Case Study of Persons with Cancer Participating in a Community-Based Exercise Program: An Exploration of Meaning and Change

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Case Study of Persons with Cancer Participating in a Community-Based Exercise Program: An Exploration of Meaning and Change

Abstract
Increasingly, research supports the importance of incorporating exercise into the cancer care paradigm. While quantitative studies have substantiated the significant effects of exercise on physical functioning, the individual’s perspective of participating in an exercise program has rarely been considered. The purpose of this study was to explain the impact of a community-based exercise program on the lives of persons with cancer and their caregivers. Based on Bandura’s Social Cognitive Theory, a single explanatory case study with multiple embedded units of analyses was conducted. Interviews were conducted with 10 individuals representing participants with cancer, their caregivers, and health care providers. Data were analyzed using Yin’s case study method. Four themes emerged (Sense of Community, Building Relationships, Bridging the Gap, and Living Life Abundantly), which identified the unique characteristics of this community-based exercise program. Incorporation of these characteristics into program planning may benefit other communities that aspire to offer a similar program to improve patient outcomes and enhance quality of life.

Keywords
Case Study, Exercise, Cancer, Community-Based

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Case Study of Persons with Cancer Participating in a Community-Based Exercise Program: An Exploration of Meaning and Change

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Increasingly, research supports the importance of incorporating exercise into the cancer care paradigm. While quantitative studies have substantiated the significant effects of exercise on physical functioning, the individual’s perspective of participating in an exercise program has rarely been considered. The purpose of this study was to explain the impact of a community-based exercise program on the lives of persons with cancer and their caregivers. Based on Bandura’s Social Cognitive Theory, a single explanatory case study with multiple embedded units of analyses was conducted. Interviews were conducted with 10 individuals representing participants with cancer, their caregivers, and health care providers. Data were analyzed using Yin’s case study method. Four themes emerged (Sense of Community, Building Relationships, Bridging the Gap, and Living Life Abundantly), which identified the unique characteristics of this community-based exercise program. Incorporation of these characteristics into program planning may benefit other communities that aspire to offer a similar program to improve patient outcomes and enhance quality of life. Keywords: Case Study, Exercise, Cancer, Community-Based

An estimated 1.5 million new cases of cancer are diagnosed in the United States annually (American Cancer Society, 2015). By 2024, the World Health Organization (2015) estimates a significant increase in cancer cases worldwide, from an estimated 14 million to 22 million affected. As the population continues to grow in size and age, cancer treatment becomes a global concern. To combat this potentially global burden and recognizing that there are a myriad of treatments and therapies, scientific communities are beginning to promote the inclusion of health promotion and health prevention measures into cancer care. One intervention that has demonstrated promising benefits is exercise.

Exercise is Medicine

Over the past two decades, the plan of care in the treatment of cancer has changed. Exercising during cancer treatments has heralded a paradigm shift in cancer care. The traditional school of thought regarding non-pharmacological treatments, such as exercise, was to rest and reduce physical activity. Major stakeholders, including the American Society of Clinical Oncology (ASCO), American College of Sports Medicine (ACSM), American Cancer Society (ACS), Commission on Cancer, and the National Comprehensive Cancer Network (NCCN), now recommend exercise as a vital component in the cancer care paradigm for persons during and following cancer treatment.
Research has provided support for the positive influence exercise has on the psychological and physical health of a person. Exercise is associated with decreased fatigue and increased quality of life (Banzer et al., 2014; Ferrer, Huedo-Medina, Johnson, Ryan, & Pescatello, 2011; Haas, 2011). Evidence also substantiates that exercise during treatment is safe (Haas, Kimmel, & Hermanns, 2012; Rajotte, Yi, Baker, Gregerson, Leiserowitz, & Syrjala, 2012). Physical activity may also reduce the risk of cancer. Studies have confirmed a link between exercising and the prevention and survival rates of certain cancers (Giovannucci, Liu, Leitzmann, Stampfer, & Willett, 2005; Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005; Irwin, Smith, McTieman, Ballard-Barbash, Cronin, Gilliland, Baumgartner, Baumgartner, & Bernstein, 2008; Meyerhardt, Heseltine, Niedzwiecki et al., 2006).

