Use of a DVD-based Strength Training Program by Breast Cancer Survivors in the Home Setting

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UNIVERSITY OF MIAMI

USE OF A DVD-BASED STRENGTH TRAINING PROGRAM BY BREAST CANCER SURVIVORS IN THE HOME SETTING

By

Ashley Falcon

A DISSERTATION

Submitted to the Faculty of the University of Miami in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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USE OF A DVD-BASED STRENGTH TRAINING PROGRAM BY BREAST CANCER SURVIVORS IN THE HOME SETTING

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Background: Breast cancer (BCa) is the most common type of cancer diagnosed among women in the United States. Advances in cancer detection and treatment have led to improved survival, and focus has shifted towards addressing the adverse physiological and psychological effects associated with BCa and its treatments. Evidence supports regular physical activity (PA) as an effective means of managing the negative side effects of BCa treatments and improving health-related quality of life (QOL). Strength training is of particular importance for BCa survivors who experience treatment-related functional limitations. Despite this fact, PA levels among BCa survivors are below those recommended for health, and decline further after diagnosis. Healthcare professionals (HCP) have been considered an ideal source for exercise promotion; nonetheless, an inadequate number of HCPs recommend PA to their BCa patients. As such, there is a need to identify new mediums for delivering exercise information and instruction programming that incorporate BCa survivors’ preferences and can be easily used by HCPs to encourage PA among their patients.

Methods: Two studies were conducted successively. Study 1 was a qualitative analysis in which female BCa survivors were asked to view a DVD-based exercise program prior to
attending one of five focus groups. A semi-structured guide was used by a trained moderator to facilitate discussion. The focus groups were digitally recorded and later transcribed verbatim. Transcripts were analyzed using a thematic analysis approach based on principles of grounded theory. Study 2 was a randomized pilot trial conducted among 23 BCa patients who were 4-weeks to 2-years post-surgery. Women were randomly assigned to one of two 12-week interventions: 1) twice-weekly DVD-based strength training (ST), or 2) weekly health education (HE) DVD viewing. The primary outcome was upper body strength as measured by a one-repetition maximum (1-RM) chest press. Measures of safety (i.e. pain and lymphedema symptoms) and quality of life (i.e. SF-36, FACT-B, and fatigue) were also taken at baseline and post-intervention.

**Results:** For the first study, 45 BCa survivors were screened, 33 of whom participated in a focus group. The analysis resulted in two major themes: (1) factors that encourage, and (2) factors that serve as barriers to use of a DVD-based exercise program. Within these categories several sub-themes were identified, including changing notions of the relationship between physical activity and health status, pros and cons of using a DVD-based exercise program, information gaps in the healthcare setting, and time points of greater receptivity for use of a DVD-based exercise program. For the second study, 20 participants completed a post assessment. Mean adherence for study completers was 72.7% for ST and 75.0% for HE participants. A repeated measures ANCOVA, controlling for baseline measurements, time since surgery, and current treatment status, revealed a significant increase in upper body strength among ST participants (13.2 vs. 1.8 lbs., p=0.019), as well as significant improvements in shoulder flexion (right arm: 7.1 vs. -3.1°, p=0.001; left arm: 8.9 vs. -2.7°, p=0.006) and abduction (right arm: 12.5 vs. 3.5°, p=0.006).
p=0.012; left arm: 15.8 vs. 1.5°, p<0.001). HE participants showed greater QOL improvements in general QOL (p=0.029), fatigue-related disruption (p=0.005), and role limitations due to physical (p=0.002) and emotional (p=0.002) functioning.

**Discussion:** Study 1 findings suggest that DVD-based exercise programming is an acceptable resource for female BCa survivors. Identified themes can inform the development of future DVD-based exercise programs so that they adequately address BCa survivors' needs throughout the cancer continuum. Study 2 results demonstrate that post-operative BCa patients can safely use a DVD-based strength training program unsupervised in the home setting to improve upper body strength and range of motion. HCPs can feel confident about using proven DVD-based exercise programs to help their BCa patients regain strength and function after BCa surgery.
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Chapter 1
Introduction

Background

In 2014, breast cancer (BCa) continues to be the most common form of cancer diagnosed among women in the United States (Siegel et al., 2014). It is projected that one in eight American women (12.3%) will develop invasive BCa in their lifetime, with the probability of developing the chronic disease increasing with age (Siegel et al., 2014). An estimated 232,670 new cases of BCa are expected in 2014, accounting for 29% of all cancers diagnosed among women (Siegel et al., 2014). It also is predicted that BCa will be responsible for approximately 15% of cancer deaths among American women (Siegel et al., 2014).

