

Community-Based Exercise Programs for Cancer Survivors

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Background: Cancer exercise programming in the community has been emerging in response to the increasing numbers of cancer survivors and social factors favoring movement away from a sedentary lifestyle.

Objectives: This article examines several community-based exercise programs for cancer survivors as exemplars of successful programs.

Methods: The article investigates where the research is leading as technological advances and cloud-based technologies change the fitness landscape. Links to valuable resources for healthcare providers interested in current physical activity recommendations for cancer survivors are also offered.

Findings: Accumulating evidence suggests that cancer survivors who engage in an active lifestyle have less fatigue, better quality of life, improved sense of well-being, and, in the case of breast and colon cancers, a reduced risk of recurrent disease.

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Early diagnosis and more effective treatments have resulted in increasing numbers of cancer survivors in the United States, with 3 million survivors in 1971 increasing to more than 15.5 million in 2016 (American Cancer Society, 2016). About 20 million survivors are predicted to be alive in the United States in 2026 (American Cancer Society, 2016). As the number of cancer survivors has grown, so too has the focus on survivorship care, which is now an important subdiscipline of cancer care. A component of this care is maximizing physical fitness, an often sought-after goal during and after cancer treatment. Physical fitness is achieved when one engages in physical activity routinely and with intention (usually referred to as exercise, but the term *physical activity* is often used interchangeably). In this article, the authors will discuss the following questions regarding community-based exercise programs for cancer survivors: (a) How have we arrived here? (b) What are some examples of successful community programs? and (c) How do we leverage what we have learned from these programs and

exercise research to develop more effective programming for cancer survivors?

Background

Exercise recommendations for cancer survivors are commonly highlighted in educational documents and on the websites of many cancer support organizations. These presentations speak to the current recommendations regarding exercise and cancer survivors. But how were these recommendations generated? Concurrent to the evolution of cancer survivorship care was the emergence of the fitness movement, which started in the 1970s (see Dalleck [2012] for a review on the history of physical fitness). In general, the modern movement was a byproduct of two observations: (a) American adults and children were physically unfit (Kraus & Hirschland, 1954) and (b) sedentary behavior caused hypoactive metabolic and cardiovascular disease (Morris, Heady, Raffle, Roberts, & Parks, 1953). Therefore, activities, such as jogging, aerobics, yoga, and Zumba, became fitness

trends, and research in exercise physiology, psychology, and programming steadily grew. In time, exercise research infiltrated special populations, including cancer survivors. This focus on the potential benefits of exercise in the cancer population took hold in the 1990s, ultimately adding scientific evidence that exercise has specific and beneficial effects in the cancer population (Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005; Meyerhardt, Ma, & Courneya, 2010). These benefits are now well known and include physiologic and psychological benefits, as well as risk reduction for cancer recurrence in certain cancers.

Initial exercise studies were carried out in the breast cancer population (Mock et al., 1994; Winningham et al., 1994) and predominated in this group for many years. As a result, breast cancer survivors were the first to adopt exercise events and programming as part of their cancer survivorship care. Additional forces that shaped cancer exercise programming emerged from the early research efforts. The studies revealed the exercise preferences of cancer survivors (Jones & Courneya, 2002; Rogers, Courneya, Verhulst, Markwell, & McAuley, 2008), precautions relevant to the cancer type (Doyle et al., 2006), and the benefits of exercise to attenuate cancer-related fatigue (Courneya, Mackey, & McKenzie, 2002; Mock et al., 1994). As a result, a grassroots flurry of exercise programs within communities appeared, many of which were developed by cancer survivors or their families, such as the Susan G. Komen Race for the Cure® and the Leukemia and Lymphoma Society's Team in Training® programs. These special fitness events stimulated the development of training programs and everyday cancer exercise programs. Many organically grown cancer exercise programs are now situated in communities as independent programs, in cancer support organizations, and increasingly in the cancer center itself. An advantage of these programs is that they offer exercise ranging from very low- to high-intensity training.

