centers will participate in one of four annual courses. To date three courses have been held including 322 professionals from 154 institutions. Nationally recognized expert faculty bring together the most current FC evidence-based knowledge and present multiple resources to help improve FC support organized across the physical, psychological, social, and spiritual domains. During the course, teams develop three FC focused goals to be implemented in their home institution. Post-course follow up at 6, 12, and 18 months assesses the level of goal achievement. Each 2-person team applies the skills acquired during the course to achieve excellence in oncology FC support within their own institution.

The goal of the Improving QOL and Quality of Care for Oncology FC Project is to improve QOL and quality of care for those impacted by a loved one’s cancer across the trajectory of illness by increasing institutional support and accessibility of resources.

The specific aims of this 5-year, NCI funded project are to:

1. Develop a comprehensive FC curriculum for training an interdisciplinary professional audience from cancer centers.
2. Implement the FC curriculum in four national workshops to competitively selected teams and provide 18 month follow up support.

3. Develop a network of course participants to share experiences in dissemination of the FC curriculum to participating cancer centers.
4. Evaluate the impact of this curriculum by measuring process and outcomes of the educational activities on FC and change-efforts initiated by the participants that impact FC.
5. Disseminate the findings through peer-reviewed publications, various oncology organizations and professional networks.

Course framework

The course framework includes three components: 1) changes in practice; 2) principles of adult education; 3) selection of the education content for improved QOL for FC. This framework provides directions for change (Deming's performance improvement [52]), guidance for teaching (Knowles' adult learning assumptions [53]), and an approach for selection of content (FC QOL [54]). Understanding the illness trajectory of cancer [2,55] provides an additional component to the framework for the curriculum by providing a broad timeframe and blueprint for anticipated needs.

The course consists of a combination of didactic presentations and small group interactive sessions. National pediatric, adult, and geriatric experts present evidence-based information on QOL issues facing FC and give examples of successful approaches cancer centers have used to address these issues. Small group interactive sessions focus on significant issues including sexuality concerns, spousal caregiving, distance caregiving, pediatric FC, spiritual care, support groups and family meetings, and family communication in oncology. Each participant receives an extensive course syllabus as well as a toolbox which includes caregiver materials and books from national organizations such as NCI and the American Cancer Society (ACS). Throughout the course a FC focused resource fair offers examples of available teaching materials, books, booklets/pamphlets, and DVDs. Additionally, the resource fair provides course participants the opportunity to display their home institution's FC support materials. These hands-on displays give participants practical ideas that could be implemented in their own institutions.

Prior to coming to the course, participants work together as a team to establish three FC institutional goals. During the course, these goals are refined and revised as ideas from the discussion and networking lead to more specific strategies for implementation in their home institution.

Agenda

The agenda includes an intensive three-day training course (Table 1) which is organized around the illness trajectory and the four domains of the QOL for FC model [56], i.e. physical, psychological, social, and spiritual well-being. In each domain, State-of-the-Science lectures present the latest findings on the impact of cancer family caregiving and examine the efficacy of supportive interventions. Models of Excellence presentations give examples of existing FC support programs and services offered in different cancer settings.

A major theme throughout all sections of the conference is the personal needs of the caregivers rather than only focusing on caring for the patient. Strategies and support for personal care of the caregiver are included in all sections and resource materials.

Evaluation

The evaluation is conducted at three intervals and includes 1) pre-course, (application); 2) during the course, (content and speakers); and 3) post-course, (6, 12, and 18-month goals, interviews, and survey follow-up). The application includes characteristics of the team members, the institution, and the patients cared for in the institution. Each application is scored on an evaluation form that was specifically designed to capture the commitment to change; interest and leadership experience; commitment of the institution as illustrated by the support letters from the institution; recommendations from the institution administrators; as well as the represented disciplines and the geographic location.

Along with the application, teams complete three surveys, 1) Institutional Survey, 2) Educational Programs, and 3) Institutional Assessment. The Institutional Survey is used to identify the teams' own interest in making institutional changes as well as their view of the institution's readiness for change. The Educational Programs Survey identifies the institution's educational programs offered to healthcare professionals regarding oncology FC content over the past two years. The Institutional Assessment, based on a number of previous studies at City of Hope, is a self-rating tool with information about the FC services and resources available at their institution. The assessment consists of nine categories including: vision and management standards; practice standards; visiting standards; spiritual, religious, and cultural standards; psychosocial and emotional standards; communication standards; quality improvement standards; family education; and community network and partnerships.

