

Developing and implementing a survivorship program in a community cancer center

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Advances in the early detection and treatment of cancer have contributed to an increased number of cancer survivors. This article introduces the most recent definition of cancer survivor and the empirical data demonstrating the barriers to optimal quality of life that cancer survivors often face after treatment. The article then describes a novel set of psychosocial interventions used in a community cancer center to overcome those barriers.

There are more than 10.1 million cancer survivors, according to 2006 estimates. This number is expected to grow as early diagnosis and treatment improves.¹ Although no standard definition of “cancer survivor” exists, the Centers for Disease Control and Prevention recently expanded the definition to include “people who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis, including family members, friends, and caregivers.”² Using this definition, one out of three people in the United States could be classified as a cancer survivor, raising the number of survivors from 10.1 million to approximately 100 million people. In this

article, we use the term “cancer survivor” to refer to cancer patients who have completed their treatment; we use the phrase “survivors and loved ones” to encompass the wider group.

Survivorship barriers

Cancer survivorship is a distinct but often overlooked phase of cancer care that involves physical, emotional, social, and spiritual challenges. Cancer survivors and their loved ones report that, following cancer treatment, their lives are altered in a number of realms, including³:

- exercise and weight management;⁴
- employment;⁴
- psychological (fear of cancer recurrence and anxiety);⁵
- cognitive functioning;⁶
- spirituality.⁵

Although oncologists acknowledge the significance of these diverse quality-of-life issues, providing resources to meet survivors’ needs can be prohibitively expensive. The development, cost, and coordination of a comprehensive survivorship program can be too large an undertaking for most community oncology practices to bear.

KEY POINTS

The Helen F. Graham Cancer Center developed a program to address patients’ concerns about cancer treatment and survivorship, using a self-help manual and a series of educational seminars on the topics in the manual.

Topics include fear of recurrence, stress management, concentration and memory, physical exercise, nutrition, family communication, communicating with your physician, and volunteering.

A Survivorship Journal is designed to be easily updated and reproduced in other institutions.

The program is so successful that a third component has been developed to help survivors improve their quality of life through a multidisciplinary team approach.

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Objectives and goals

Initial objectives of our survivorship program were to develop an evidence-based intervention that included a self-help-style manual and a matched, complimentary series of professionally led educational seminars. An additional objective was to develop the manual and seminars in a format that could be reproduced at other community cancer centers. The program's goals included increasing survivors' knowledge and providing hands-on interactive tools to improve quality of life.

The first component, the Survivorship Journal, is a self-help-style manual designed so that patients can use it without professional assistance. The second component, Life After Cancer—a Survivor's Guide, is a professionally led series of educational seminars that provide an interactive companion to the Survivorship Journal materials. The combination of self-help manual and educational seminars provides a good foundation for the program, accommodating varying needs and interests of cancer survivors.

Program topics

We identified program topics by literature review, professional input, and surveys of cancer survivors. The literature search examined the scientific journals in medicine, nursing, and psychology. This search revealed broad survivorship issues such as relationships, physical changes, emotional changes, medical care, and financial issues. Based on these general topic areas, a survey instrument was created and administered to cancer patients who had completed their treatments. The survey data were examined using frequency and content analysis, which determined that the following eight topic categories are of most interest to our patients:

- Fear that cancer will come back

Benefits of a survivorship program

Patients and loved ones seeking information often request physician time in the form of added phone calls and unplanned appointments for what are often nonmedical issues. This can create an unnecessary strain on an oncology practice, upsetting scheduling, consuming valuable time, and affecting finances. But other survivors, sensitive to physician time constraints, are reluctant to burden their doctors with what they perceive as "minor" complaints. Some patients, concerned about being labeled ungrateful for the treatment that led to survival, suffer unnecessarily with solvable issues.

As a result, these patients often search for answers through popular

media sources such as the Internet. Without education and guidance, survivors are easily led to unreliable sites that provide information not empirically based. In addition, health literacy issues can prevent some cancer survivors from 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 usage of the medical system and/or community oncologists' practice. The Helen F. Graham Cancer Center in Newark, DE developed its Survivorship Program to help survivors overcome barriers; access appropriate resources; and improve their quality of life.