The growth of survivor exercise programs has been accompanied by an increasing demand for fitness professionals with the knowledge and experience to assess and prescribe exercise safely. This led to a professional certification program, the Certified Cancer Exercise Trainer® (CET), created jointly by the American College of Sports Medicine (ACSM) and the American Cancer Society (ACS) in 2004. There are now more than 450 certified CETs. The demand, however, outweighs the available CETs, and creative solutions are warranted to leverage the available resources and maximize the impact these professionals have on the greater cancer community.

Community Exercise Programs

Dragon Boat Racing Teams

In 1996, Canadian Donald McKenzie, an exercise physiologist, established a dragon boat team with the idea that this type of physical activity would improve the well-being and physical fitness of breast cancer survivors (McKenzie, 1998). Dragon boat racing has its roots in ancient China. Today, the dragon decorations on the boat harken back to that origin. The boat itself is similar to that used in rowing; it is long

and narrow and is powered by a team of 10–22 individuals, including a steerer and a drummer, who sets the tone for the paddling cadence by drumming. In the setting of full axillary dissections, a routine practice in the 1990s, women were cautioned against activities that theoretically put them at risk for lymphedema. As a result of research done by McKenzie (1998), cautionary refinements were made; for example, the use of compression garments to decrease development of lymphedema was recommended during exercise that involved repetitive motions and/or weight lifting. Therefore, the worry of lymphedema was minimized, and breast cancer survivors were liberated from a culture of disability. McKenzie's study was followed by other studies that confirmed the safety and positive outcomes when breast cancer survivors engaged in exercise that involved their upper extremity on the ipsilateral side of their axillary dissection (Buchan, Janda, Box, Schmitz, & Hayes, 2016). There are now breast cancer survivor dragon boat teams worldwide, with a network of activities guided by the International Breast Cancer Paddlers' Commission (2016).

The LIVESTRONG® at the YMCA Program

The goal of the LIVESTRONG® at the YMCA program is to empower adult cancer survivors to practice a healthy lifestyle. Specifically, the program aims to increase muscle mass, physical strength, and cardiorespiratory endurance, with the resultant benefits of improving functional ability, personal energy levels, self-esteem, and quality of life. The program is led by specially trained YMCA instructors who lead a cohort of survivors through small group sessions that meet twice a week for 75 minutes for 12 weeks. Each session includes healthy lifestyle education and an exercise component. Fitness and quality-of-life assessments are obtained during weeks 1 and 12. These assessments are used by the instructors to create a participant's tailored physical activity plan and as the basis for the participant's pre- to post-outcome evaluation. This program is offered free of charge to cancer survivors, is anecdotally well received, and, in several outcome analysis studies, produced psychological and physiologic improvements (Musanti, n.d.; Rajotte et al., 2012). Cancer survivors may attend the program only once, and all programs are supported by YMCA sites. Unfortunately, if community support is limited, the YMCA may not be able to offer this program. In some instances, alumni programs evolve and provide the necessary maintenance behavior survivors need to realize prolonged benefit.

FitSTEPS for Life®

The not-for-profit Cancer Foundation for Life (CFFL) was established in 2001 to meet the need for exercise options for cancer survivors in the community. The CFFL was founded on the core principle that all individuals with cancer have the potential to improve their physical and mental functioning capacity and quality of life (Haas, Kimmel, Hermanns, & Deal, 2012).

The CFFL program FitSTEPS for Life® (FSFL) provides access to a cost-free, long-term program of individualized and supervised exercise and nutritional guidance to all

patients with cancer regardless of type of cancer, stage of cancer, existence of comorbid diseases, or magnitude of disability (including wheelchair or oxygen dependency). Unlike many programs, no limit exists to the duration of time an individual can participate in the program. In-kind contributions from churches, community centers, and local healthcare agencies provide space to conduct the program, negating the need for the CFFL to purchase or rent facility space. CFFL has developed evidence-based exercise protocols and instructions for home- and site-based exercise for the FSFL participants. FSFL follows a formal process for participation, requiring a physician referral to the program, informed consent of the participant and data collection—including demographics, vital signs, and fitness prescriptions, which are maintained in a participant database. During admission to the FSFL program, short- and long-term goals of the participant are established. The participant is monitored for untoward responses to exercise during the sessions. The participant is provided the option to use the treadmill or elliptical machine, depending on joint conditions. Aerobic exercise is followed by stretching and weight-lifting exercises, completing the comprehensive prescription and being in compliance with current recommendations. Participants are encouraged to exercise at least three days per week with an increase of intensity or duration by 10%–15% each week. In addition, FSFL offers participants assistance with equipment assessment and training, gait and transfer analysis and training, balance assessment, nutritional recommendations, and patient education. The participant experience is guided by the type of cancer the participant has and any specific issues he or she may be experiencing. Group classes (e.g., tai chi) are also available.

