

Model for a Community-Based Exercise Program for Cancer Survivors: Taking Patient Care to the Next Level

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Abstract

This article describes the development and refinement of a not-for-profit, community-based exercise program, the Cancer Foundation For Life (CFFL), designed to improve quality of life (QOL) for persons with cancer, regardless of type or stage of disease. Beginning in 2001, policies and procedures were developed, and personnel were hired and trained. Program evaluation measured safety, exercise adherence, demographic variables, and QOL. CFFL had nearly 3,000 referrals and handled more than 66,000 patient encounters in

2010. Financial and social resources for the program have been established through collaboration with existing institutions (churches, cancer centers, hospitals, and community centers), in conjunction with community support. American College of Sports Medicine guidelines presented at the ASCO 2010 meeting recommend exercise for persons with cancer. The CFFL program provides a cost-effective and safe exercise program for persons with all types and stages of cancer that meets these recommended guidelines.

Introduction

There are currently 12 million cancer survivors in the United States.¹ Nearly all of them are plagued by troubling or debilitating physical and psychosocial adverse effects related to the disease and its treatment. These adverse effects include fatigue, cognitive dysfunction, and depression, all of which can erode patients' quality of life (QOL).

Observational and interventional studies suggest that exercise may alleviate many cancer-related adverse effects, thus improving QOL.²⁻⁴ New guidelines recommending exercise for cancer patients developed by the American College of Sports Medicine were presented at the 2010 ASCO meeting.⁵ Yet despite the emerging evidence and professional guidelines, exercise is not a standard of care for persons with cancer, and patient access to exercise programs remains limited.

The oncology profession's failure to incorporate exercise into routine clinical practice stems from multiple factors. Perhaps the most significant are the lack of reimbursement and the dearth of safe, effective exercise programs that address the needs of older and seriously debilitated patients with complex, comorbid chronic diseases. This article describes how one community met those challenges through development of an exercise program available at no cost to all persons with cancer, regardless of type or stage. A roadmap for further expansion of the program is reported, and research opportunities into the benefits of exercise for cancer patients are highlighted.

Literature Review

Several studies have suggested that exercise can decrease cancer-related fatigue and depression, thus improving QOL.^{3,6} Furthermore, exercise has been shown to be the nonpharmacological intervention with the strongest evidence for managing cancer-related fatigue.^{7,8} A meta-analysis of 24 studies published from 1980 to 1997 indicated that physical activity in patients with cancer resulted in improvements in functional capacity.² A review of 34 randomized trials reported that exer-

cise improved "physiologic measures, objective performance indicators, self-reported functioning and symptoms, psychological well-being, and overall health-related quality of life."⁹ A meta-analysis of nine controlled trials involving 452 women with breast cancer reported that findings supported improved cardiorespiratory fitness; the results were nonsignificant for fatigue and weight gain.¹⁰

Despite the value of such research, few exercise programs targeting the oncology population are available, and no studies of a community-based, long-term exercise program with large sample sizes were identified. This represents a significant gap in practice and in the literature and limits any conclusions that can be drawn about the impact of exercise for patients with cancer in a real-life setting and its effects on their QOL.

Emergence of the Cancer Foundation For Life

Program Need

Incorporating an exercise intervention into oncology practice as a standard of care that results in a life-long behavior change is challenging. The exercise recommendations are more easily adopted for patients without comorbidities and the treatment-related adverse effects experienced by patients with cancer. This may provide significant obstacles for patients and referring oncologists.

Patients with cancer may feel intimidated or self-conscious in an exercise environment in which they are exercising next to bodybuilders. Exercising alongside individuals with similar health issues builds camaraderie and support. Group exercise sessions can reduce this obstacle but may compromise the necessity of individualizing an exercise program for more debilitated participants.

Limited reimbursement for cancer rehabilitation and out-of-pocket expenses not covered by insurance may discourage patients from exercising. Commercial gym membership fees and costs for a personal trainer may be cost prohibitive for

implementation and administration of a safe, effective program. Even when insurance covers the costs of rehabilitation, the duration of participation is generally predetermined and may not reflect the individual rehabilitative requirements of the patient. Exercise is a life-long behavior change and cannot be limited to a 6-week prescription.

