Survivorship Care in a Community Cancer

The Challenges

Cancer survivors report that many areas of their lives are altered following cancer treatment,[1] including exercise and weight management;[2] employment issues;[2] fear of cancer recurrence and anxiety;[3] cognitive functioning;[4] and spirituality.[3] Although oncologists acknowledge the significance of these diverse quality of life issues, providing resources to deliver all of the services necessary to meet survivors' needs is challenging. The development, expense, and coordination of a comprehensive survivorship program that is both broad enough to cover this vast range of issues and substantive enough to be effective is an undertaking too large for most community oncology practices to bear.

Meeting the Challenges

Comprehensive multidisciplinary support is needed to provide optimal survivorship care that will empower survivors in redefining their lives post-treatment.[5] Community cancer centers are an ideal location for structured, evidence-based multidisciplinary care for survivors. Through local cancer centers, survivorship care can be provided through personal contact within a familiar healthcare system.

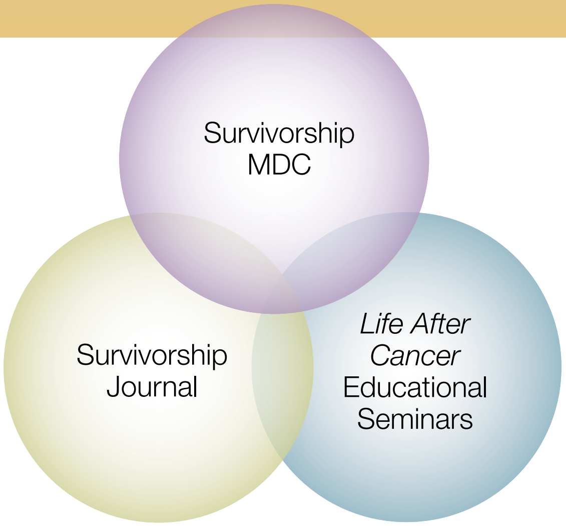

Figure 1: Program Components

As the literature documents, cancer survivors have important unmet needs for information.[6] In their search for information on how to define their new "normal," cancer survivors often request physician time in the form of added phone calls and unscheduled appointments for what are frequently non-medical issues. Other cancer survivors, sensitive to physician time constraints, hesitate to burden their doctor with what they perceive as "minor" complaints. Some survivors, not wanting to be seen as ungrateful for their survivorship status, suffer unnecessarily with solvable issues. These real and perceived barriers often lead patients to search for answers through popular media sources such as the Internet. Without education and guidance, cancer survivors are easily led to viewing sites that are not empirically based. Health literacy issues prevent some cancer survivors from accessing and understanding even reliable information in any format. Misinformation or misunderstanding of accurate information can actually lead cancer survivors to engage in behaviors that may increase use of the medical system and/or the community oncologists' practice.

The Helen F. Graham Cancer Center at Christiana Care (HFGCC) was charged by its community to treat cancer patients throughout the cancer continuum. Therefore, in May 2005, HFGCC initiated development of a cancer survivorship program consisting of three parts (see Figure 1):

- A Survivorship Journal
- A *Life After Cancer* educational seminar series
- A Survivorship Multidisciplinary Center (MDC).

The *Life After Cancer* educational seminars started in March 2006, and the first Survivorship Journals were disseminated in June 2006. These two components were followed by the Survivorship MDC in 2006.

Overall program development was initially guided by the Director of Cancer Psychology and a masters-prepared clinical nurse specialist. A masters-prepared social worker joined the leadership team during the development and initiation of the Survivorship MDC. Here is how we developed our program from May 2005 to September 2006.

Identification of Needs

To determine the needs of post-treatment cancer survivors, we began by conducting a literature search of the scientific journals in medicine, nursing, and psychology. This search revealed many broad survivorship issues such as relationships, physical changes, emotional changes, medical care, and financial issues; however, we found an obvious lack of patient-support material providing specific guidelines for addressing these issues. The National Cancer Institute publication *Facing Forward Series: Life After*

Center— A Comprehensive Multidisciplinary Approach

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Cancer Treatment was the only self-instructed guide that we found.[7]

Our next step was to survey cancer survivors treated at HFGCC to determine which survivorship topics were most important to our population of survivors. The survey we developed and administered included both forced-choice (i.e., Yes or No) and open-response questions to allow for the survivors' own comments. The data analysis entailed using both frequency tabulation for the forced-choice questions and content analysis for the open-ended questions. Our survey data correlated with the literature review data, and we identified the following eight topics as those of greatest interest to our survivors:

1. Fear that cancer will come back
2. Stress
3. Memory and concentration changes
4. Exercise
5. Weight changes
6. Issues with family
7. Communicating with medical team
8. Volunteer opportunities.