Advances in cancer detection and treatment have led to increased survival rates among women with BCa. Based on data from 2003-2009, five-year relative survival rates have improved to 89% for all cancer stages, and as high as 99% for localized BCa (Howlader et al., 2014). As such, there are over 2.8 million BCa survivors currently living in the United States. Higher rates of survival have given rise to a shift of focus towards BCa survivorship concerns, as evidenced by the National Cancer Institute’s (NCI) establishment of the Office of Cancer Survivorship in 1996. The OCS is tasked with improving the quality of life (QOL) of cancer survivors, largely through efforts aiming at mitigating the negative effects of cancer and its treatments.
Breast Cancer Treatments and their Side Effects

Several types of treatment are available for BCa patients, including radiation therapy, chemotherapy, hormone therapy, targeted therapy, and surgery (NCI, 2014). Radiation therapy, delivered internally or externally, involves the administration of high energy x-rays used to kill or slow the growth of cancer cells, while chemotherapy aims to kill or stop cancer cell division using drugs that act regionally or systemically (NCI, 2014). Hormone therapy acts through the removal or inhibition of hormones that cause cancer cells to grow, while targeted therapy involves the use of drugs or other substances, such as antibodies, to target and attack specific cancer cells so that normal cells are left unharmed (NCI, 2014). Finally, BCa surgical options range from breast-conserving strategies, such as a lumpectomy or partial mastectomy, to more invasive options, such as a total mastectomy or modified radical mastectomy (NCI, 2014). During or in concert with BCa surgery, one or more lymph nodes also may be surgically removed (NCI, 2014). Depending on the diagnosed cancer stage, BCa treatment can include one or more of these treatment options, with many BCa survivors undergoing multiple treatments (NCI, 2014).

While undergoing one or more BCa treatments is often life-saving, treatments also can produce a number of adverse physiological and psychological secondary effects (Brem & Kumar, 2011; Markes et al., 2009; Reiger et al., 2009; Lee et al., 2008; Schneider et al., 2007; Albert et al. 2006; Bicego et al., 2006; Visovsky et al., 2006; Blomqvist et al., 2004). Potential physiological sequelae of BCa surgery include numbness, pain, reduced range of motion, decreased cardiovascular fitness, loss of muscle strength, lymphedema, and scarring (Brem & Kumar, 2011; Schmitz et al., 2010; Markes et al., 2009; Schneider...
et al., 2007; Albert et al. 2006; Blomqvist et al., 2004;). Other therapy options (i.e. radiation, chemotherapy, and hormone therapy) can cause additional physiological complications, including nausea and loss of appetite, hair loss, weight gain, immune suppression, skin damage, neuropathy, cardiotoxicity, and premature menopause (Brem & Kumar, 2011; Schmitz et al., 2010; Markes et al., 2009; NCI, 2009). In addition to the initial BCa diagnosis, these physical side effects can negatively impact psychological well-being by way of elevated levels of distress, fatigue, difficulty sleeping, loss of self-esteem, depression, and anxiety (Binkley et al., 2012; Byun & Kim, 2012; Reigle et al., 2009; Bicego et al., 2006; Visovsky et al., 2006). These treatment-related concerns have motivated the exploration of effective strategies to help improve the BCa survivorship experience.

Several strategies aimed at alleviating one or more negative side effects of BCa treatment have been evaluated. Mustian et al. (2007) conducted a review of integrative nonpharmacologic behavioral interventions for the management of cancer-related fatigue. Several therapies, including psychosocial interventions (i.e. stress management, coping skills, and education), mindfulness-based stress reduction, and sleep therapy, demonstrated significant improvements in cancer-related fatigue when compared to a control group (Mustian et al., 2007). Fors and colleagues (2011) have conducted a more recent review of psychosocial interventions among BCa survivors, reporting overall mixed results across intervention strategies. For instance, cognitive behavioral therapy has shown significant improvements in QOL both during and after primary treatment, while psychoeducation and social support interventions provided no conclusive results (Fors et al., 2011). In addition to interventions focusing solely on psychosocial
approaches, physical activity (PA) interventions also have been evaluated and provide promising results for the mitigation of a wider range of negative physiological and psychological treatment-related side effects (Loprinzi et al., 2011; Sabiston & Brunet., 2011; Schmitz et al., 2010a).

