Improving Survivorship Care: A Community Cancer Center's Approach

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In the spring of 2006, Franciscan Skemp Healthcare (FSH), a 160-bed hospital located in La Crosse, Wisconsin, took a bold step forward in addressing the needs of cancer survivors and their families. The Cancer Center applied and was accepted as one of 48 teams competitively selected from cancer programs across the United States to participate in the July 2006 *Survivorship Education for Quality Cancer Care* conference, a National Cancer Institute (NCI)-supported program at the City of Hope (COH) in Duarte, California. The conference brought together national experts and teams representing healthcare professionals from across the United States to learn how to improve cancer survivorship care in their home communities. (For more information, see page S11.) Attending the conference from FSH was a BSN-prepared nurse with oncology nursing certification who serves in a unique role as Cancer Guide at our program, and a Cancer Center social worker.

Conference Highlights

The conference theme centered on institutional change and the development and implementation of new programs—with the goal of improving quality of care and quality of life for cancer survivors. Attendees received updates on the current status of cancer survivorship in the United States. National experts in the field of cancer survivorship provided "State of the Science" seminars, describing how survivorship affects four dimensions of quality of life: physical, psychological, social, and spiritual. Innovative community programs supporting quality of life for the cancer survivor were featured in "Models of Excellence" seminars.

Where to Begin?

Participants were encouraged to develop institutional goals with COH providing follow-up and support for 18 months post conference. The FSH team developed the following three goals:

1. By January 1, 2007, 90 percent of FSH/Mayo Cancer Center staff and providers will participate in survivorship education offered through two, one-hour workshops and demonstrate understanding measured by a pre- and post-test.
2. By June 1, 2007, 50 percent of radiation and medical oncology patients who have completed treatment will receive a survivorship care plan that will also be sent to the primary care provider.
3. By June 1, 2007, 75 percent of radiation and medical oncology patients who have completed treatment will


The multidisciplinary Survivorship Planning Team at Franciscan Skemp Healthcare included representatives from all areas of the Cancer Center.

PHOTOGRAPHS COURTESY OF THE CANCER CENTER AT FSH.

receive a "Life after Treatment" packet of survivorship resources to support them in their transition.

With the excitement generated by the survivorship conference and the full support of FSH administration, the Cancer Center then began to create the area's first cancer survivorship program. The staff who attended the COH conference became the project coordinators. Our first goal was to provide survivorship education for Cancer Center staff and providers through two in-service training sessions. Using resources and information from the COH conference, we developed educational sessions focused on recommendations from the Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition,* including the excellent video by the same title.[1] The specific training objectives for both in-service sessions are outlined in Table 1.

The Planning Process

More than 90 percent of the Cancer Center staff attended the in-service trainings. With enthusiasm high, finding volunteers to serve on the Cancer Survivorship Planning Team was not a problem. The 18-member team, which included representatives from all areas of the Cancer Center, held its first meeting in November 2006. FSH primary care providers also participated in the Planning Team serving in a consultative capacity throughout the planning process. (Table 2 is a complete listing of Cancer Center staff; an asterisk denotes participation on the Survivorship Planning Team.)

The Survivorship Planning Team received exceptional support and guidance from the Cancer Center director and providers. Throughout the planning process their energy and commitment to the project helped propel the team forward. Team brainstorming sessions focused on nine core areas of survivorship planning that, due to finite staff and resources, were refined to focus on the following six areas:

1. Cancer survivorship care plan and exit interview process
2. Institutional, provider, and community awareness and communication
3. Pilot project policy, procedures, and outcomes
4. Psychosocial and spiritual care, including patient and family follow-up support (hospice, spirituality, bereavement, loss, and grief)
5. Wellness programming
6. Survivorship resources for patients and families.

Facilitated by a group leader, work groups met independently on a weekly or bi-weekly basis for six months, and reported back to the larger planning group each month.

Publicity and Marketing Strategy

The planning team worked with the FSH marketing director to develop a communication plan to announce our survivorship program, which would be the area's first. We developed an internal and external communication plan that included a situation analysis, program components, communications objectives, audiences, spokespersons, and the target date for launch to area media.

The planning team brainstormed names for the new program. The chosen name was then taken to focus groups and also went through our internal approval process. On March 7, 2007, via news releases, TV, and radio interviews as well as an internal bulletin, the Cancer Center announced the formation of *Living Well: A Program for Those Surviving Cancer,* with a pilot project to begin June 1, 2007.