These eight topics became the foundation of our survivorship program's three separate but interrelated components: the journal; the seminar series, and the multidisciplinary survivorship center.

Cancer survivors can access one, two, or all three of these components based on their needs, learning styles, and schedules. Because caregivers not only experience the effects of their loved one's cancer but also play an integral role in supporting survivors' efforts in making positive life change, caregivers and (other support persons) are identified as co-survivors and are encouraged to attend and participate in our survivorship program.

Developing a Multidisciplinary Survivorship Program

Staff from multidisciplinary Cancer Care Management at the Helen F. Graham Cancer Center volunteered to help develop both the Survivor Journal and the *Life After Cancer* educational seminar series. Staff was encouraged to participate in a working group that reflected their personal interest and/or professional expertise. Professionals from all levels of training (i.e., doctoral to clerical) joined the work groups and provided input. It is important to note that many staff members reported appreciation for being invited to work on a project with a specific focus on cancer survivors and outside of their usual work routine. Many also expressed that they enjoyed the opportunity to learn new skills or further develop unused skills in the process of program development.

The initial costs of developing this program were supported by HFGCC. To help offset some of these costs, the leadership team worked to secure grant funding from the American Cancer Society for printing of the first 500 Survivorship Journals. Additional grant funding is being sought for the Survivorship MDC. The grant funding, in combination with staff volunteering their time, allows HFGCC to provide its survivorship program to patients free of charge. All components of the program are open to all cancer patients regardless of where they were treated for cancer.

Each of the eight topic areas had a working group consisting of three to five staff members. Guiding the project were the Director of Cancer Psychology and a masters-prepared clinical nurse specialist. To help assure a level of uniformity across all eight topic areas, one of the project leaders participated in each of the eight working groups. All topic materials were developed using evidence-based resources when available. In areas for which we had professional experts on staff (i.e., nutrition: registered dietitian; stress management: psychologist; physical exercise: physiatrist), those staff experts led the working group to research best practices and guide the development of topic materials. Altogether, this phase of the project took about nine months.

Survivorship Journal

The Survivorship Journal is a professionally produced 116-page educational resource that includes individual self-help modules on the eight survivorship topic areas. The journal is in a three-ring binder format that is easily reproducible. We selected this format to ensure the longevity of the journal. The binder format will allow for content modifications based on survivors' feedback and evidenced-based updates. Additionally, this format works well for duplication and customization of the journal at other cancer centers. A long-term goal is to provide these materials and a training seminar to other community cancer centers and/or providers.

The modules are organized uniformly across topics and are designed to engage survivors in active learning exercises. Each module opens with a brief topic introduction and learning objectives followed by a short pre-test related to module information. The pre-test is designed to allow survivors to measure their current knowledge of the topic and to prepare them for the information to follow.

Next is a self-completed stage-of-change assessment using the transtheoretical model of change.[8] This assessment was included to help cancer survivors gain a better understanding of their current readiness to make the changes suggested in the module.

Following the assessment are the topic-focused educational/self-help components. These pages are designed to be highly interactive and provide opportunities for

At the Helen F. Graham Cancer Center, a scrapbooking program for cancer survivors offered participants an opportunity to review and share their stories.

PHOTOGRAPH COURTESY OF THE HELEN F. GRAHAM CANCER CENTER

survivors to reflect, respond, and engage with the materials. For example, in the stress management section, survivors use one chart to list their stressors, a second chart to list their stress reducers, and a third chart to match stressors to stress reducers. In this way, stress management becomes more concrete and manageable for survivors and caregivers.

The educational materials are followed by a personal contract where the survivor develops an action plan for putting the newly-learned material into practice.

Following the personal contract is a post-learning stage of change assessment. An evaluation of the section materials and a post-test with an answer key conclude each module. The post-test contains the same questions as the pre-test to allow survivors to measure their learning.