**Physical Activity among Breast Cancer Survivors**

*Aerobic Activity*

Habitual participation in aerobic activity has been shown to enhance BCa survivors’ health-related QOL and aid in the management of the negative side effects associated with BCa treatments (Loprinzi & Cardinal, 2011; Speck et al., 2009; Mustian et al., 2009; Cheema et al., 2008). A comprehensive review of the current evidence by a roundtable of the American College of Sports Medicine led to the recommendation that cancer survivors follow the 2008 Physical Activity Guidelines for Americans, making modifications for cancer type and treatment-related side effects if needed (Schmitz et al., 2010a). Intervention studies have demonstrated physiological improvements for immune function, as well as cardiovascular fitness, flexibility, and body composition (Loprinzi & Cardinal, 2011; Sabiston & Brunet., 2011). Other associated benefits of aerobic activity include improved sleep and sexual functioning, in addition to decreased pain and incontinence (Sabiston & Brunet., 2011). Aerobic activity intervention studies also has been shown to enhance QOL through a number of proposed mechanisms, including improved body image and self-esteem, improved mood (i.e. distress, anxiety, and depression), and reduced cancer-related fatigue (Loprinzi & Cardinal, 2011; Sabiston & Brunet., 2011). Furthermore, evidence from cohort studies show that BCa survivors who
participate in regular aerobic activity enjoy reduced risk of cancer recurrence and significantly lower risk of death relative to survivors who are not similarly active (Sabiston & Brunet., 2011; Irwin et al., 2008). For instance, Irwin and colleagues (2008) reported a 67% lower risk of death among BCa survivors who engaged in at least nine metabolic equivalent (MET) hours per week of aerobic activity two years post-diagnosis as compared to those who did not engage in aerobic activity.

Despite the proven benefits of regular aerobic activity, an insufficient number of BCa survivors are achieving recommended levels (Irwin et al., 2003; Courneya, et al., 1998). In a retrospective observational study, Courneya et al. (1997) reported that only 28% of BCa survivors performed regular aerobic activity during treatment. In a prospective cohort study, Irwin and colleagues (2004) reported that only 32% of women with BCa were meeting aerobic activity guidelines of 150 minutes per week of moderate-intensity aerobic activity three years post-diagnosis, as compared to 43% of women overall in the United States during the same time period (U.S. Department of Health and Human Services [USDHHS], 2010). Moreover, BCa survivors who were physically active prior to their BCa diagnosis often decrease their level of aerobic activity post-diagnosis (Irwin et al., 2004; Irwin et al., 2003). For example, Irwin et al. (2003) reported a decrease in aerobic activity from pre- to post-diagnosis of 58% and 62% among BCa survivors with Stage I and Stage II-IIIa BCa, respectively.

**Strength Training**

The focus on PA as a means of addressing side effects of BCa treatments has broadened from its initial focus on aerobic activity to also include other types of activity, including strength training. Strength training is of particular importance for BCa
survivors who experience muscle wasting and functional limitations directly resulting from BCa treatments (Loprinzi & Cardinal, 2011; Sabiston & Brunet., 2011; Smoot et al., 2010; Sweeney et al., 2006; Shamley et al., 2007). Previously, recommendations advised BCa survivors to limit the use of their affected arm (Kent, 1996). It was believed that use of the affected arm could result in the development of lymphedema (Schmitz et al., 2010b). However, more recent work has shown that strength training is both safe and effective for decreasing the occurrence of lymphedema exacerbations and symptoms (Strasser et al., 2013; Kwan et al., 2011; Schmitz et al., 2010c; Cheema et al., 2009; De Backer et al., 2009; Johansson et al., 2005). Improved muscular strength also aids in the performance of activities of daily living, can prevent injuries associated with disuse of the upper body, and improves body composition and bone health (Strasser et al., 2013; De Backer et al., 2009; Stevinson et al., 2007). BCa survivors may also experience psychological benefits, such as decreased distress and improved QOL, from participating in regular strength training (Steindorf et al., 2014; Ohira et al., 2006).