Despite the recommendation to incorporate exercise into cancer care, very few patients are prescribed to exercise as part of their cancer treatment. Several challenges contribute to the lack of exercise prescriptions for this population. While Kimmel, Haas, and Hermanns (2014) advocate for the development of a “standard of care” model, there is no such model at the present time to guide practitioners. Lack of reimbursement may create a barrier to patients with cancer to engage in exercise as exercise facilities charge for use and cancer treatment is prohibitively expensive. Healthcare providers’ misunderstanding of the benefits and risks of exercise may contribute to lack of referrals (Kimmel et al., 2014). For example, the presence of side effects such as fatigue, depression, and bone marrow suppression, and bone metastasis may hamper healthcare providers’ recommendations to exercise. Lastly, the availability of programs designed to handle the special needs of persons receiving treatment for cancer plays a pivotal role in prescribing exercise for this population. To date, few programs dedicated to cancer survivors have been reported. Among those reported, the majority are limited by either a specific cancer type (Knobf, Thompson, Fennie, & Erdos, 2014), the number of sessions offered (Cheifetz, Park Dorsay, Hladish, Macdermid, Serediuk, & Woodhouse, 2014; Noble, Russell, Kraemer, & Sharratt, 2012), or to those with no evidence of disease following treatment completion (Rajotte et al., 2012).

**FitSTEPS for Life**

One exercise program specifically created to address the individual needs of persons with cancer is the FitSTEPS for Life (FSFL) program offered through the not-for-profit organization, the Cancer Foundation for Life (CFFL). The FSFL individualized, community-based program is specifically designed to assist the individual to achieve and maintain as much functional mobility and endurance as possible. There are no restrictions as this program is offered to persons with any type or stage of cancer, regardless of concomitant comorbidities; however, physician referral is required. This program is unique in many ways: (1) all exercise is individually tailored; (2) all participants are supervised by staff degree in exercise science who are trained and keenly aware of the special needs of persons with cancer; (3) there is no cost to participants; (4) it is perpetual, provided for the lifetime of the patient; and (5) participants’ caregivers are welcome to exercise at CFFL locations. The program is currently offered at 14 locations in northeast Texas and one location in Arizona. A home-based program is also available. To date, FSFL is the only known evidence-based cancer rehabilitation program in the United States that is community-based and is free to all participants for lifetime duration (Haas & Kimmel, 2011; Kimmel, Haas, & Hermanns, 2014). CFFL has a 15-year history of being highly successful in providing a safe and effective exercise program for persons diagnosed with cancer (Haas et al., 2012; Kimmel, Haas, & Hermanns, 2014). The 55% adherence to the exercise program is higher than the 48% national average for exercise participation. What is not clear is what factors contribute
to the success of this program. Melin-Johansson and colleagues (2015) explored the individual perspective of participating in a comprehensive rehabilitation exercise program. However, no studies that specifically examined exercise programs were located. Identifying the unique characteristics of the program that encourage participants to engage and adhere to exercise as a health promotion activity may benefit other communities that aspire to offer a similar program to improve patient outcomes and enhance quality of life.

**Purpose**

The purpose of this study was to explain the impact of a community based exercise program on the lives of persons with cancer and their caregivers. Specific research questions were:

1. How does the FSFL program impact exercise behavior?
2. Why is the FSFL environment conducive to a change in exercise behavior?
3. How does a change in exercise behavior affect quality of life?

**Design**

Prior to beginning the study, the investigators consulted with an experienced case study researcher. Next, the researchers independently reviewed case study designs, individually selecting an appropriate design. The investigators then met and extensively discussed the approach. The primary author has an extensive background in oncology and has served on the board of directors for CFFL for many years. She also serves as the CFFL Research Director. The second author has a strong background in qualitative methods. She and the primary author have collaborated on a number of research projects focusing on quality of life in chronic illness. The third author has a background in oncology and palliative care; she also has expertise in qualitative methods. During her dissertation, the third author connected with the primary author to use her quality of life model (Haas, 1999). Later she came to the United States to work with the primary author; it was during this time the current research project was developed and conducted. The research team has continued to collaborate following her return to Sweden. Research questions were derived and the study protocol was developed, with agreement among the researchers to allow for flexibility as the study progressed.