The post-course follow-up and support continues for the next 18 months at 6, 12, and 18 month intervals. Post-course data consists of goal achievement updates, Educational Programs survey, Institutional Survey, and team phone interviews. The updates identify goal achievements and provide a numerical rating (percent) of completion. The project director conducts the phone interviews to discuss support systems and barriers encountered during goal implementation and to offer support from the project office, such as connecting teams with similar goals, providing resource options, and discussing successful strategies used by other institutions.

Results

Descriptive statistics (frequencies and means) were used to examine the distribution of participants, institutional characteristics, and survey results. Quantitative data from the applications and post-course evaluations were entered, audited for accuracy, and analyzed using the Statistical Package for the Social Sciences (SPSS) for Windows version 16.0 (SPSS Inc., Chicago, IL, USA).

Three hundred twenty-two individuals (154 teams) from 39 states and Washington D.C. participated in the first three FC courses. The majority (93%) of the participants were female. Ninety-one percent of the participants were Caucasian with the remaining 9% representing Hispanic/Latino (2%), Asian (4%), and 1% each, African-American, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander and unknown cultural groups. The most common disciplines were registered nurses (48%) and social workers (38%); the remaining 14% were represented by a wide range of disciplines such as physician, spiritual care provider, psychologist, administrator, attorney, and health educator.

One hundred fifty-four nationwide institutions sponsored teams for the FC training courses. The majority (62%) of the institutions were community cancer centers with the remaining from NCI designated cancer centers (22%), ambulatory cancer clinics (5%), children's hospitals (4%), VA hospitals (3%), community cancer support agencies (1%), and other

(4%). The institutional patient populations were predominately Caucasian (68%) with the remaining 32% representation from African-American (11%), Hispanic/Latino (11%), Asian (6%), and American Indian or Alaska Native(1%) and Native Hawaiian or other Pacific Islander (1%), and 2% unknown cultures.

Table 2, the Institutional Assessment, presents detailed data regarding the FC support services and standards present within participants' home institution, prior to attending the course. The assessment includes seven areas of FC support of: Vision and management; practice; visiting; spiritual, religious, and cultural; psychosocial and emotional; communication; and quality improvement. Two additional subscales identify the availability of family education and community network/partnerships. Of the subscales, availability of family education was the highest rated with 91% responding positively. Visiting standards were present in 83% of the institutions, followed by practice standards at 81%, spiritual, religious, and cultural standards at 78%, community network and partnerships at 73%, communication standards at 68%, vision and management standards at 65%, quality improvement standards at 61% and lastly, psychosocial and emotional standards at 59%.

The pre-course Educational Program survey results reveal that over the last three years, the most frequent educational program offered to healthcare professionals related to oncology FC content was focused on the FC psychological well-being (32%). Quality of care for FC of pediatric cancer patients was least frequently offered (13%).

Results from the Institutional Survey, Table 3, reveal more than 75% of the institutions have some type of FC support services, with the majority of the core members made up of social workers (64%) and nurses (45%), followed by spiritual care providers (40%), volunteers (26%), and physicians (23%). Other disciplines making up the FC support services include art, music, or physical therapists and psychologists. The main barriers to improving care of oncology FC were lack of FC knowledge by professionals and lack of personnel/staff.

On a 1–10 scale (10=best), both the administrative support and staff were highly receptive to improving oncology FC support, 9.1 and 8.9 respectively; while the effectiveness of the institution's FC support rated only moderate at 4.8.

Post course evaluations revealed the participants' were highly satisfied with the course and the faculty. Their overall opinion of the course was positive, (4.8) on a scale of 1 to 5, (5 = best). Participants found the oncology FC content stimulating and thought provoking, (4.8). Overall, the course met their objectives and their expectations, (4.7). The presentations were clearly presented, (4.8); composed of high quality material (4.7); and were valuable to the participants as clinicians, (4.7).

In the open comment section on the evaluation, participants identified the strengths of the course.

Strengths of the course as:

“...providing what we know from the evidence and giving suggestions or stimulating ideas how to translate research to caregiving solutions”

“...evidence-based information, time for networking with others in the field, clinical research professionals. Vast resources of practical ideas for small steps to help family caregivers.”