The CFFL functions under direct supervision of an executive director and clinical managers. All clinical managers and trainers hold degrees in kinesiology, are certified by the ACSM, and are trained to work with the special needs of individuals with cancer and cancer survivors. A strong volunteer network helps support the daily functioning of the FSFL center. To date, FSFL is only offered in Texas.

Improving Current Programming

Two reviews of the state of the knowledge regarding exercise in patients with cancer include comprehensive reviews of the progress made to help survivors meet current recommendations regarding physical activity (Courneya, Rogers, Campbell, Vallance, & Friedenreich, 2015; Demark-Wahnefried et al., 2015). They also identify important gaps

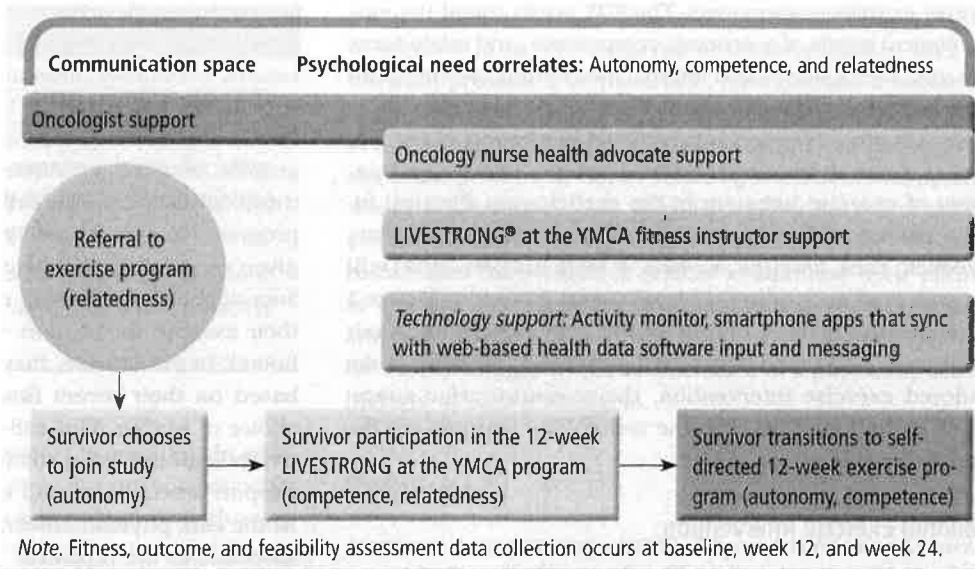


FIGURE 1. Optimizing Wellness: Health Advocacy for Active Living in Cancer Survivors

in the knowledge and points of inadequate support for programming. One such gap that needs to be addressed is the high attrition rate of survivors who initiate exercise but fail to maintain it over time. This number was reported to be at least 40% at six months (Haas et al., 2012). The benefits of exercise are realized only when it becomes habitual, so high attrition rates are a significant concern that warrant additional study and the development of mitigation strategies.

Theory posits that sustaining a behavior is dependent on external and internal sources of motivation (Deci & Ryan, 2012). Sources of external motivational support for cancer survivors include (a) recommendation of the oncologist (Jones, Courneya, Fairey, & Mackey, 2004), (b) prompts to exercise (Bourke et al., 2013), (c) providing physical activity information, and (d) self-monitoring through the use of a fitness tracker that allows for quantification of the exercise session (Bourke et al., 2013; Vallance, Plotnikoff, Karvinen, Mackey, & Courneya, 2010). Data suggest a simultaneously delivered combination of external and internal motivations are important to a cancer survivor's decisions to maintain an exercise routine (Musanti, Martins, Kahn, & Padavan, n.d.). These findings suggest that additional testing of cancer exercise programming is needed that includes these components of external motivation and further explores the drivers of internal motivation (Musanti, 2012; Musanti et al., n.d.; Schmitz et al., 2010).