Rates of BCa survivors engaging in strength training are currently unknown. However, only 20.7% of all middle-aged women in the general population are meeting recommended guidelines of performing strengthening exercises at least twice weekly, with rates of participation dropping further with age (USDHHS, 2012; Physical Activity Guidelines Advisory Committee, 2008). Given the trends in aerobic activity among BCa survivors, as well as their PA levels relative to the general population, the rates of strength training among BCa survivors are expected to be lower than general population estimates and likely decrease further post-diagnosis (Stevinson et al., 2007; Irwin et al., 2004; Irwin et al., 2003).
Barriers to Physical Activity among Breast Cancer Survivors

Barriers to being physically active are common in the general population and are often even greater for BCa survivors who face the added challenge of BCa- and treatment-related side effects (Mustian et al., 2009). Lack of time and transportation, as well as cancer-related barriers such as fatigue and lack of energy, help explain why PA levels are low and decline post-diagnosis (Stevinson, 2010; Stevinson, et al., 2007; Irwin et al., 2004; Irwin et al., 2003). Fear of injury and the development of lymphedema also may continue to be barriers specific to strength training among BCa survivors (Schmitz et al., 2010b; Kent et al., 1996). These worries have been associated with a lack of information, including limited knowledge about side effects, their potential to linger long after surgery, and the interventions to treat them (Binkley et al., 2012). Greater efforts are needed to provide information to and encourage PA among BCa survivors to help overcome these barriers.

Healthcare Providers’ Role in Physical Activity Promotion

Healthcare providers (HCP) have been considered a logical choice as the promoters of PA given the positive influence that they have on their cancer patients (Karvinen et al., 2010). For instance, cancer survivors who have a discussion about exercise with their oncologist report greater frequency and more total minutes of aerobic activity than survivors whose oncologists did not initiate exercise discussions (Jones & Courneya, 2002; Segar et al., 1998). Likewise, BCa survivors have reported wanting to receive information and education regarding post-surgery impairments and activity limitations from HCPs (Binkley et al., 2012). Nevertheless, an insufficient number of HCPs
recommend PA to BCa survivors (Daley et al., 2008; Jones & Courneya, 2002; Denmark-Wahnefried et al., 2000; Segar et al., 1998; Young-McCaughan et al., 1991). Several barriers, including providers’ lack of time and unfamiliarity or uncertainty regarding the benefits of various types of PA for cancer patients, have been reported and may help explain this phenomenon (Karvinen et al., 2010; Stevinson et al., 2007; Jones et al., 2005). Updated guidelines that incorporate more recent data and encourage both aerobic activity and strength training among BCa survivors can help guide HCPs with their PA counseling (Schmitz et al., 2010a). Nevertheless, new methods of delivering educational information and exercise programming that can be used by HCPs in a way that overcomes provider-specific barriers and helps facilitate BCa patients’ uptake of PA, especially strength training, are essential.

**Breast Cancer Survivors’ Exercise Preferences and Home-Based Interventions**

In addition to the role HCPs may play in promoting PA, BCa survivors’ exercise preferences also should be taken into consideration in order to encourage participation in and maximize adherence to PA participation. Jones et al. (2002) surveyed predominantly BCa survivors (n=299) to determine their exercise programming preferences. The majority of cancer survivors preferred exercising unsupervised, at home, and alone in a program that starts before treatment. Among BCa survivors, home-based programs are preferred over in-person, clinic-based programs given that they help to eliminate barriers, such as lack of time and transportation (Rogers et al., 2008; Denmark-Wahnefried et al., 2000).

Previous research in this population has demonstrated the efficacy of home-based PA interventions on outcomes such as aerobic activity level, fatigue, QOL, and range of
The majority of these studies assessed walking interventions ranging from 12 to 26 weeks in duration (Cadmus et al., 2009; Matthews et al., 2007; Pinto et al., 2005; Segal et al., 2001). Significant increases in aerobic activity were found among BCa survivors post-treatment (Matthews et al., 2007; Pinto et al., 2005). A 4-week intervention that combined aerobic activity and strength training intervention demonstrated significant increases in days and minutes of strength training, as well as improvements in QOL and fatigue (Mustian et al., 2009); while a shoulder flexibility intervention showed a return to pre-surgery range of motion after engaging in stretching exercises for 105 days (Louzada-Petito et al., 2012).