“...emphasis on systems (re: families, systems change within organizations, etc.)”

“...identifying caregiver burden.”

“...interdisciplinary approach, collaboration between all different areas.”

Institutional goals were diverse and varied in their area of focus. For example, a team focused on the need for increased staff education regarding FC issues and provided a 4-part series organized around the QOL domains at monthly staff meetings. Another team concentrated their effort on bringing about an institutional culture change in treating the patient/FC dyad as a unit of care rather than as separate entities. Table 4 categorizes the goal areas of focus and provides examples of each of the categories. At the 6-month follow-up interval, teams reported on the status of their three institutional goals. A 100% response rate found 45% of goals were complete, with the remaining 55% in process. Table 5 gives examples of the outcomes of completed goals.

Discussion

Addressing the needs of the cancer FC is steadily, albeit slowly, gaining nationwide attention. The aging population; complexity of treatments; prolonged survivorship; shorter hospital stays with sicker patients being discharged to home; and cut-backs in reimbursements and limited insurance coverage, are all significant factors leading to more demands being placed on the FC. While the need for caregiving education and support escalates, FC continue to have limited access to the resources needed to help them provide quality care for their loved one. Although healthcare providers have long been aware of FC needs, training to address these needs has been limited. Results from the pre-course educational program surveys regarding FC support found limited resources for healthcare professionals. Consistent with findings in the literature, the participants' settings had focused previous staff education primarily on the psychological aspects, leaving gaps in other important QOL domains, i.e. physical, social, and spiritual [21,33]. The *Improving QOL and Quality of Care for Oncology FC* project helps to bridge the gap between the caregiver's needs and the support available to meet these needs.

Immediate post-course evaluations indicate participants are highly satisfied with the course content, faculty, and resources and feel they are better prepared to support FC. Participants' written comments articulate the benefit of working together as a team, the value of the networking opportunities, and the importance of meeting in an interdisciplinary forum. Although the long-term effectiveness of the training is yet to be determined, participants' 100% response rate at the 6-month follow-up interval suggests the course has generated a confident knowledge-based effort toward building support and resources for FC. One additional national course will be offered in 2013 and all sites will receive follow up evaluation up to 18 months post courses so that we can ultimately learn more about the outcome of their goal achievement.

Conclusion

There is a critical need to improve support for oncology FC. The FC project is a first step in addressing this need. If healthcare professionals better understand and support caregivers, QOL for FC will improve and the care they provide to patients will be enhanced.