Educational Seminar Series

The *Life After Cancer* educational seminar series consists of professionally mediated, didactic seminars that match the topics in the Survivorship Journal. The goal of this series is two-fold: to generate survivor interest and program awareness and to allow cancer survivors to progressively build upon information learned.

Seminars are about 60 to 80 minutes in length. Most of the seminar content is based on materials from the Survivorship Journal; however, all seminars contain supplemental materials and information. The seminars are led by the professional staff at HFGCC with some professional volunteers from the community when deemed appropriate. The seminars are designed to be highly interactive and creative and include didactic learning (i.e., PowerPoint presentations) and audience participation through discussions and activities. For example, in the Physical Activity seminar, the HFGCC physiatrist uses the first half of the program to provide cancer-specific physical activity information to the audience and to answer questions. During the second half of the seminar, the audience moves around the conference room visiting professionally guided learning stations that demonstrate such activities as stretching properly, using a pedometer, yoga positions, and Tai Chi. For this program, the yoga and Tai Chi instructors donate their time. As another example, the Nutrition seminar, which is conducted by the HFGCC dietitian, groups participants into teams and uses a Jeopardy game show simulation to educate survivors about nutrition after cancer.

Survivors are encouraged—but not required—to attend the entire seminar series. The programs are offered approximately once a month and are publicized through brochures, cancer provider referral, media articles, and signs in HFGCC's lobby.

To generate awareness and interest in the program, we began the series with the topics of greatest interest to our cancer survivors: Fear of Recurrence and Stress Management. By first helping to equip survivors with the skills necessary to cope with the fear of recurrence and stress, we believed that we would better enable them to focus on the later series topics.

In addition, we planned the order of seminar series to facilitate progressive learning. For example, one recommendation for improving concentration and memory is to manage fatigue through physical activity and proper nutrition. To build on this information, the seminar on Physical Activity and Nutrition immediately follows the program on Concentration and Memory. We scheduled the Physical Activity program, which encourages walking and other outdoor activities, during a season when the weather is conducive to outdoor activities. Likewise, the Nutrition program, which encourages eating fruits and vegetables, is scheduled just before local fruit and vegetable crops come in season. The seminar on Volunteering is the last in the series in hopes that those survivors who have attended the *Life After Cancer* seminars may have addressed many of their own needs and might now be interested in contributing to future programs and helping others through volunteering.

Our Cancer Care Management Department already had a scrap-booking program in the planning stages when we began organizing the *Life After Cancer* series. This program was designed to offer participants an opportunity to review and share their life story using their own photos. Recognizing the emotional healing that takes place through storytelling, we made the decision to include this scrapbooking program in the *Life After Cancer* series, although it was not the result of the literature review or surveys.

Survivorship Multidisciplinary Center

The third component of our comprehensive survivorship program is the Survivorship MDC, which is held in the Helen F. Graham Cancer Center. We adapted this center from the oncology multidisciplinary clinic model that provides a patient-centered approach to treatment plan development through a collaborative effort of multiple specialists in one appointment.[9] The Survivorship MDC is supported with grant funding and is offered to patients free of charge. In the Survivorship MDC, the cancer survivor receives a multidisciplinary team consultation with a psychologist, a clinical nurse specialist, and a masters-prepared oncology social worker in a single visit.

Each healthcare specialist concentrates on his or her area of expertise. The psychologist brings expertise in the areas of anxiety/depression, adjustment to illness, and changes in cognitive functioning. The clinical nurse specialist brings expertise in the areas of functional/physical changes, nutrition, and physical exercise. The masters-level social worker brings expertise in the areas of financial and insurance issues, family role changes and communication, and community and governmental resources.

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Cancer survivors can access the Survivorship Multidisciplinary Center through physician, nurse, or self referrals. Appointments can be scheduled as early as four weeks after the completion of primary cancer treatment or at any time in a survivors' life when survivorship-related issues arise. As noted above, the effects of cancer are experienced by caregivers and support persons as well, therefore co-survivors, or caregivers, are encouraged to attend and participate in the Survivorship MDC. Co-survivors play an integral role in supporting survivors' efforts to make positive life change post treatment.