- Stress
- Memory/concentration changes
- Exercise
- Weight changes
- Family issues
- Communicating with the medical team
- Volunteer opportunities

Both the Survivorship Journal modules and the educational seminar series reflect these categories.

Survivorship Journal

The Survivorship Journal is a professionally produced, 116-page educational resource that includes eight individual modules providing self-help materials on the above topics. Each module contains elements designed to engage the survivor in active learning exercises and provide uniformity across topics throughout the journal. The elements include:

- Topic introduction and section objectives
- A test to determine prior knowledge of the information
- A self-assessment of readiness to make behavioral changes using the

Transtheoretical Model of Change⁷

- Topic-focused components and active learning exercises
- Personal contract for developing a plan of action for personal change
- Second stage of change assessment
- Evaluation of the module materials
- Post-test with an answer key

The Survivorship Journal is contained in a three-ring binder, which allows us to easily integrate changes based on survivor feedback and evidence-based updates, and to duplicate the program at other cancer cen-

TABLE 1
Life After Cancer Program series guidelines

- Creative format
- Highly interactive
- Evidence based
- Professionally mediated
- Strategic topic order
- Matching journal topics
- Length of 60–80 minutes
- Attendance in entire series not required—survivors self-select programs of interest

TABLE 2

Life After Cancer Program

<p>Fear of recurrence</p> <ul style="list-style-type: none"> ■ The issue of greatest urgency to largest number of survivors
<p>Stress management</p> <ul style="list-style-type: none"> ■ Coping skills
<p>Concentration and memory</p> <ul style="list-style-type: none"> ■ Techniques to improve cognitive abilities ■ Timed during spring/summer months to encourage outdoor activity
<p>Nutrition</p> <ul style="list-style-type: none"> ■ Recommendations for more healthful eating ■ Tailored to availability of fresh fruits and vegetables
<p>Family communication</p> <ul style="list-style-type: none"> ■ What are you trying to say? ■ Breaking barriers and building skills
<p>Communicating with your physician</p> <ul style="list-style-type: none"> ■ Tips on preparing your questions ■ Recording the conversation
<p>Volunteering</p> <ul style="list-style-type: none"> ■ Recruit volunteers for future survivorship programs

ters. At present we are developing a training course that professionals can use this program in their community-based cancer centers.

Life After Cancer—the survivor’s guide series

The educational seminar series consists of professionally led didactic seminars that match topics in the Survivorship Journal. All seminars apply materials from the Survivorship Journal, with many seminars providing supplementary materials and information. These seminars are designed to be highly interactive and include audience participation in discussions and ac-

tivities. Table 1 lists the guidelines used to develop the series.

The educational seminar series was structured around two goals: to generate program awareness and interest; and to arrange programs in a manner that would allow survivors to progressively build upon information learned (Table 2).

Survivors’ response

Response to the Survivorship Program’s first year was outstanding. The eight educational seminars held in 2006 had a total of 482 attendees. The fear of recurrence program had the greatest number of attendees, with 120 participants. Program evaluations were extremely positive.

The first 500 Survivorship Journals were printed through a partnership grant from the American Cancer Society, South Atlantic Division. More than 400 journals were provided to cancer survivors over 5 months. Data on the usability and understandability of the Survivorship Journal are being collected and should be available in 2007.

Survivor program attendance, verbal feedback, and requests for and interest in the Survivorship Journal all indicate that survivors are seeking knowledge and support to improve their quality of life. To further assist survivors in this quest, a third component, a Survivorship Multidisciplinary Center (MDC), has been developed.

The Survivorship MDC is staffed by a clinical psychologist, a clinical nurse specialist, and a licensed clinical social worker and is designed to help survivors explore changes in quality of life through a multidisciplinary team approach. The team works with survivors to identify their goals and de-

velop a personal survivorship plan.

Copies of the Survivorship Program will be available through the training program under development. For additional information, please contact the first author, Dr. Kendall, at jkendall@christianacare.org.

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