A subsection of home-based PA interventions that utilize video- or digital video disc (DVD)-based exercise programs for BCa survivors are beginning to receive greater attention and may present a reliable means of providing trustworthy information to BCa survivors (Ingram et al., 2010; Haines et al., 2010; Kilgour et al., 2008; Mock et al., 2005; Headley et al., 2004; Ott et al., 2004). Two studies have assessed aerobic activity (i.e. walking and seated aerobic exercises) taught via videotape among BCa survivors undergoing treatment, reporting improvements in fatigue, functional capacity, and PA level (Mock et al, 2005; Headley et al., 2004). Kilgour et al. (2008) showed improvements in shoulder range of motion after an 11-day shoulder flexibility intervention in which stretching exercises were modeled via videotape. More recently, studies using a video or DVD have assessed combined interventions, joining strength training with aerobic activity and balance activities (Haines et al., 2010) or stretching (Ingram et al., 2010). Haines and colleagues (2010) found that a 6-month combined
intervention among BCa survivors undergoing chemotherapy provided short-term improvements in QOL and physical functioning, while Ingram and colleagues (2010) results are forthcoming. Resistance training also has been combined with other holistic treatments, including dietary supplementation and medication, yielding increases in the amount of weight lifted from baseline to 6-months in BCa survivors post-treatment (Ott et al., 2004). While efforts to assess DVD-based interventions among BCa survivors appear to be promising, additional research is needed to build upon this limited evidence base.

Studies that have used video- or DVD-based instruction have focused primarily on psychosocial outcomes and have typically included multimodal or aerobic-only training. Interventions that include strength training or similar activities have predominantly used proxy measures to assess upper body strength (i.e. dynamometry for assessing grip strength) and have, in all but one study (Haines et al., 2010), opted to use a usual care control group rather than an attention control. Further study is needed to assess the effectiveness of home-based strength training exercise programs using DVD instruction that have a primary focus on strength training for BCa survivors and can be easily disseminated in a clinical setting.

**The Strength & Courage DVD**

Strength & Courage (S&C) is a commercially available DVD-based exercise program designed to help BCa survivors regain flexibility and upper body strength post-surgery (S&C, 2007). The S&C DVD contains five chapters that consist of postural, post-operation, flexibility, and strengthening exercises, as well as information detailing aerobic exercise guidelines. An introductory chapter gives BCa survivors an overview of
the DVD, as well as encouragement to regain strength and function after BCa surgery. A certified personal trainer leads the exercises in Chapters 1 and 2, while an American College of Sports Medicine Health Fitness Specialist with an American Cancer Society cancer exercise trainer certification models exercises in Chapters 3 and 4. BCa survivors participate in the various exercises, as well as provide personal stories about their efforts to improve their strength and return to activities they enjoyed engaging in pre-surgery. Bonus features of the S&C DVD package include a section about the effects of strength training on lymphedema, as well as a printable exercise log. A description of the S&C DVD chapters, including recommended activity frequencies and progressions provided by chapter, is provided in Table 1.1.

Table 1.1. Strength & Courage DVD Chapter Descriptions and Recommended Activity Frequencies and Progressions.

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<th>Chapter Titles</th>
<th>Chapter Descriptions</th>
<th>Recommended Activity Frequency and Progression</th>
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<tr>
<td><strong>Chapter 1:</strong> Posture Exercises</td>
<td>8 stretches for the neck, shoulders, and back</td>
<td>5 repetitions per exercise, 2 times/day, progressing to 10 repetitions, 2 times/day</td>
</tr>
<tr>
<td><strong>Chapter 2:</strong> Post-operation Exercises</td>
<td>4 stretches for the shoulders and back</td>
<td>5 repetitions per exercise, 2-3 times/day, progressing to 10 repetitions, 2-3 times/day</td>
</tr>
<tr>
<td><strong>Chapter 3:</strong> Flexibility Exercises</td>
<td>Stretches for the neck, shoulders, back, and arms</td>
<td>Hold each stretch for 10-30 seconds</td>
</tr>
<tr>
<td><strong>Chapter 4:</strong> Strength Training Exercises</td>
<td>8 strengthening exercises for the chest, shoulders, and arms: wall push-up, chest press, front deltoid exercise, lateral raise, rear deltoid exercise, shoulder shrug, tricep kickback, and bicep curl</td>
<td>2 sets of 10 repetitions per exercise, 2 times/week using no or 1 pound weights progressing to 5 pound weights</td>
</tr>
<tr>
<td><strong>Chapter 5:</strong> Aerobic Exercise Recommendations</td>
<td>Discussion of weekly aerobic recommendations and encouragement to participation in aerobic activity (including walking, jogging, swimming and dancing)</td>
<td>15 minutes of moderate-intensity activity, 3-5 days/week, progressing to 30 minutes of moderate-intensity activity, 3-5 days/week</td>
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The S&C DVD is a standalone tool that may be well suited as a home-based exercise program. The informational sections provide BCa survivors with important information
about the safety of engaging in strength training post-surgery. Likewise, the modeling and modification of exercises encourages safe performance of recommended exercises. In fact, the DVD format may be integral in ensuring exercise safety while fulfilling the exercise programming preferences of BCa survivors. Currently, anecdotal evidence supports the usefulness of the S&C DVD (S&C, 2007), but scientific evaluation is needed to confirm the safety and efficacy of using the S&C DVD in an unsupervised, home setting.