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References

1. Hopkinson J, Brown J, Okamoto I, Addington-Hall J. The Effectiveness of Patient-Family Carer (Couple) Intervention for the Management of Symptoms and Other Health-Related Problems in People Affected by Cancer: A Systematic Literature Search and Narrative Review. *Journal of Pain and Symptom Management*. 2012; 43:111–142. [PubMed: 21719250]
2. Given BA, Given CW, Sherwood PR. Family and Caregiver Needs over the Course of the Cancer Trajectory. *J Support Oncol*. 2012; 10:57–64. [PubMed: 22222251]
3. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors. *Cancer*. 2008; 112:2556–2568. [PubMed: 18428199]
4. Levine C, Halper D, Peist A, Gould D. Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care. *Health Affairs*. 2010; 29:116–124. [PubMed: 20048369]
5. Given B, Sherwood PR. Family care for the older person with cancer. *Seminars in oncology nursing*. 2006 Feb;22:43–50. [PubMed: 16458182]
6. Institute of Medicine (IOM). Retooling for an Aging America: Building the Health Care Workforce. Washington, D. C.: The National Academies Press; 2008.
7. Schumacher KL, Stewart BJ, Archbold PG, Caparro M, Mutale F, Agrawal S. Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum*. 2008; 35:49–56. [PubMed: 18192152]
8. National Cancer Institute (NCI). [Accessed 5/2/2012] Family Caregivers in Cancer: Roles and Challenges (PDQ®). Resources regarding interventions for caregivers. Available at: <http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/HealthProfessional/>
9. American Cancer Society. Cancer Facts and Figures 2012. Atlanta, GA: 2012.
10. Meeker MA, Finnell D, Othman AK. Family Caregivers and Cancer Pain Management: A Review. *Journal of Family Nursing*. 2011; 17:29–60. [PubMed: 21343621]
11. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*. 2010; 19:1013–1025. [PubMed: 20014159]
12. Rabow MW, Hauser JM, Adams J. Supporting Family Caregivers at the End of Life. *JAMA: The Journal of the American Medical Association*. 2004; 291:483–491. [PubMed: 14747506]
13. Coristine M, Crooks D, Grunfeld E, Stonebridge C, Christie A. Caregiving for women with advanced breast cancer. *Psycho-Oncology*. 2003; 12:709–719. [PubMed: 14502595]
14. Teschendorf BSC, Ferrans C, O'Mara A, Novotny P, Sloan J. Caregiver Role Stress: When Families Become Providers. *ACS Cancer Control*. 2007; 14:183–189.
15. Family Caregiver Alliance. Caregiver Assessment: Principles, Guidelines and Strategies for Change Report from a National Consensus Development Conference. San Francisco, CA: 2006.
16. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA: a cancer journal for clinicians*. 2010 Sep-Oct;60:317–339. [PubMed: 20709946]
17. National Alliance for Caregiving. Caregiving in the U.S. 2009
18. Mellon S, Northouse LL, Weiss LK. A Population-Based Study of the Quality of Life of Cancer Survivors and Their Family Caregivers. *Cancer Nursing*. 2006; 29:120–131. [PubMed: 16565621]
19. Given BA, Given CW, Kozachik S. Family Support in Advanced Cancer. *CA: a cancer journal for clinicians*. 2001; 51:213–231. [PubMed: 11577488]
20. Coluzzi PH, Grant M, Doroshow JH, Rhiner M, Ferrell B, Rivera L. Survey of the provision of supportive care services at National Cancer Institute-designated cancer centers. *Journal of Clinical Oncology*. 1995; 13:756–764. [PubMed: 7533828]
21. Northouse L, Williams A-L, Given B, McCorkle R. Psychosocial Care for Family Caregivers of Patients With Cancer. *Journal of Clinical Oncology*. 2012; 30:1227–1234. [PubMed: 22412124]
22. Tamayo G, Broxson A, Munsell M, Cohen M. Caring for the Caregiver. *Oncology Nursing Forum*. 2010; 37:E50–E57. [PubMed: 20044332]
23. DuBenske LLWK, Gustafson DH, Guarnaccia CA, Cleary JF, Dinauer SK, McTavish FM. Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliat Support Care*. 2008; 6:265–272. [PubMed: 18662420]