A single explanatory case study with multiple embedded units of analyses was identified as the appropriate design for this study as this type of methodology is designed to analyze a unique case, which can be a company, a person, or an event (Yin, 2014). This methodology captures the complexity of the research problems and provides a deep understanding of both the phenomena and its context. Additionally, it seeks to answer the “how/why” type questions (Yin, 2014) and is used to understand the uniqueness of the CFFL program (Haas & Kimmel, 2011; Haas, Kimmel, Hermanns, & Deal, 2012).

**Theory and Propositions**

Bandura’s Social Cognitive Theory (1986) served as the theoretical basis to guide this study. Bandura proposes a triadic reciprocation among person/behavior/environment. The theoretical concepts for this case study are represented by: CFFL FSFL program (environment); exercise (behavior); and QOL (person).

In accordance with case study design (Yin, 2014), theoretical propositions were made:
1. The FSFL program (environment) will increase exercise (behavior).
2. The FSFL program provides a unique setting (environment) to support persons with cancer to engage in exercise (behavior).
3. Engaging in an exercise program (behavior) will lead to an improved QOL (person), as evidenced by increased independence, decreased stress, increased energy, and increased functional status.

Sample and Setting

Following Institutional Review Board approval, a purposeful sample was selected. Creswell (2014) purports that purposeful sampling allows the researcher to select individuals and sites for a study to inform an understanding of the research problem. Yin (2014) contends that multiple cases are selected carefully so that the researcher can predict similar results across cases. In line with the suggestions of Creswell and Yin, the cases for this study were selected purposively, in an effort to provide the best presentation of the phenomenon across cases. The sample (n=10) represented three units of analysis: (1) four individuals with cancer participating in the FSFL program, (2) three caregivers whose spouses were both participants in FSFL and in this study, and (3) three healthcare providers working in the FSFL program. The FSFL participants were selected to represent a range of ages, gender, cancer diagnoses and stages, and presence/absence of co-morbidities (Table 1). The rationale for seeking maximum variation was to hear perspectives of individuals with different life and cancer experiences. The settings for the interviews included two different FSFL sites in east Texas and one home-based location. Records and documents were accessed through FSFL headquarters.

Table 1. Description of the Participants with Cancer

<table>
<thead>
<tr>
<th></th>
<th>Gender</th>
<th>Stage, Diagnosis, Co-Morbidities</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) 73 year old</td>
<td>male</td>
<td>Stage I penile cancer, Parkinson’s</td>
</tr>
<tr>
<td>(B) 57 year old</td>
<td>male</td>
<td>Stage IV brain cancer</td>
</tr>
<tr>
<td>(C) 72 year old</td>
<td>male</td>
<td>Stage IV melanoma, rheumatoid arthritis</td>
</tr>
<tr>
<td>(D) 34 year old</td>
<td>female</td>
<td>Stage I-II breast cancer</td>
</tr>
</tbody>
</table>

Methods

Procedures

As recommended by Yin (2014), a protocol was developed to guide data collection for the case study; all researchers had access to all the information regarding the research procedures applied in order that the case study could be replicated. Additionally, an interview guide was developed (See Appendix A).

Yin (2014) contends that embedded case studies include collecting various levels or sources of data. In this study, primary and secondary data were collected. Interviews were the primary method of data collection. Appointments were made and the interviews were conducted at a private location and time convenient to the participant. Seven (n=7) interviews were conducted using a semi-structured approach. The three caregiver spouses were...
interviewed concurrently with the exercise participant. The semi-structured approach allowed the opportunity to ask for additional information as well as explore unexpected ideas shared by participants (Hesse-Biber & Leavy, 2010). Secondary data were collected through observation of the participants exercising at the FSFL center along with observations made during the interviews. Documents, including exercise logs and participants' files, along with video records of participants progressing over time also contributed to observations and provided multiple data sources.

The interviews were audio recorded and transcribed verbatim. Two interviewers were present for three interviews; in each case the qualitative expert from Sweden, who conducted the interviews, was accompanied by the primary author who was present to augment rapport and trust. There were also two participants present (patient and caregiver) so that a single participant would not feel intimidated by having two researchers present. Four interviews were conducted by one interviewer with one or two participants present (patient or healthcare providers).

Data Analysis

The descriptive and interpretive lens of Yin’s (2014) ideological methodology was used to analyze the data. Yin describes five analytic techniques: pattern matching, explanation building, time-series analysis, logic models, and cross-case synthesis. Explanation building, a subset of pattern matching, is built on theoretical propositions and was deemed the most appropriate since the FSFL program and this study were based on Bandura’s (1986) Social Cognitive Theory (SCT). Throughout this iterative process Bandura’s SCT guided the analyses. Data collection and analysis were done concurrently.