Program Overview

The goal of the *Living Well* program is to improve quality of care and quality of life for cancer survivors and their families and caregivers; and to provide for continuity of care between oncologists, specialists, and primary care providers ensuring that all of the survivors' health needs are met. Over a six-month period, from November 2006 to May 2007, the Survivorship Planning Team finalized program policies and procedures (see Table 3).

The *Living Well* program has two components. Part One consists of an array of supportive services, resources, and educational events offered to all patients and families during the course of their treatment and beyond. Part Two is a six-month pilot program. For this pilot project—following the suggestion from COH conference leaders—the team choose to start small. With input from oncology providers, we decided to unroll the pilot survivorship project for patients with lymphoma, head and neck, and colorectal cancer. Our rationale was that this population would include high-risk patients of both genders and various ages.

The pilot program addresses end-of-treatment survivorship needs, including a comprehensive cancer survivorship care plan for the patients and their primary care providers and other specialists, and follow-up interviews within six weeks of the end of treatment to provide support for survivorship needs and set new goals for healthy living.

Cancer Survivorship Care Plan and Patient Exit Interview

We developed a survivorship care plan template by using the Cancer Survivorship Care Plan from the IOM Fact Sheet (Cancer Survivorship Care Planning, November 2005)[2] and by looking at various survivorship care plans. The template provides a summary of treatment and addresses the risk of recurrence, surveillance, prevention, coordination of care between providers, and improving quality of life. Table 4 outlines the components of the survivorship care plan.

Much discussion centered on how to make the plan electronically available to all FSH providers, as FSH does

continued on page S20

The reception desk at the Cancer Center at Franciscan Skemp Healthcare in LaCrosse, Wisconsin.

Table 1. Survivorship In-service Training Objectives

November 2006 In-service*: "Introduction to Cancer Survivorship"*

1. Describe the current status of adult cancer survivorship in the United States.
2. Recognize the impact of cancer survivorship on quality of life.
3. Share conference goals for FSH Cancer Center for survivorship program.

December 2006 In-service: *"Developing a Comprehensive Cancer Survivorship Program"*

1. View *From Cancer Patient to Cancer Survivor: Lost in Transition.*
2. Describe essential components of survivorship care.
3. Discuss barriers facing cancer survivors.
4. Look at existing model programs.
5. Brainstorm ideas for FSH survivorship program.

Table 2. FSH Cancer Center Staff *

1 director*
3 medical oncologists*
1 radiation oncologist
1 radiation physician assistant*
1 oncology certified clinical nurse specialist*
1 pharmacist
1 pharmacy technician
1 phlebotomist
9 oncology certified nurses*
1 research nurse
1 cancer registrar
1 cancer registry assistant
1 Cancer Guide nurse*
1 dietitian*
1 chaplain*
1 social worker*
1 radiation supervisor*
1 radiation dosimetrist
1 radiation physicist
5 radiation therapists*
1 radiation medical secretary
6 patient service representatives (receptionist/scheduler/patient roomer) *
3 Reiki volunteers
1 massage therapist
10 volunteers*

*Denotes representation on the Cancer Survivorship Planning Team.

Table 3. *Living Well* Policies and Procedures

- ✓ Patients with head and neck, lymphoma, or colorectal cancer will receive a Survivorship Care Plan at the end of their treatment summarizing critical information needed for the survivor's long-term care.
- ✓ The Cancer Center interdisciplinary team will review the plan and update as needed.
- ✓ A hard copy of the Survivorship Care Plan will be sent to the primary care provider, and be available on the electronic portal.
- ✓ Cancer Center oncologists will be responsible for follow-up cancer surveillance, including tests and scans.
- ✓ Primary care providers will be responsible for follow-up cancer prevention, healthy living goals, and primary care needs.
- ✓ Select patient populations will be directed to their primary care provider for cancer surveillance or to an identified other provider, i.e., ENT, Urology, etc.
- ✓ The Cancer Center will contact the patient's primary care provider at the end of treatment to notify them that the patient has ended his or her course of treatment and schedule an appointment.
- ✓ In the event the patient does not have a primary care provider, or wishes to change providers, the Patient Service Representative will assist the patient to follow up with the primary care provider of his or her choice.
- ✓ At the completion of treatment, or within six weeks of completing treatment, the patient will meet with the Cancer Guide for an exit interview.