To that end, the authors have designed a program called the Optimizing Wellness: Health Advocacy for Active Living in Cancer Survivors, which is now undergoing feasibility testing. Components of this program include an individually tailored exercise intervention and a created communication space, which contains personal and technological support, within which the fitness team can easily exchange information. The fitness team is defined as the survivor, the fitness professional, an oncology nurse, and the survivor's oncologist. This program is designed using self-determination theory (SDT) to guide the type and choice of evidence-based

cancer exercise components. The SDT posits that if the psychological needs of autonomy, competence, and relatedness are met, then external and internal motivations are enhanced and behavior change is more likely to be sustained over time. The goal is to test if this model of support is feasible and if it enhances motivational development and sustainability of exercise behavior in the participants. Physical fitness, quality of life, motivational state, and feasibility data (Reelick, Faes, Esselink, Kessels, & Olde Rikkert, 2011) will be collected at baseline, 12 weeks, and 24 weeks. Figure 1 provides the general outline of the components and their relationship to the SDT psychological needs. Details of the tailored exercise intervention, the communication space, the personal support, and the technology support are described in this article.

Tailored Exercise Intervention

Once a survivor is referred by the oncologist, eligible survivors complete the consent process and are enrolled in the supervised, 12-week LIVESTRONG at the YMCA program. Supervised exercise builds competence, and the group setting supports the psychological need of relatedness through

interaction with other cancer survivors. During the first session, survivors undergo initial fitness testing, including aerobic endurance, muscular strength, and flexibility measurements, which are the basis of the exercise prescription that is implemented through the 12-week program. Demographic, medical and cancer history, quality of life, and motivational data are also collected. At the completion of this program, survivors undergo repeat fitness testing and are given an updated exercise prescription by the research team. Survivors are then free to choose where they will continue their exercise for 12 more weeks (i.e., at a fitness center or home). In either case, they are provided specific exercises based on their recent fitness testing and related to their choice of setting. This self-determined choice supports the psychological need of autonomy. Personal and technological support are initiated and continue during these 12 weeks. At the end, physical fitness, quality of life, and motivational assessments are repeated.

The communication space is an umbrella within which technology and personal support are situated, such that information flows between the participant, the fitness professional, and the oncologist. The flow is facilitated by oncology nurse health advocates (ONHAs) through engagement with the participant.

Personal support: Studies have found that cancer survivors prefer to receive physical fitness instruction and information from someone knowledgeable about their cancer diagnosis (Jones & Courneya, 2002). To best provide this desired expertise in a model that is replicable in varying setting, *Optimizing Wellness: Health Advocacy for Active Living in Cancer Survivors* used the LIVESTRONG at the YMCA fitness instructors and ONHAs as agents of information. The ONHAs are volunteers from the local chapter of the Oncology Nursing Society (ONS) and have committed to working with one or two survivors each through the 24 weeks of the study. The rationale behind the ONHA and the use of the LIVESTRONG at the YMCA program is that the ONHA and the LIVESTRONG at the YMCA program fitness instructors possess knowledge about exercise and cancer. However, the depth of their knowledge differs by their respective disciplines. To ensure competence in providing exercise education and instruction to cancer survivors, fitness instructors at the LIVESTRONG at the YMCA receive education about cancer as part of their orientation to this specific fitness instructor role. The ONHAs attend a four-hour exercise educational session in addition to completing *Incorporating Physical Activity Into Cancer Care*, an ONS webcourse developed to educate oncology nurses regarding physical activity benefits and risks in the cancer population (www.ons.org/content/incorporating-physical-activity-cancer-care). Working together, they complement each other's area of expertise. As part of this program, the role of the instructor at LIVESTRONG at the YMCA is extended to include communicating with the ONHA, if necessary, during the first 12 weeks. The relationship between the fitness instructor, the ONHA, and the survivor is fostered during the first couple sessions of the LIVESTRONG at the YMCA, during which the ONHA meets the survivor, becomes familiar with his or her exercise prescription, and teaches the survivor how to use