**Theoretical Framework**

Although the S&C DVD does not directly discuss a theoretical framework, the DVD incorporates several constructs of the Social Cognitive Theory to encourage participation in PA (Glanz et al., 2008). The DVD-based program relies heavily on *observational learning* as it provides trained professionals and BCa survivors that model safe and appropriate performance of several exercises. The modeling of various exercises also aims to build *behavioral capacity*, providing BCa survivors with the knowledge and skills to safely and effectively perform strengthening exercises. In turn, greater knowledge and aptitude can positively influence BCa survivors’ *self-efficacy*, or the confidence in their abilities to safely perform the strengthening exercises. The introductory testimonials with BCa survivors sharing how the S&C DVD has benefited them may also help to encourage positive *outcome expectations* and *outcome expectancies* among BCa survivors who also intend to use the S&C DVD as they begin to anticipate and place value on the physiological and psychological benefits obtainable as a result of participation. Lastly, the use of the exercise log provided on the DVD can aid
BCa survivors with self-monitoring of their exercise sessions as they work to integrate regular PA into their lives.

**Dissertation Objectives and Overview**

Previous research has begun to assess the utility of home-based PA programs using video- or DVD-based instruction for BCa survivors (Ingram et al., 2010; Haines et al., 2010; Kilgour et al., 2008; Mock et al, 2005), but more attention is needed on home-based programs focusing on strength training. The S&C DVD is a promising intervention that may benefit BCa survivors, although scientific evidence is needed to confirm its effectiveness. This dissertation uses the S&C DVD to expand the research literature on the safety and effectiveness of home-based exercise programs focused on strength training for BCa survivors by exploring the following:

**SPECIFIC AIM 1:** To describe the PA beliefs, behaviors, and preferences of BCa survivors, particularly as they relate to strength training.

**Hypothesis 1:** Participants who believe PA is important for their health and well-being, will be more likely to engage in aerobic activity than strength training.

**SPECIFIC AIM 2:** To evaluate the acceptability of a DVD-based exercise program for BCa survivors post-surgery.

**Hypothesis 2:** There will be higher acceptance rates for using a DVD-based exercise program among BCa survivors who are: older versus younger; currently
inactive versus active; and those who have recently undergone BCa surgery versus those who underwent surgery less recently.

**SPECIFIC AIM 3:** To determine the effects of a 12-week DVD-based exercise program on muscular strength, assessed by a one-repetition maximum strength bench press test, of BCa survivors relative to a control group.

*Hypothesis 3:* Changes in muscular strength measurements from baseline to post-intervention will be significantly greater among the treatment group as compared to the control group.

**SPECIFIC AIM 4:** To examine the safety of a 12-week DVD-based exercise program for BCa survivors post-surgery by means of self-reported pain, upper body disabilities, and lymphedema symptoms relative to a control group.

*Hypothesis 4:* Changes in measures of safety from baseline to post-intervention will not be significantly different between the treatment and control groups.

**SPECIFIC AIM 5:** To assess the effects of a 12-week DVD-based exercise program on quality of life of BCa survivors post-surgery relative to a control group.

*Hypothesis 5:* Changes in quality of life measurements from baseline to post-intervention will be significantly greater among the treatment group as compared to the control group.

These objectives are examined in the subsequent chapters. Chapter 2 of this dissertation addresses Specific Aims 1 and 2, detailing findings from a qualitative
analysis of the acceptability of the S&C DVD among BCa survivors. Chapter 3 provides a detailed overview and examination of the process of and lessons learned regarding to recruiting BCa survivors from a clinical setting for participation in a DVD-based strength training intervention in the home setting. Chapter 4 addresses Specific Aims 3, 4, and 5, presenting the main findings of the DVD-based strength training intervention. Finally, Chapter 5 offers concluding remarks in an effort to summarize the overall findings and suggest future directions of scientific inquiry.
Chapter 2
Qualitative Assessment of a Strength Training DVD for Breast Cancer Survivors

Background

Nearly 2.9 million women are currently living with breast cancer (BCa) in the United States (Siegel et al., 2013). Whether recently diagnosed or in remission, BCa survivors commonly experience physiological and psychological side effects associated with BCa and its treatments (e.g. surgery, chemotherapy, radiation therapy, and hormone therapy). These side effects, including fatigue, pain, lymphedema, distress, reduced range of motion, and loss of physical functioning also adversely affect their quality of life (Courneya & Friedenreich, 1999; Courneya, 2003; Blomqvist et al., 2004; Albert et al., 2006; Bicego at al., 2006; Visovksy et al., 2006; Schneider et al., 2007; Markes et al., 2009; Reigle & Wonders, 2009).