24. van Ryn M, Sanders S, Kahn K, et al. Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue? *Psycho-Oncology*. 2011 Jan;20:44–52. [PubMed: 20201115]
25. Sherwood PR, Given BA, Donovan H, et al. Guiding research in family care: a new approach to oncology caregiving. *Psycho-Oncology*. 2008; 17:986–996. [PubMed: 18203244]
26. Hricik A, Donovan H, Bradley SE, et al. Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor. *Oncol Nurs Forum*. 2011; 38:149–155. [PubMed: 21356653]
27. Given B, Given CW, Sikorskii A, Jeon S, Sherwood P, Rahbar M. The Impact of Providing Symptom Management Assistance on Caregiver Reaction: Results of a Randomized Trial. *Journal of Pain and Symptom Management*. 2006; 32:433–443. [PubMed: 17085269]
28. Bessa Y, Moore A, Amey F. Caring for a Loved One with Cancer: It Is My Job. *Journal of Psychosocial Oncology*. 2012; 30:212–238.
29. Funk L, Stajduhar K, Toye C, Aoun S, Grande G, Todd C. Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008). *Palliative medicine*. 2010 Sep;24:594–607. [PubMed: 20576673]
30. Hudson PL, Thomas K, Trauer T, Remedios C, Clarke D. Psychological and Social Profile of Family Caregivers on Commencement of Palliative Care. *Journal of Pain and Symptom Management*. 2011; 41:522–534. [PubMed: 21123026]
31. Northfield S, Nebauer M. The Caregiving Journey for Family Members of Relatives With Cancer. *Clinical Journal of Oncology Nursing*. 2010; 14:567–577. [PubMed: 20880815]
32. Oh S, Meyerowitz B, Perez Martin A, Thornton A. Need for Cognition and Psychosocial Adjustment in Prostate Cancer Patients and Partners. *Journal of Psychosocial Oncology*. 2007; 25:1–19. [PubMed: 17360313]
33. Kim Y, Spillers RL, Hall DL. Quality of life of family caregivers 5 years after a relative's cancer diagnosis: follow-up of the national quality of life survey for caregivers. *Psycho-Oncology*. 2012; 21:273–281. [PubMed: 22383269]
34. Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle C, Willan A, Viola R, Coristine M, Janz T, Glossop R. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*. 2004; 170:1795–1801. [PubMed: 15184333]
35. Dionne-Odom J, Bakitas M. Why Surrogates Don't Make Decisions the Way We Think They Ought to: Insights From Moral Psychology. *J Hosp Palliat Nurs*. 2012; 14:107–108. 10.1097/NJH.1090b1013e31824c31852e31824.
36. Abernethy A, Currow D, Fazekas B, Luszcz M, Wheeler J, Kuchibhatla M. Specialized palliative care services are associated with improved short- and long-term caregiver outcomes. *Supportive Care in Cancer*. 2008; 16:585–597. [PubMed: 17960433]
37. Harding R, List S, Epiphanou E, Jones H. How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliative medicine*. 2012; 26:7–22. [PubMed: 21737481]
38. Mazanec P, Daly B, Ferrell B, Prince-Paul M. Lack of Communication and Control: Experiences of Distance Caregivers of Parents With Advanced Cancer. *Oncology Nursing Forum*. 2011; 38:307–313. [PubMed: 21531681]
39. Aoun SM, Kristjanson LJ, Currow DC, Hudson PL. Caregiving for the terminally ill: at what cost? *Palliative medicine*. 2005; 19:551–555. [PubMed: 16295288]
40. Wittenberg-Lyles E, Goldsmith J, Demiris G, Oliver DP, Stone J. The Impact of Family Communication Patterns on Hospice Family Caregivers: A New Typology. *J Hosp Palliat*. 2012; 14:25–33. 10.1097/NJH.1090b1013e318233114b.
41. Curtis JR, White DB. Practical Guidance for Evidence-Based ICU Family Conferences. *Chest*. 2008; 134:835–843. [PubMed: 18842916]
42. Wright A, Baohui Z, Alaka R, Mack J, Trice E, Balboni T, Mitchell S, Jackson V, Block S, Maciejewski P, Prigerson H. Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment. *JAMA: The Journal of the American Medical Association*. 2008; 300:1665–1673. [PubMed: 18840840]

43. Dobrof J, Ebenstein H, Dodd S, Epstein. Caregivers and Professionals Partnership Caregiver Resource Center: Assessing a Hospital Support Program for Family Caregivers. *Journal of palliative medicine*. 2006; 9:196–205. [PubMed: 16430359]
44. Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the Quality of End-of-Life Care in the Pediatric Intensive Care Unit: Parents' Priorities and Recommendations. *Pediatrics*. 2006; 117:649–657. [PubMed: 16510643]
45. Reinhard, S.; Given, B.; Huhtala Petlick, N.; Bemis, A. Supporting Family Caregivers in Providing Care. In: Hughes, RG., editor. *Patient Safety and Quality An Evidence-Based Handbook for Nurses*. Rockville, MD: Agency for Healthcare Research and Quality (US); 2008. p. 1400
46. Glajchen M, Zhukovsky D. Anatomy of a Family Meeting: Fact, Fiction, and Controversies (505). *Journal of Pain and Symptom Management*. 2010; 39:408.
47. Mazanec, P. Distant Caregiving of a Parent with Advanced Cancer. Case Western Reserve University; 2009. Doctoral dissertation
48. Levine C, Halper D, Peist A, Gould D. Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care. *Health Affairs*. 2010; 29:116–124. [PubMed: 20048369]
49. Ferrell B, Ervin K, Smith S, Marek T, Melancon C. Family perspectives of ovarian cancer. *Cancer practice*. 2002 Nov-Dec;10:269–276. [PubMed: 12406048]
50. Krouse R, Nelson R, Ferrell B, Grube B, Juarez G, Wagman L, Chu D. Surgical Palliation at a Cancer Center: Incidence and Outcomes. *Arch Surg*. 2001; 136:773–778. [PubMed: 11448388]
51. McCahill L, Krouse R, Chu D, et al. Indications and use of palliative surgery-results of society of surgical oncology survey. *Annals of Surgical Oncology*. 2002; 9:104–112. [PubMed: 11829424]
52. Deming, W. *Out of the Crisis*. Cambridge:MA: Massachusetts Institute of Technology, Center for Advanced Engineering Study; 1982.
53. Knowles, M. *The Adult Learner: A neglected species*. 2nd edition. Houston, TX: Gulf Publishing; 1973.
54. Ferrell B, Grant M, Borneman T, Juarez G, ter Veer A. Family caregiving in cancer pain management. *Journal of palliative medicine*. 1999 Summer;2:185–195. [PubMed: 15859815]
55. Jeannine MB. Palliative Care for Adults Across the Cancer Trajectory: From Diagnosis to End of Life. *Seminars in oncology nursing*. 2010; 26:222–230. [PubMed: 20971403]
56. Ferrell BR, Grant M, Borneman T, Juarez G, ter Veer A. Family caregiving in cancer pain management. *Journal of palliative medicine*. 1999; 2:185–195. [PubMed: 15859815]