The process of data analysis began with reflecting on the questions from the study protocol. Following each interview, the transcripts were reviewed to ascertain whether the research questions were adequately addressed and evaluated to determine if propositions needed revision.

The transcripts were reviewed multiple times and line-by-line analysis was used (Miles, Huberman, & Saldaña, 2014). Manual open coding was used to extract patterns and themes from the transcriptions as well as reviewing the added notations from the multiple sources of data (Miles, Huberman, & Saldaña, 2014). Once individual researchers identified patterns and themes, the researchers jointly reviewed for intercoder agreement; consistency of over 95% was established (Lincoln & Guba, 1985). Using the three theoretical propositions as a guide, tentative connections were established and assessed for fit (Yin, 2014). As a final step, a table for data display was created (see Table 2).

Quality Control

Four criteria are recommended to ensure rigor of a case study design: (1) construct validity, (2) internal validity, (3) external validity, and (4) reliability (Yin, 2014). Construct validity was maintained through the use of multiple sources of data and creating a chain of evidence during the data collection phase. Primary data were collected from participants, caregivers, and health care providers. Secondary data were collected through observation, interviews, documents, and video records. Key informants reviewed the draft of the case study to ensure validity of the findings (Lincoln & Guba, 1985).

Internal validity was established by explanation building and exploring rival explanations (Yin, 2014). Explanation building, a type of pattern matching, refers to the process of explicating ‘how’ and ‘why’ something occurs. Explanatory case studies typically rely on narrative data to support or refute theoretical propositions (Yin, 2014). During data
analyses, narrative data provided strong support for study propositions. Rival explanations refer to the examination of alternative influences that may account for the “how” and “why” something occurs (Yin, 2014). In this case study, consideration was given to alternative influences on participants’ experiences. During the research design phase, external validity was addressed through the use of Bandura’s (1986) SCT to guide study development. As recommended by Yin (2014), generalizability was established by collecting the data at multiple locations. In addition, the sample represented different genders, age groups, diagnoses, and physical abilities. A protocol was established and strictly followed to ensure reliability and that the findings were consistent with collected data. Adherence to “how” and “why” questions contributed to establishment of external validity (Yin, 2014). Additionally, appropriate documentation and record keeping was maintained in an effort to reduce errors and minimize biases (Yin, 2014).

Findings

Themes

The findings of this study confirm the benefits of the FSFL program through subjective data as shared by the participants, their caregivers, and FSFL care providers. Findings were further supported by objective data gleaned from existing documents and video recording.

Findings were grouped into three themes: (1) Bridging the Gap, (2) Sense of Community/Building Relationships, and (3) Living Life Abundantly. Though unplanned, the three themes corresponded directly with the research questions. The themes and sub-themes are listed below.

Table 2. Themes and Sub-themes

<table>
<thead>
<tr>
<th>Research Questions and Theoretical Propositions</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>RQ 1: How does the FSFL program impact exercise behavior?</td>
<td>Sense of Community</td>
<td>• Responsibility to One Another</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Caregiver Involvement</td>
</tr>
<tr>
<td>P 1: The FSFL program (environment) will increase exercise (behavior).</td>
<td>Building Relationships</td>
<td>• Companionship</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social-to-Social Interactions</td>
</tr>
<tr>
<td>RQ 2: Why is the FSFL environment conducive to a change in exercise behavior?</td>
<td>Bridging the Gap</td>
<td>• Investment in Individualized Time</td>
</tr>
<tr>
<td>P 2: The FSFL program provides a unique setting (environment) to support persons with cancer to engage in exercise (behavior).</td>
<td></td>
<td>• Feeling Special/Safe</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Fiscally Possible</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Encouragement</td>
</tr>
<tr>
<td>RQ 3: How does a change in exercise behavior affect quality of life?</td>
<td>Living Life Abundantly</td>
<td>• Quality of Life</td>
</tr>
<tr>
<td>P 3: Engaging in an exercise program (behavior) will lead to an improved QOL</td>
<td></td>
<td></td>
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</tbody>
</table>
Sense of Community

When asked, “Why is the CFFL FSFL environment conducive to a change in exercise behavior?” participants remarked that it was a sense of community and building relationships at the FSFL that contributed to a change in their exercise behavior. These two themes were each grouped into sub-themes. Sense of Community included two sub-themes: (1) Responsibility to other participants and (2) Caregiver involvement.