In 2001, retired oncologist Gary Kimmel, MD, developed a conditioning program for cancer patients. Development of this program followed a hybrid business/service model (Figure 1) with the aims of identifying needs of the cancer patient population, building community support, gaining commitment from the oncology medical providers in the area, generating ongoing financial support for sustained delivery of services, planning future expansion of services and locations, and evaluating and refining the service delivery process. On the basis of his years of experience in delivering oncology care, Dr Kimmel was familiar with the needs of the community. To gain buy-in and support from the local community, he assembled a board of directors consisting of community members, including those with expertise in fund raising, finance, exercise, research, law, and business management. That year, the not-for-profit Cancer Foundation For Life (CFFL) was established in Tyler, TX to meet the need for exercise options for cancer survivors in the community. In contrast to other programs, CFFL took the stance that all patients with cancer have the potential to improve their physical and mental function along with their QOL. Through CFFL's individualized, community-based exercise program, FitSTEPS For Life (FSFL), all persons with cancer, regardless of type or stage of disease, had access to a free program of tailored and supervised exercise with no limit to duration of participation.

Program Support

To support initial start-up costs, every practicing oncologist in the community made a financial commitment to CFFL and promised to refer patients to the FSFL program. These oncologists, along with other health care providers, foundations, and philanthropists, became founding members of CFFL. Each member committed to donating \$75,000 over a 3-year period. Additional support came from a small grant from the Lance Armstrong Foundation and a local businessman who provided treadmills at cost.

CFFL collaborates with local doctors, area hospitals, cancer centers, churches, and other community organizations that provide patient referrals and facilities for FSFL operations. Space for all FSFL centers is provided in kind. Some collaborating facilities provide equipment donations, and some monetary support. These contributions help offset the cost of FSFL staff working in those facilities.

Program Evolution

That first year, CFFL received 15 patient referrals. Dr Kimmel delivered treadmills to the patients' homes, evaluated the patients, and instructed them on exercise. As it gained in popularity and exposure, CFFL expanded the home-based exercise program and opened its first exercise facility at a centrally lo-

cated church in January 2003. As the program continued to grow, other churches, community centers, cancer centers, and a hospital in-patient oncology unit agreed to donate available space to provide the FSFL program.

Over the next 9 years, CFFL developed exercise protocols and instructions for home exercises. Exercises for flexibility and strength were added. Additional personnel were hired and volunteers trained to accommodate significant program growth. CFFL also defined policies for patient evaluation, exercise implementation and progression, participant monitoring, and intervention in the event of a health crisis. For example, personnel are trained to recognize symptoms that preclude exercise participation. A patient arrived at one of the CFFL exercise centers complaining of increased shortness of breath. A brief assessment was conducted, and a 911 call was placed to the local emergency transport service. The patient was transported and admitted to a local hospital with a pulmonary embolism.

A formal process has been established for participation in the FSFL program. Patients with cancer are eligible regardless of their degree of disability or position in the cancer continuum (just diagnosed, relapsed, in remission, or cured). Once a patient's physician makes the referral to FSFL, staff members enter the person's demographic information along with diagnosis and any comorbid conditions (eg, diabetes, obesity, hypertension) into the participant database. Clinical personnel contact the patient to schedule an initial visit. After the visit is scheduled, the referral is sent to the appropriate local facility.

During the initial visit, the participant is interviewed to determine personal, medical, and exercise history. Short- and long-term goals are established. After consents are signed and vital signs recorded, the participant is placed on a treadmill or elliptical (depending on joint condition). Aerobic exercise is followed by stretching to enhance flexibility and dumbbell weight-lifting exercises to strengthen upper extremities. One core exercise (squats or stability ball) is recommended. Activity is ceased when the participant reports mild fatigue. After the exercise session, an activity plan is developed and a follow-up exercise schedule established. Participants are encouraged to exercise at least three times per week and to increase exercise intensity or duration by 10% to 15% each week.

Program Evaluation and Refinement

The demand for exercise programs targeting persons with cancer is evident in the rapid growth of the FSFL program. The headquarters location in Tyler, TX serves as the major health care resource for the county's urban population and many surrounding rural townships. The county's estimated population is 196,409. In 2007, CFFL expanded operations to Dallas, the ninth largest city in the nation, with a population of 1.24 million. Like Tyler, Dallas serves as the major health care resource for its population and for regional cities and towns.