Table 1

Course Agenda

DAY 1	DAY 2	DAY 3
Welcome	QOL DOMAIN: PHYSICAL WELL-BEING <ul style="list-style-type: none">State of the Science Lecture: Physical Well-Being and Family Caregivers: Family Members Providing Care and Caring for ThemselvesModels of Excellence: Physical Well-Being	Responsible Conduct of Research
Improving Quality of Life and Quality of Care for Oncology Family Caregivers and Review of Course Materials/ Resources		Goal completion
The Challenge of Quality Care for Family Caregivers in Adult Cancer Care		QOL DOMAIN: SPIRITUAL WELL-BEING <ul style="list-style-type: none">State of the Science Lecture: Spiritual Well-Being and Family Caregivers: Deriving Meaning and Faith in CaregivingModels of Excellence: Spiritual Well-Being
Break	Break	
The Challenge of Quality Care for Family Caregivers in Pediatric Cancer Care	QOL DOMAIN: PSYCHOLOGICAL WELL-BEING <ul style="list-style-type: none">State of the Science Lecture: Psychological Well-Being and Family CaregivingModels of Excellence: Psychological Well-Being	
Lunch and Roundtable Discussions (Seating by type of cancer setting)		Program Summary Evaluations/Closing
The Future of Geriatric Oncology and Implications for Family Caregivers		
Family Communication in Oncology Care	Goal Development and Revisions	
Break	Lunch and Team Goal Work	
Breakout Session <ul style="list-style-type: none">Sexuality ConcernsDiversity in Family Caregiver CommunitiesSpousal CaregivingDistance CaregivingFamily Communication in Oncology Care	Breakout Session <ul style="list-style-type: none">Assessment of Psychological Symptoms/ Screening of Family CaregiversPediatric Family CaregivingSpiritual CareSupport Groups and Family MeetingsFamily Communication in Oncology Care	
Family Caregiver Film Clips	Break	
Evaluations	QOL DOMAIN: SOCIAL WELL-BEING <ul style="list-style-type: none">State of the Science Lecture: Social Well-Being and Family CaregivingModels of Excellence: Social Well-Being	
	Evaluations	

Table 2

Institutional Assessment (n=154 teams)

Area of Family Caregiver Support (mean % of institutions responding Yes)	Criteria	% of institutions responding Yes (n=154)
Family Education (91)	1 Symptom management strategies & printed material are available	98%
	2 Disease specific materials are free & accessible	97%
	3 Families have access to library for additional resources	86%
	4 Computer access for families to use as additional resource support is available	84%
Visiting Standards (81)	1 Families participate in care as desired	97%
	2 Welcoming for Families	91%
	3 Children are welcomed with supervision	84%
	4 24-hour visiting with number, hours & age, for close friends/family	75%
	5 Support for family activities of daily living (ADLs) is available	66%
Practice Standards (procedures, policies care protocol) (81)	1 Confidentiality standards are clearly communicated	98%
	2 Interdisciplinary care consult services are available	92%
	3 Complementary or integrative therapies are supported	86%
	4 Cultural/religious guidelines are integrated	85%
	5 Advance care planning supports are available & the plan is communicated	82%
	6 Population served is defined & communicated	81%
	7 Care standards are implemented and include guidelines for education & support of F C	43%
Spiritual, Religious, and Cultural Standards (78)	1 Links/communication with community spiritual care is established	85%
	2 Prayer & other spiritual/religious practices are overtly available	77%
	3 All staff are expected to integrate spiritual/cultural care within practice	75%
	4 Support is available 24-hr a day	73%
Community Network and partnerships (73)	1 Home care services are available & linked to other healthcare organization services	89%
	2 Healthcare partnerships with formal & informal community organizations to meet support needs for FC	83%
	3 Services are provided that achieve continuity of care within & between community & healthcare organizations	82%
	4 Care is offered by faith-based ministries & healthcare coordinated	59%
	5 Formal relationship is established between healthcare & community faith-based ministries to meet care needs of FC	53%
Communication Standards (68)	1 Care preference, values, spiritual, emotional, & relationship needs as well as treatment decisions are consistently honored	87%
		80%
		36%