Physical activity (PA), especially aerobic training, has been shown to effectively alleviate side effects experienced by BCa survivors (Segar et al., 1998; Mustian et al., 2009; Speck et al., 2010; Loprinzi & Cardinal, 2011; Sabiston & Brunet, 2011). Not only can regular PA help restore physical functioning and fitness, but it can also reduce fatigue, pain, and lymphedema symptoms as well as lower risk of death relative to inactive survivors (Irwin et al., 2003; Stevenson et al., 2007; De Backer et al., 2009; Loprinzi & Cardinal, 2011; Sabiston & Brunet, 2011). Strength training is especially beneficial for BCa survivors who experience significantly diminished upper body mobility and function as well as increased risk for lymphedema post-surgery (Cheema et al., 2008; De Backer et al., 2009; Schmitz et al., 2009).
Despite the proven benefits of regular PA, an insufficient number of BCa survivors meet recommended levels of aerobic activity; moreover, women who are physically active prior to diagnosis decrease their activity levels post-diagnosis (Courneya & Friedenreich, 1998; Irwin et al., 2003; Irwin et al., 2004; Stevenson et al., 2007; Schmitz et al., 2010a). While the prevalence of strength training behaviors among BCa survivors is currently unknown, trends in aerobic activity among BCa survivors coupled with low rates of strength training among middle-aged women in the general population, irrespective of cancer status, suggest low rates of strength training among BCa survivors (Centers for Disease Control, 2006). Interestingly, these findings conflict with previous depictions of BCa survivors as being highly motivated to make lifestyle changes or receive exercise counseling following a diagnosis (Jones & Courneya, 2002; Stevinson et al., 2007). It is likely that common barriers to being physically active are compounded by the added challenges of dealing with a cancer diagnosis, including treatment-related side effects (Mustian et al., 2009). For instance, general barriers like lack of time and transportation, as well as cancer-related fatigue, lack of energy, and fear of injury, may all help to explain some of the decreased activity (Irwin et al., 2003; Irwin et al., 2004; Stevinson et al., 2007; Stevinson, 2010). Research is needed to fully explain why PA levels are low and decline post-diagnosis in BCa survivors (Irwin et al., 2003; Irwin et al., 2004; Stevinson et al., 2007; Stevinson, 2010).

Healthcare providers (HCP) have been considered an ideal source for the provision of PA recommendations given their positive influence on cancer patients (Segar et al., 1998; Jones & Courneya, 2002; Karvinen et al., 2010). Nevertheless, an insufficient number of HCPs recommend PA to BCa survivors (Young-McCaughan & Sexton, 1991; Segar et
al., 1998; Jones & Courneya, 2002; Daley et al., 2008). Consequently, alternative methods of delivering educational information and exercise programming aimed at increasing PA levels among BCa survivors are needed. Approaches that take BCa survivors’ preferences into consideration are ideal as they are likely to maximize adherence. Jones and Courneya (2002) surveyed 299 survivors, predominately BCa survivors, to determine exercise programming preferences. The majority of survivors preferred to exercise unsupervised, at home, and alone in a program that would start before treatment (Jones & Courneya, 2002). Denmark-Wahnefried et al. (2000) reported that among BCa survivors home-based programs were preferred over in-person, clinic-based programs given that they help to eliminate barriers such as lack of time and transportation. In fact, DVDs providing exercise instruction to BCa survivors have been used in a handful of research studies and are available for purchase (Mustian et al., 2009; Haines et al., 2010; Ingram et al., 2010). Nevertheless, to our knowledge, no studies have assessed the acceptability of a DVD-based exercise program that can be completed in the home setting without supervision.