Growth. Since its inception, CFFL has expanded from a home-based program to 14 sites in East Texas and the Dallas metroplex. FSFL doctor referrals increased from 168 in 2001 to 2,456 in 2010 (Figure 2A). Patient encounters rose from 15 in 2001,

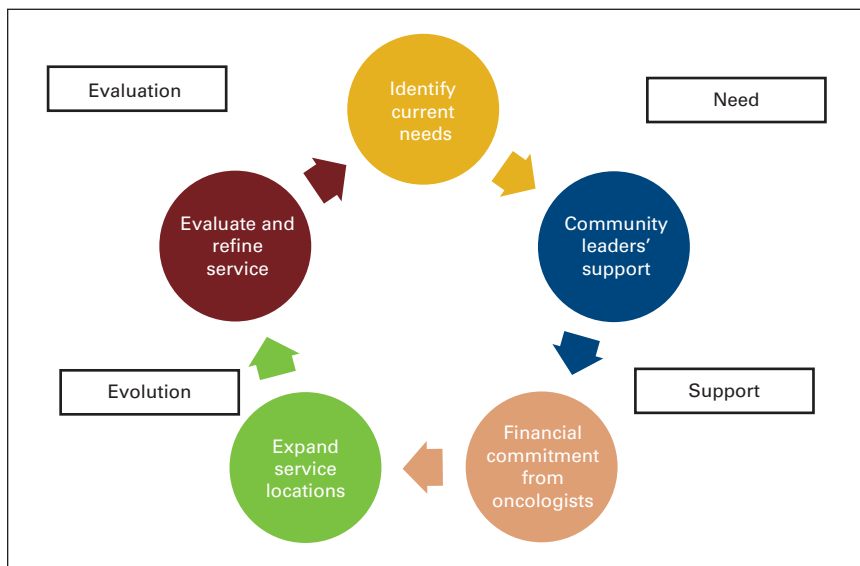


Figure 1. Business/service hybrid model used to establish the Cancer Foundation For Life.

to 7,000 in 2004, to 66,017 in 2010 (Figure 2B). The population served by CFFL does not represent the typical individual served by community exercise facilities nor is it representative of those who typically participate in exercise studies. Participants are older, often have comorbid disease, and represent all stages and types of cancer (Table 1). Several require assistive devices for mobility, including walkers, canes, wheelchairs, and scooters; a few require supplemental oxygen.

Adherence. Given the fragile condition of many participants, CFFL staff members were not surprised by an observed 50% drop-out rate (defined as not visiting an exercise facility for 3 or more months). To further assess the issue of adherence, staff began tracking the reasons that participants stopped attending the CFFL exercise centers. It was determined 46% of dropouts stopped attending as a result of complications from cancer, complications from other diseases, new illness, or exercising on their own. However, it was also noted that the number of patients identified as permanent dropouts was equaled by the number of returning participants previously identified as dropouts. It appears that the concept of exercise as an intervention for adverse effects associated with cancer and its treatment has been embraced by the majority of persons referred to the FSFL program. Many participants do return after taking a break to deal with illness or complications from treatment.

In an effort to increase adherence during treatment, a telephone calling program was initiated to keep participants engaged. Staff members call any participant who does not attend for 1 week. The calls are to voice concern; to determine whether the participant is experiencing complications; and, if they are not, to encourage them to return to the exercise center. Since the inception of the phone calls, the percentage of participants leaving the program has decreased from 50% to 30%.

Safety. Several cancer patients have two or more physicians providing care because of comorbid disease such as hypertension, cardiovascular disease, arthritis, and diabetes. The exercise

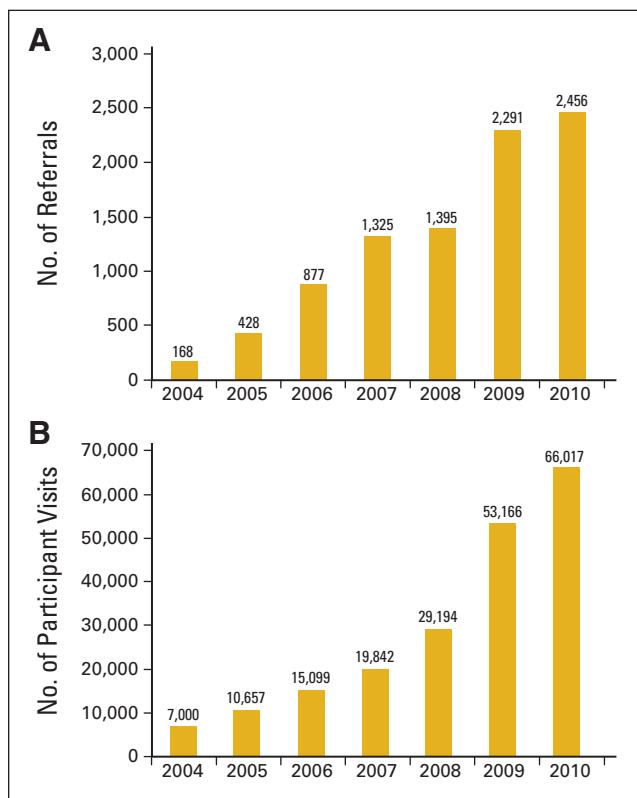


Figure 2. (A) No. of referrals to Cancer Foundation For Life, 2004 to 2010 (N = 8,940); (B) No. of participant visits to Cancer Foundation For Life, 2004 to 2010 (N = 200,975).