Table 4. Survivorship Care Plan Components

- List of providers
- Diagnosis (type of cancer, grade, stage)
- Treatment history (type of treatment, drugs, dosages, possible adverse effects and responses)
- Potential long-term effects from therapy
- Recommended cancer surveillance
- Signs and symptoms of cancer recurrence
- Psychosocial and spiritual concerns
- Healthy living goals
- Cancer team recommendations and patient goals
- Resources (availability of psychosocial services in the community).

not currently have an electronic medical record (EMR). With the help of FSH information technology specialists, a care plan template was incorporated into the existing Clinician Portal, an electronic patient information repository.

The patient receives the care plan within six weeks of completing treatment at an exit interview with the Cancer Guide. The purpose of the exit interview is to:

- Go over the care plan and follow-up recommendations
- Review patient needs and establish mutually-agreed-upon goals for healthy living
- Make referrals as needed, i.e., behavioral health, integrative therapies, support groups, community services
- Provide the Survivorship Resource Packet
- Ensure the patient has an appointment established with primary care provider
- Encourage participation in ongoing program offerings.

Pilot Patient and Physician Surveys

Pre-pilot surveys were developed to serve as a baseline to evaluate the pilot project. The surveys were sent to patients who had completed cancer treatment in the three-month period prior to the start of the pilot project. Primary care providers for these patients received a physician survey.

An 11-question survey was sent to 37 patients with a 46 percent response rate. Results indicated a need for better communication about the risk of cancer recurrence (70.5 percent felt informed or very informed), the potential late effects of treatment (82.3 percent felt informed or very informed), and setting goals for healthy living (82.4 percent felt supported).

Twenty-seven provider surveys (12 questions) were sent, with a 37 percent response rate. These results indicated the need for better communication about the risk of cancer recurrence (10 percent felt informed) and potential late effects of treatment (30 percent felt informed).

The *Living Well* pilot project ran from June 1 to December 31, 2007. Sixty-eight patients were enrolled in the project. Twenty-nine patients have completed their treatment, and 15 exit interviews have been completed to date. Verbal feedback has been positive from both patients and providers. Project coordinators are currently gathering data and mailing post-pilot surveys. Final program evaluation will be completed when all pilot patients have completed their cancer treatment, received their care plan, and participated in the exit interview.

From the beginning, the Survivorship Planning Team followed the FSH institutional approval process, involving administrative officials, the Cancer Center Clinical Practice Committee, and the FSH Cancer Committee. When the pilot project evaluation is complete, the results will be shared with the FSH Clinical Practice Committee.

Moving Forward

The Survivorship Planning Team faced challenges along the way. Staff time and energy are limited, and the project coordinators have other full-time responsibilities. As we move forward with the program, we will need to:

- ✓ Identify who will keep the Survivorship Care Plan up to date.
- ✓ Decide which cancer diagnoses will be included in the survivorship program and when.
- ✓ Integrate the Survivorship Care Plan into the EMR without having to re-create the wheel. FSH is currently moving toward an entirely electronic system.
- ✓ Know the staffing requirements required to effectively coordinate the program.
- ✓ Ensure that staff has adequate time and resources to address all the pressing needs of the survivorship program.
- ✓ Identify reimbursable services.

Despite these challenges, the Survivorship Planning Team is committed to the success and continuation of the *Living Well Survivorship Program*. With the help of volunteers, cancer survivors, and existing staff, our goal is to expand services to include the following six areas:

1. Sexuality and intimacy
2. Genetic counseling
3. Rehabilitation and pain and symptom management
4. Community awareness and education
5. Caregiver and family support
6. Survivor and family retreats.

The support of the entire institution, administrators, providers, nurses, and other Cancer Center staff has been key to the success of the project. The survivorship training, resources, and online and phone support provided by City of Hope Survivorship Education staff has been crucial. However, the wholehearted, hands-on support from the Cancer Center director, our oncology providers, and the entire Cancer Center staff has truly brought about the success of the *Living Well Cancer Survivorship Program,* improving survivorship care and quality of life for our patients and families.

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References

[1] Hewitt M, Greenfield S, Stovall E. (Eds.) *From Cancer Patient to Cancer Survivor. Lost in Transition*. Institute of Medicine; Washington, D.C: The National Academies Press: 2006.

[2] Institute of Medicine Fact Sheet. (November, 2005) Cancer Survivorship Care Planning. Available at *http://www.iom.edu/Object.File/Master/30/879/fact%20sheet%20-%20care%20planning.pdf*. Last accessed March 6, 2008.