During the initial Survivorship MDC appointment, the survivor receives a multidimensional assessment of functioning, a Survivorship Plan for moving into life after cancer treatment, and access to the Survivorship Journal and the *Life After Cancer* educational seminars. The assessment, which is completed at home before the appointment, has three core components: 1) the City of Hope Cancer Survivor Quality of Life Scale, 2) the Hospital Anxiety and Depression Scale,[10] and 3) a medical history questionnaire, which ends with patients listing their top three survivorship concerns. The assessment data is used to guide the initial, one-hour appointment with all three professionals.

The initial appointment concludes with the development of a Survivorship Plan. This plan is conceptualized much like the medical treatment plan. It is an individualized set of measurable actions that the survivor agrees to engage in to overcome his or her identified survivorship concerns. To maximize treatment fidelity and efficacy, Survivorship Plans are limited to no more than three goals. For example, if the survivor wants to increase physical activity and improve nutrition a likely Survivorship Plan could be:

Objective 1: To increase physical activity.
Goal 1: To go for a 10-minute walk three times per week.
Objective 2: To improve nutritional intake.
Goal 2: To include vegetables with evening meal five times per week.

Survivorship MDC participants receive a two-week follow-up phone call from a team member and a six-week follow-up appointment. The follow-up phone call provides an opportunity to evaluate the survivors' success in adhering to the Survivorship Plan and to offer professional coaching and problem-solving assistance. At the six-week follow-up appointment, the Multidisciplinary Center team works with the survivor to evaluate the success of the Survivorship Plan, reinforce positive changes made to date, and emphasize the continued use of the newly attained skills of making positive change by setting and evaluating the completion of reasonable goals.

The City of Hope Cancer Survivor Quality of Life Scale and the Hospital Anxiety and Depression Scale are repeated at the six-week follow-up to assess the survivors' status as well as the programs' efficacy. If the survivor is struggling with the Survivorship Plan or a new issue has arisen, an additional follow-up appointment can be made to allow a focused and thorough multidisciplinary evaluation of this issue.

The Survivorship MDC also functions as a referral service in the event that the survivors' issues are too intense for the program's current structure. For example, if the assessment instruments and interview determine that the survivor meets criteria for a psychiatric illness (i.e., depression), the survivor would be referred to a psychiatrist. If survivors have an unresolved pain or rehabilitation issue, they could be referred to a pain or physical medicine and rehabilitation specialist. These follow-up appointments can be scheduled before the survivor leaves the MDC.

A database is used to collect and store the Survivors' MDC data. The assessment and the Survivorship Plan data are shared with the survivors' medical providers (i.e., oncologists, primary care physician) following written consent. These data can help the survivors' medical providers increase their understanding of their patients as well as increase their knowledge of the non-medical, post-treatment issues that cancer survivors endure.

Lessons Learned

Although we anticipated that development of a comprehensive survivorship program would require a significant commitment of time and energy, we underestimated just how much effort it would require to meet the predetermined deadlines. We found that priorities and deadlines for the three components often overlapped. This created stress for the Cancer Care Management staff who often reported to the leadership team that it was difficult to manage the competing priorities of their usual job requirements and the new program responsibilities. To overcome these issues, the leadership team demonstrated respect for professional autonomy, cultivated a sense of ownership for the project piece the staff member was working on, and provided recognition for completed tasks and exceptional work. The overwhelmingly positive response from survivors and caregivers has demonstrated to both the leadership team and staff members that the effort was worth the extra time and energy.

Plans are currently underway to explore an organized effort to include survivors and volunteers in the development and operation phases of all components of the survivorship program.

Future Directions

Plans are currently underway to explore an organized effort to include survivors and volunteers in the development and operation phases of all components of the survivorship program. In addition, we are pursuing outside funding opportunities so that we can recruit additional qualified professional staff.

We will continue to assess the survivorship educational programs in terms of their relevance to the current needs of our cancer survivor population. In 2007, we plan to add two new modules: "Return to Work" and "Personal Growth" to both the journal and seminar series. For cancer survivors returning to their former work roles or pursuing new careers, "Return to Work" is designed to provide direction and support. The "Personal Growth" module is intended to give survivors an opportunity to further explore meaning, purpose, and changes in priorities in their lives after cancer treatment. The development of a survivorship support group and/or advisory board is also being considered.

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