intervention must be recognized as safe by all these physicians to ensure that any single provider is comfortable making a referral without consulting colleagues. Since its inception, the CFFL has focused on developing an exercise program that was safe and efficacious. The policies and procedures for exercise initiation and progression are detailed. Any untoward events are promptly reported to the medical and clinical directors. After 9

Table 1. Demographic Characteristics of Cancer Foundation For Life Participants (N = 1,340)

Characteristic	% of Patients
Age, years	
Mean	65.4
Range	18-92
Sex	
Female	72
Male	28
Ethnicity	
African American	13
White	80
Hispanic	4
Cancer type	
Breast	49
Colorectal	9
Lung	6
Lymphoma	7
Prostate	9
Other	20
Stage of disease	
I	20
II	20
III	18
IV	12
Unknown	30
Currently in treatment	
Chemotherapy	40
Radiation therapy	19
Comorbid diseases	68
Assistive devices used	
Mobility aids	9
Oxygen	3

years and more than 66,000 patient encounters, not a single adverse event has occurred as a result of exercise. The well trained staff and volunteers have diagnosed non-exercise-related complications, such as elevated blood pressure or shortness of breath. When these occur, exercise is delayed or cancelled and the participant is referred to their medical provider. When necessary, emergency personnel are summoned.

Cultivating relationships. CFFL is dependent on referrals from physicians. From the onset, the program has not been associated with any particular oncology practice. This plan was deliberate to avoid any suggestion of association with a competitor's practice. Referrals are welcome from any physician in the community. Quarterly visits are made to oncology practices to update the physicians on results of and any changes to the program. Any physician referring a patient also receives monthly written reports. These reports include a list of referred patients, including those who declined participation, and the current level of activity for those attending the program. Relationships with the various oncology practices are also enhanced

through waiting room brochures and presentations to chemotherapy classes and support groups.

Plans for the Future

CFFL has sought to address a major health need in East Texas by offering an individualized, free-of-charge exercise program available to all patients with cancer. Years of development and refinement have resulted in a program that is replicable in any community. Ongoing evaluation research is underway to measure the effectiveness of a community-based exercise program for patients with cancer. A national research team, with experts in exercise, cancer, epidemiology, and economics, has been assembled to plan and complete studies of the effectiveness of this community-based intervention. Studies currently in development include a comparison of sustainers versus dropouts; a randomized controlled trial to compare exercise and delayed exercise in persons with stages I, II, and III cancers; a cost-effectiveness study to compare the impact of a community-based exercise program on health care costs; and qualitative studies regarding patients' and caregivers' perceptions of their QOL and ability to manage and cope with fatigue. This additional research will focus on demonstrating a standard-of-care exercise program that is a scalable model for best practices to be incorporated into the routine cancer care paradigm. Studies will further address gaps in the literature by discussing the specific outcomes and needs of the elderly and persons with all types and stages of cancer, by offering the program for unlimited duration, and by assessing outcomes for extended time periods in longitudinal studies.

Although hundreds of cancer patients in East Texas and the Dallas metroplex have benefited from participation in the FSFL program, exercise is still not a standard of care for persons with cancer. That may be changing. The recent American College of Sports Medicine guidelines recommending exercise for patients with cancer, presented at the 2010 ASCO Annual Meeting, will encourage such patients to exercise during and after treatment and encourage oncology care providers to offer that treatment option. The FSFL program is compliant with those guidelines.

The program offers easily mastered exercises and accommodates almost any combination of chronic diseases and level of disability. Goal setting, appropriate exercise progression, self-efficacy building, accountability, mentoring, modeling, incentives, group exercise, and monitoring of program metrics all ensure safety and enhance adherence to the program. FSFL has helped set the stage for more patients with cancer to improve their QOL through exercise and fitness.

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The authors indicated no potential conflicts of interest.

Author Contributions

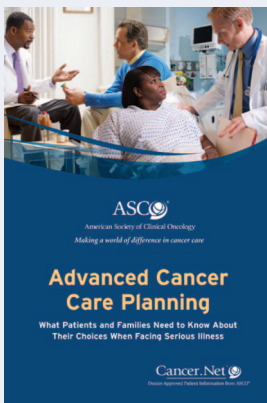
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