Responsibility to One Another

In addition to the companionship and the social interaction, further validation of why the FSFL environment is conducive to changing exercise behavior is because the participants felt a responsibility to the other participants. This was evident in comments shared by the exercise participants. The cancer diagnosis brings the participants closer because they can relate to each other and support each other. This support is witnessed in their commitment to exercise at FSFL because they feel a sense of responsibility to support each other. For example, Participant E discussed a conversation with another program participant and noted “…just even a minute ago I was talking to X and she was telling me that I always have a positive attitude and that she appreciates that, it makes me want to be that way so much more… “She further commented “I hope by coming it encourages them to stick with it because I know they encourage me a lot.” Echoed in the sentiments of participants, the responsibility to participants was also shared by the CFFL healthcare provider

…because cancer patients feel blessed when they can help someone else. There’s no more gratitude they experience because they know what this suffering is and I can help this person through this suffering period. So it engenders an enormous amount of support within this exercise activity together, so that’s an important part, I think, if what we try to do is encourage relationship building.

The participants’ comments, coupled with those of the staff clearly attribute the uniqueness of the FSFL environment to the participants’ increase in exercise behavior. Many of the participants have been exercising at the FSFL program for years. It is hypothesized that without such an environment, the commitment to exercise in this population would not be sustainable. As the wife of Participant C stated: “He liked being accountable, liked having goals.” The responsibility to other participants, caregivers, and healthcare providers was evident in the narratives and the long-term participation of the participants.

Caregiver Involvement

An additional factor unique to FSFL that was also attributed to an increase in exercise participation in the cancer population is caregiver involvement. Participants and their caregivers can exercise together. An instance was shared when the wife of Participant A spoke about how she and her husband were exercising together until she had a medical condition that prevented her from exercising. She was adamant that she would return to
exercising with him, and during her hiatus she stated, “I am trying to help with the [FSFL] fundraiser.” The caregiver involvement was witnessed in many facets.

**Building Relationships**

The second theme to emerge from the question, “Why is the CFFL FSFL environment conducive to a change in exercise behavior?” was Building Relationships. This theme also included two sub-themes: (1) Companionship and (2) Social-to-Social Interaction.

**Companionship**

Companionship was the sub-theme that supported the proposition that the FSFL program increased exercise. Participant B talked about the importance of having other patients around.

Most of them have been around longer than me. They are in good shape, you see them performing and say I wish I could do that…and you know, I am still not as good on the treadmill as they are.

A young female, Participant D, commented, “the camaraderie. There’s a lot of really nice people here. Uhm, in…no one is judgmental or…they are just real encouraging and positive. I really enjoy it.” The caregiver and wife of Participant A stated: “He has friends here; people he looks forward to seeing.” A CFFL healthcare provider stated, And I think the wonderful thing I see in our facilities, or if you can get these folks together is, the incredible um, companionship of sharing this burden if you will and turning it from a burden into a sense a blessing…

Participant D talked about another participant who was also a volunteer,

She was telling me that she had cancer a couple of years ago, so even though we don’t talk about it a lot just knowing that someone has been through the same kind of things you feel kind of connected to them and that helps I think.”

She went on to passionately state, “they miss you when you’re gone…

Countless other stories of companionship among the participants were shared, and, reflections of instances in which companionship was felt between the participants and CFFL FSFL personnel were also shared.

**Social-to-Social Interaction**

Social-to-social interaction was identified as a unique aspect of the FSFL environment that provided the impetus for the participants to return to the program and continue to exercise. Social-to-social interaction differs from companionship as it goes beyond the camaraderie established by persons sharing a space. The social-to-social interaction extends camaraderie by building relationships that encourage and foster a commitment to exercise. Participant B’s wife noted: “They [the participants at FSFL] are all very passionate and want to improve. We exchange stories of our lives.” Participant A’s wife commented “…people he looks forward to seeing…You can do it. You can do it. You can do it.” Participant C stated “I think what I enjoy the most is having people come who care; that means a lot to me.” The
supportive environment fostered by a social interaction is deemed to be instrumental in the success of the commitment to exercise and improve.