American Cancer Society

Guidelines on Nutrition and Physical Activity for Cancer Prevention
www.cancer.org/healthy/eathealthygetactive/acsguidelinesonnutritionphysicalactivityforcancerprevention/index

American College of Sports Medicine/American Cancer Society

Certified Cancer Exercise Trainer
<http://certification.acsm.org/acsm-cancer-exercise-trainer>

Cancer Foundation for Life®

www.cancerfoundationforlife.org

Cancer Support Community

www.cancersupportcommunity.org

International Breast Cancer Paddlers Commission

www.ibcpc.com

Leukemia and Lymphoma Society

Team in Training
www.teamintraining.org

LIVESTRONG® at the YMCA

www.livestrong.org/what-we-do/program/livestrong-at-the-ymca

National Cancer Institute

Physical activity and cancer
www.cancer.gov/about-cancer/causes-prevention/risk/obesity/physical-activity-fact-sheet

Oncology Nursing Society

Get Up, Get Moving
www.ons.org/practice-resources/get-up-get-moving

Susan G. Komen Race for the Cure®

www5.komen.org

U.S. Dragon Boat Racing

<http://usdbf.org>

FIGURE 2. Exercise-Related Patient Resources

Implications for Practice

- ▶ Inform survivors about evidence-based exercise programs available in survivors' communities.
- ▶ Help survivors meet the current recommendations for initiating and maintaining a physically active lifestyle by referring survivors to those exercise programs.
- ▶ Embrace new technologies to become an active partner in assisting survivors to stay motivated for a physically active lifestyle.

the activity monitor and the associated technology. In addition, the ONHA's commitment to the survivor includes being engaged with the survivor at least once per week through scheduled and unscheduled interactions via text messaging, phone conversations, or email. To facilitate the conversation, the survivor agrees that the ONHA may access his or her fitness data on the web-based activity program, Microsoft Health Vault®. This access includes notifications sent to the ONHA of long periods (days) of inactivity by the survivor, so the ONHA can proactively reach out to the survivor and offer support. Qualitative work has indicated that oncologists also want follow-up information when they suggest exercise (Musanti et al., n.d.); therefore, the web-based program is used during routine oncology visits as a focus for follow-up discussions regarding exercise. The ONHA continues to provide knowledgeable support throughout the study period.

Technological support: Technological support includes the wearable Microsoft Band 2® activity monitor coupled with the Trialogics® clinical software system. This software system has the capability of real-time data collection with alerts, which are triggered by study team-developed algorithms, such as the alert to the ONHA that the survivor has missed successive exercise sessions. The system uses smartphone technology to transfer alerts and data, and deliver and receive messages through texting. Messages are automatically sent two to three times per week and consist of reminders, exercise information, and motivational messages. The option for social media connections are available through fitness mobile applications (apps) that can be linked through the Microsoft Health app. Survivors may voluntarily choose to use the social apps with the ONHA and other members of the group.

The Optimizing Wellness: Health Advocacy for Active Living in Cancer Survivors will provide data that extend the understanding of motivational evolution and exercise maintenance behavior using community resources and technology in cancer survivors. Qualitative and quantitative data analysis, as well as feasibility analysis, will inform the discussion of future research direction and the potential for expanding this model into other communities.

Conclusion

Cancer exercise programs within the community have risen to meet the needs of cancer survivors through the dedi-

cated work of professionals and survivors working together to improve lives. The longevity of these programs, such as the ones presented in this article, have become a tribute to these efforts. A recognition of the importance of physical activity programming is clearly demonstrated by the consensus of the prominent cancer-related government and professional organizations that physical activity be promoted in cancer survivors (see Figure 2). In addition, cancer exercise researchers have urged providers to continue their efforts to develop programming that embraces new technologies and data systems relevant to cancer survivors and extends the ability to support the maintenance of a physically active lifestyle in cancer survivors.

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