Area of Family Caregiver Support (mean % of institutions responding Yes)	Criteria	% of institutions responding Yes (n=154)
	<ol style="list-style-type: none"> 2 Care preferences, values, spiritual, emotional, & relationship needs as well as treatment decisions are consistently & accurately communicated between care settings & professional providers 3 Standards & expectations about excellent FC support are routinely communicated to community 	
Vision and Management Standards (65)	<ol style="list-style-type: none"> 1 Administration supports implementation of initiative to improve FC support 2 Medical staff supports implementation of initiatives to improve Family Caregiving 3 Managers' objectives include focus on FC 4 Vision for excellence in FC support is created 5 Examples of excellent FC support are honored & stories are made visible 6 Education resources are designated to support development of competencies & practices in FC support 7 Organization's annual objective include focus on needs of FC 	89% 88% 73% 61% 50% 50% 47%
Quality Improvement Standards (61)	<ol style="list-style-type: none"> 1 Routine feedback from patients, FC, & community partners is obtained 2 Quality priorities include response to above 3 Research to continue developing new ways to improve FC support is developed or findings are applied to practice change initiatives 4 Annual objectives & priorities include focus on FC support 	81% 71% 47% 46%
Psychosocial and Emotional Standards (59)	<ol style="list-style-type: none"> 1 Families are given info about support groups & encouraged to participate 2 Waiting time to join a support group is less than 2 weeks 3 Support groups are held at locations convenient for families 4 Crisis response teams are present for significant losses 5 Referral & support is available 24-hr 6 Support is available for professional caregivers 7 Support groups for families are available regardless of diagnosis(es) 8 Quality of support group leadership is monitored & a consistent standard is maintained 9 Support groups are offered day & evening hours 10 Virtual support groups available (e.g. chat groups, telephone conference groups) 	78% 68% 67% 66% 66% 65% 59% 55% 44% 24%

Table 3

Institutional Survey (n=154 teams)

Administrative and Staff Support		
Scale: 1=Worst to 10=Best	Mean	Range
How supportive do you believe your administration is in improving oncology FC support?	9.1	8.8 – 9.5
How receptive do you believe your staff are in improving oncology FC support	8.9	8.7 – 9.1
How comfortable do you believe your staff is in caring for oncology FC?	6.1	5.8 – 6.4
How effective do you believe oncology FC support is in your institution?	4.8	4.6 – 5.2
Barriers to improving care for oncology FC at your institution	% of institutions identifying barriers	
Lack of FC Knowledge	74%	
Lack of Personnel/Staff	71%	
Financial constraints	55%	
Other barriers to improving care for onc FC at your institution	23%	
Staff Philosophy excludes FC concerns	16%	
Lack of Administrative Support	12%	

Table 4

Institutional Goals (n=154 teams)