**Bridging the Gap**

Bridging the Gap was one of the content themes that emerged from the individual interviews as well as the video and observation data supporting the second proposition: The FSFL program provides a unique setting (environment) to support persons with cancer to engage in exercise (behavior). The definition of the term, bridge is to make a connection where there is a great difference (http://idioms.thefreedictionary.com/bridge+the+gap). FSFL is bridging the gap as stated by a CFFL healthcare provider, “so our tools are living tools, that’s why its FIT Steps for Life. It is your steps to living a full life and that’s what it’s all about.” Three sub-themes emerged within the “Bridging the Gap” umbrella: investment in individualized time, special/safe, and encouragement.

**Investment in Individualized Time**

Investment in individualized time was repeated throughout the transcripts. The unique characteristic of individualized time invested by FSFL health care providers was echoed repeatedly. Participant A’s wife commented, “They don’t ever leave him – from the time he gets here ‘til the time he leaves, they’re 100% with him. They have a plan and work their plan.” Many of the participants shared their experiences with other therapies and attempts to exercise. For example, the wife of Participant A stated that he was dismissed from physical therapy: “So, he’s been fired by two physical therapists...the PTs said that you’re not educable, we can’t handle you, we’re not coming back, can’t do a thing with you.” Participant A stated, “I’ve been very fortunate to...have some personal attention. They give me personal attention.” Healthcare personnel at FSFL stated “bring him here every day and I’ll have him playing golf.” Participants and their caregivers emphatically stated that FSFL provided the participant with individualized time to work on their individualized exercise regime. One of the staff members stated,

The difference between the population we work with and athletes, you know, you tell an athlete to run through a brick wall and they can do it – they can do anything you tell them to do. You know whereas with this population you have to really, carefully kind of tailor their exercise program so you know what their needs are and what they are capable of doing. Well, the reality of it is you look at the guidelines of exercise and they are not for someone that is 70 years old with cancer plus several other conditions. But you kind of have to meet them where they are. You’re not going to do them any good trying to force them to meet these guidelines quickly so you have to meet them where they are and see what they can do and kind of progress them from there.

Similar to other entities, the exercise is individualized; unique to FSFL is the fact that there are no constraints in terms of reimbursement and if no progress is seen, FSFL does not dismiss the participant.
Feeling Special/Safe

The FSFL setting was viewed as a supportive and safe environment that recognized that each participant was a special person; this aided in supporting the participants to participate in exercise. The wife of Participant A passionately observed,

You can see how each person who walks through that door is treated. They are treated as an individual. It’s not a number…oh here is [name]…you know, they ask how they…you…are. They really care – it’s really a family. Uhm, and, there’s no embarrassment. You fall or stumble or trip or look like an idiot – nobody cares. There’s no danger – it’s safe. You can’t say that about very many places. Mentally, emotionally, physically, spiritually safe. That gives the courage to try.

Participant B fervently shared “I am somebody up here. They know who I am and what I need and they are willing to help me. I felt like a number before.”

Fiscally Possible

Several participants noted the importance of the cost free aspect of the program; eliminating the financial burden made it possible to participate in structured exercise. Participant B’s wife explained that physical therapy was discontinued because “the insurance ran out.” Participant B added, “I feel like I’ve gained more from this program for free than I have spending hundreds of thousands of dollars in other programs”. Participant D appreciatively stated,

I love that it’s free. That’s huge. I mean that was another reason I didn’t go to the gym—we have three kids and money is tight—so we can’t afford to do a lot of stuff. So that is a huge factor…

One of the health care providers further explained the cost implications of cancer care and the importance of a cost free program: “…just for the chemo was $19k every 3 months. Doesn’t include blood counts, doctor visits…think about that. If you’re a young couple and insurance pays 80% of that…every few weeks or 6 months…that’s HUGE!”