CATEGORY	GOAL EXAMPLE
Education	<ul style="list-style-type: none"> • Develop a staff education module focusing on caregiver distress identification and interventions • Add one lecture per quarter to our community lecture series with a focus on oncology family caregivers
Support Groups	<ul style="list-style-type: none"> • Start a holistic self-care education/support group for caregivers at the Ronald McDonald House • Develop and pilot a weekly "Coffee Lounge for Caregivers" program on the Women's Health Unit
Resources	<ul style="list-style-type: none"> • Develop caregivers' resource packet to given to caregiver during patient's treatment. Resources included: self-care info; stress/relaxation; respite. • Identify resources for caregivers in English/Spanish. Develop a "Caregivers Resource Corner" in each of our 3 waiting areas.
Printed materials & Websites	<ul style="list-style-type: none"> • Develop a comprehensive print inventory of FC resources to distribute to cancer patient family members at any point of the continuum of care • Establish a general cancer supportive web page for caregivers which would include easy-to-follow links to quality websites, guidelines for symptom management, when to call the physician, when to go to the ER, etc. • Develop web-based link on existing cancer center website for caregivers with resource links for existing caregiving tools that are printable. This will enable caregiver at both tertiary and rural outreach clinics accessibility to resources.
Assessment tools	<ul style="list-style-type: none"> • Determine which caregiver assessment tool will be most appropriate for our setting and then implement it. • Develop screening/assessment tool for caregivers in order to identify specific support needs and concerns of caregivers
Orientation	<ul style="list-style-type: none"> • Implement orientation class for caregivers: 1) what CG can expect; 2) importance of self-care; 3) communication of patient and health care team; 4) education and resources • Create a caregiver orientation program to include an orientation course and packet and a tour of the cancer center/hospital
Unit of care	<ul style="list-style-type: none"> • View the patient and caregiver as a unit of care. Educate and involve the caregiver in the development of the patient's plan of care • Present in-service with focus on the concept of the patient/caregiver unit of care and the need to support the "unit".

Table 5**Completed Goals and Outcome Examples**

GOAL	OUTCOME
1. Create and implement a 5 item satisfaction survey for FC to assess and measure the effectiveness of their inpatient palliative care conference experience	Survey in use; FC complete satisfaction survey following palliative care conference; conference modifications per survey results
2. Establish a FC advisory committee to assess and make recommendations to positively impact the needs of caregivers	Advisory committee established; membership includes executive director, marketing, clinical director, 6 caregivers, and RN FC team, meets monthly. Examples of FC suggestions that brought about change: <ul style="list-style-type: none"> • Advisory committee reviews FC resources prior to distribution • Make website easily accessible for FC and keep it simple- Caregiver tab added to home page; website simplified • Honor FC at Annual Survivorship celebration - FC given same privileges and honors as survivors e.g. free admission and food; special presentations; shirts, banners and buttons honoring FC/ survivor
3. Develop and facilitate 3 support groups for oncology FC with our collaborating partners and in our community (This FC team is from a community cancer support agency)	Family caregiver support groups fully implemented; facilitates and provides resources for oncology support groups in 2 hospitals and 1 in the community setting; all 3 groups very well attended
4. Implement patient/caregiver massage/touch program, utilizing "Touch, Caring & Cancer" as a guide/model (http://www.partnersinhealing.net/dvd.htm)	Piloted a hand and foot massage workshop for patients and caregivers featuring a world-renowned touch therapy/reflexology expert. Plans are in the works to make touch/massage therapy an ongoing program.
5. Provide two opportunities for pediatric patients/families to interact/connect with other pediatric/teen oncology caregivers	Successful young adult and teen groups established. The young adult group is made up of parents caring for their child who has cancer. The teen group is teens who are taking care of a cancer patient, usually a parent or grandparent.
6. To create a kick-off event introducing the caregiver initiative: "Celebrate the Caregiver"	Presented "Caregiver Day: Grace & Gratitude" for both patient caregivers and professionals-a day-long event inviting caregivers to participate in workshops and sign up for an Integrative Medicine Program session (Reiki, Therapeutic Touch Massage). Workshops include: Managing Pain Medication, Spirituality & Caregiving, Music & Meditation, Compassion Fatigue, Yoga
7. Work with chaplain education/training program to incorporate spiritual materials from course into program	GWISH website used as resource for staff education regarding patient/FC spiritual needs
8. Develop a local resource guide that lists companies and organizations that offer special activities for caregivers to take care of themselves	A tri-fold brochure has been completed and is disseminated at monthly caregiver class
9. Create psycho-educational presentation/workshop targeted to the caregivers of survivorship patients to be presented at established survivorship clinic and at satellite centers	Conducted 4 Caregiver workshops during Survivorship Week. Developing plans to make the caregiver workshops an annual event during Survivorship Week
10. Develop a "Lobby" Caregiver Program utilizing professional staff and caregiver resource navigators to disseminate information to caregivers as they accompany patients for treatment and follow up appointments	Program occurs monthly in our center; oncology professionals are in the Lobby distributing information to patients and FC