Encouragement

Encouragement was repeated in the majority of the participant and caregiver interviews and the personnel interview. The encouragement at FSFL was determined to be an impetus to increase exercise. An exemplar was shared by Participant A’s caregiver,

After 10 years of Parkinson’s with him, uh, this has saved our life. Uh, it is our life. It isn’t just a nice place to come, or they do a good job, or aren’t they sweet, or, or they have nice equipment, - nothing like this. It’s literally a spiritual, mental, emotional, and physical experience – balance and love, training, professionalism, guidance, encouragement, sensitivity, intuition, and inspirational. They keep him interested by varying his activities and notching them up every single day. You can do it. You can do it. You can do it.
Encouragement was also exemplified in the statement made by Participant B’s caregiver,

We are really happy to be here. Really happy with the staff that we’ve met. I haven’t met a negative person. ‘Don’t waste your time on him; he will die in three weeks.’ I certainly don’t believe that and I never did believe that but I was told that several times…and you know, you shouldn’t waste your time up here in the hospital doing things that are not going to help you and so, I don’t blame them for that.

When asked what was different about FSFL, Participant C, the 72 year old male stated, “he was so encouraging and said I know you can do it, you’ve got strength in your muscles. FSFL saved my life. I really believe that. The doctor came along and he uh gave me a lot of positive words and a lot of encouragement…And I think that’s a big, big boost for me.” Further, Participant D, the 34 year old, stated, “I hope by coming it encourages them [other participants] to stick with it because I know they encourage me a lot…One day all the treadmills were full so I tried to get on the elliptical… there’s an ancient little old man next to me and he’s going…I don’t know how much time was on his thing, but he’d been on there a long time and I was at 2 minutes and I WAS ABOUT TO DIE! I thought... if he can do it…I gotta keep going!” One of the health care providers reinforced the importance of encouragement, stating, “We obviously are going to be encouraging and…really part of that is goal setting, too…” Another FSFL healthcare provider stated, “So it engenders an enormous amount of support within this exercise activity together, so that’s an important part I think of what we try to do is encourage relationship building.”

Living Life Abundantly

Living Life Abundantly was the overarching theme in which the sub-theme, quality of life emerged when the participants and their caregivers talked about the improvement in their quality of life. Findings supported Proposition 3, which stated: Engaging in an exercise program (behavior) will lead to an improved QOL (person), as evidenced by increased independence, decreased stress, increased energy, and increased functional status.

Since starting FSFL, Participant A’s caregiver stated that “It’s a night and day difference from a week ago.” Participant B’s wife attested to the improvement in quality of life,

quality of life has improved greatly. He couldn’t do anything. He really couldn’t. He didn’t have quality of life. Every day now there is some improvement. He is able to basically be able to function very well around the house and it’s because of the muscle strength he’s built and he’s able to resume his quality of life which affects my quality of life, our quality of life.

Participant D enthusiastically declared, “I feel like I’m in better…I mean I just feel better.” Functional status improved significantly. This is evidenced by interviews, records, and video documentation. Participant A’s caregiver reported,

Upon the first visit, he was able to walk 2-3 seconds at 1.3 mph on the treadmill, with assistance. By day 112, he was able to walk 28 minutes at 2.0 mph on the treadmill and complete 2 minutes on the elliptical. This is one of many examples of physical improvement the unique, tailored FSFL program
offered through the CFLL environment supported active engagement in exercise.

Further, Participant C’s wife stated,

you know what has really helped since we started the program, I have not had to call 911 in two weeks…I was having to call them because he was falling. I was having to call them sometimes three times a weekend.

The stories of significant physical and psychological improvements as a result of participating in FSFL were repetitively noted by participants and caregivers as well as the health care providers. As an FSFL provider passionately stated, “we gave them tools it awakened a whole new opportunity for their whole life. So we restore, in a sense, meaning to their life…”

Discussion

Using a single explanatory case study with multiple embedded units of analyses approach allowed for exploration and evaluation of the unique factors that contribute to the success of a community based exercise program on the lives of persons with cancer as well as the caregivers. While case studies are deemed to be a weaker design as compared to other research designs (Miles, Huberman, & Saldana, 2014; Yin, 2014), a single explanatory design with multiple units of analysis was determined to be the best approach to evaluate the effectiveness of the FSFL program. The strengths of this study include the use of multiple sources of evidence, triangulation from multiple sources, and careful attention to quality control measures.

Proposition 1

Proposition 1, which stated the FSFL program (environment) will increase exercise (behavior), was supported in this case study. The benefits of exercise are well-established for persons with cancer (Banzer et al., 2014; Ferrer et al., 2011; Haas, et al., 2012). Less clear is how to engage participants in exercise. Multiple data sources provided evidence that participants, in spite of advanced disease and co-morbidities, increased physical activity as a result of participating in FSFL. According to Bandura’s (1986) Social Cognitive Theory, the environment will influence behavior. The FSFL program appears to provide a supportive environment that is unique when compared to other many health care settings.

The commonalities shared by the participants at FSFL (e.g., all were cancer survivors or caregivers) contributed to their sense of community. The relationships built among participants fostered a supportive environment that offered companionship and social support. Beyond the relationships established, the FSFL environment cultivated a sense of responsibility to one another. Unlike most standard rehabilitation programs, caregivers were also engaged in the exercise program, further contributing to a sense of community.

Proposition 2

Proposition 2, the FSFL program provides a unique setting (environment) to support persons with cancer to engage in exercise (behavior), was also supported by study findings. Mina and colleagues (2012) purported the limited cancer rehabilitation and resources available. While most rehabilitation programs are subject to financial constraints, this case
study demonstrated the effectiveness of a unique not-for-profit community-based program. The FSFL program bridges a gap frequently experienced by the participants in standard rehabilitation programs. Offered at no cost to participants and with no time limitations, FSFL is unique when compared to other exercise programs. While other program personnel certainly care about their constituents, the participants in this study openly and repeatedly discussed the caring and encouraging nature of the FSFL staff. When compared to standard rehabilitation programs, the participants commented they did not feel like a number; conversely, they felt part of a family and that the staff genuinely cared for them. Without pressure to produce results in a pre-determined timeframe or to see ‘X’ number of patients in a given day, the FSFL staff are able to devote time to individuals to develop deep and meaningful relationships, resulting in an environment conducive to changing exercise behavior.

Proposition 3

The final proposition, engaging in an exercise program (behavior) will lead to an improved QOL (person), as evidenced by increased independence, decreased stress, increased energy, and increased functional status, was partially supported. Previous research supports the physical and psychological benefits of exercise for persons with cancer (Banzer et al., 2014; Ferrer, Huedo-Medina, Johnson, Ryan, & Pescatello, 2011; Haas, 2011; Kimmel, Haas, & Hermanns, 2014). Similar to other studies of exercise for persons with cancer, participants, caregivers, and health care providers in this case study consistently described a dramatic improvement in quality of life for FSFL participants. Multiple sources provided evidence for increased independence and functional status. While implied, no participants explicitly stated a decrease in stress or an increase in energy levels as a result of the program. Several specifically addressed improved quality of life. Clearly conveyed was the program’s impact on participants’ ability to live life abundantly.

Generalizability is limited in that all participants, caregivers, and health care providers were Caucasian. While several wives participated, no male spouses or partners were represented. In addition, the uniqueness of this program may not represent cancer rehabilitation programs in other locations. However, this program can be replicated through the innovative use of existing resources and community support. Practitioners need to be aware of the benefit of supporting patients to remain active during and following cancer treatment. Providers should explore partnerships with local organizations to provide a similar program specifically designed for the cancer population in their own communities. The lack of reimbursement limits exercise referrals for persons with cancer. In addition, physicians have little incentive to make referrals when an effective program is not available. Health care providers can advocate for such community programs through their professional organizations and legislative representatives. This case study did not identify any influence on stress; future research studies are recommended to determine impact. Additional research should explore the cost benefits of community-exercise programs, examining the impact of such programs on medication costs, medical equipment, home health services, and comorbidities. Implementing these recommendations will challenge the current cancer treatment paradigm and provide an avenue to support exercise in the cancer population.

References


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Appendix A. Interview Guide

CFFL Case Study Research
Interview Guide

- Prior to interview, discuss study (why, aim)
- Obtain signed consent
- Begin tape recording
- Direct questions to patient; caregiver present and provides supplemental information
  1. What has the FitSteps for Life (FSFL) program meant to you?
     Prompts:
     “Can you tell me more?”
     “Can you explain that?”
     “What did you think about that?”
     “How did you feel about that?”
  2. Has the FSFL program changed your life? Please explain.
     Prompts:
     “Is there something about the program that keeps you coming back?”

Healthcare provider questions:

1. What do you think this program has done for XXX?
2. How do you think it has changed their life (or has it)?
3. From your perspective, were there any unanticipated benefits XXX experienced by being in this program? Please explain.

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