Hence, the purpose of this study is to evaluate women BCa survivors’ perceptions of a DVD-based exercise program that can be completed in the home. What are these women’s perceptions of a DVD-based exercise program? Do they differ by factors such as age, pre-diagnosis PA levels, or time since surgery and/or treatment? To answer these types of questions, BCa survivors’ PA beliefs, behaviors, and preferences were examined by conducting a series of focus groups with women who are BCa survivors.
Methods

Participants

A total of five focus groups were conducted with 33 BCa survivors to ascertain their perceptions of a DVD-based exercise program. Eligible BCa survivors were recruited between August and December 2012 from the South Florida area. Recruitment efforts included outreach to local BCa support groups and the local cancer center, emails to cancer survivor listservs, flyers, mailed letters, and in-person introductions. Interested individuals were encouraged to contact me via telephone or email. Women were eligible to participate in the focus groups if they were 18 years of age or older, had access to a television and DVD player at home, were English-speaking, and had a history of BCa, regardless of stage, surgery, or treatment status.

Procedures

Initially, Study staff conducted a telephone screening call with interested BCa survivors where verbal consent was obtained and study staff confirmed their eligibility. During the telephone conversation, study staff also collected demographic information, as well as participants’ familiarity with PA guidelines and perceptions of the importance of PA in their lives. Interested participants then were mailed a follow-up letter with instructions regarding their focus group, along with a copy of “Strength & Courage,” a DVD-based exercise program designed to help BCa survivors regain flexibility and upper body strength post-surgery (Strength & Courage, 2007). Interested participants then were asked to view the DVD prior to attending the focus group. Reminder telephone calls were made to participants one day prior to their focus group.
Four focus groups were held at a local wellness center, while the fifth was held at a BCa support group meeting location. At each focus group, a semi-structured guide was used to facilitate discussion. Focus groups began with an introduction of the moderator, a review of the purpose of the study, and ground rules for the gathering. Next, participants were asked to provide written informed consent and to complete the Godin Leisure-Time Exercise Questionnaire, a self-administered 4-item survey of leisure-time exercise behaviors (Godin & Shepard, 1997). The focus groups began with general inquiries about awareness and knowledge about PA followed by specific questions about the DVD-based exercise program, including positive perceptions of the program, receptivity to the program, barriers to using the DVD, and suggestions for program improvements (Table 2.1). Probing questions were used to elicit more detailed responses when necessary. All

**Table 2.1. Focus Group Questions.**

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Tell me about how people exercise where you live. Are a lot of people physically active?</td>
</tr>
<tr>
<td>2</td>
<td>In what ways do you like to be physically active? If not, why?</td>
</tr>
<tr>
<td>3</td>
<td>Tell me about how physical activity can be related to health – do you believe there is a relationship? If no, why not?</td>
</tr>
<tr>
<td>4</td>
<td>Since your diagnosis, have you thought more about physical activity or exercise and health?</td>
</tr>
<tr>
<td>5</td>
<td>What did you like most about the overall video?</td>
</tr>
<tr>
<td>6</td>
<td>What did you like least about the overall video?</td>
</tr>
<tr>
<td>7</td>
<td>How clear were the exercise instructions and demonstrations? Please explain.</td>
</tr>
<tr>
<td>8</td>
<td>How usefulness did you find the educational and safety information?</td>
</tr>
<tr>
<td>9</td>
<td>Because all of you have experience with breast cancer, at what time during your cancer experience would you be most receptive to using this DVD?</td>
</tr>
<tr>
<td>10</td>
<td>What, if any, parts of the DVD motivate you to be physically active?</td>
</tr>
<tr>
<td>11</td>
<td>If your oncologist or surgeon told you to use this program, or a similar one, are you likely to listen and do the physical activities? Why or why not?</td>
</tr>
<tr>
<td>12</td>
<td>Is there anything that would keep you from regularly using this DVD? If so, what?</td>
</tr>
<tr>
<td>13</td>
<td>In what ways would regular use of this DVD-based exercise program benefit you?</td>
</tr>
<tr>
<td>14</td>
<td>How would you compare this type of exercise program compared to other alternatives (i.e. clinic-based supervised exercise, gyms, etc.)?</td>
</tr>
<tr>
<td>15</td>
<td>What suggestions would you have for other women like yourself who are considering participating in an exercise program like this one?</td>
</tr>
<tr>
<td>16</td>
<td>What, if anything, should the DVD include that it currently does not?</td>
</tr>
</tbody>
</table>
focus groups were digitally recorded and transcribed verbatim. The study was conducted with the approval of the University of Miami’s Institutional Review Board. Participants provided written consent at the start of each focus group.

Data Collection & Analysis

Following each focus group, content notes on nonverbal communication were documented as supplements to the focus group transcripts. Study staff analyzed transcripts and notes using a thematic analysis approach based on principles of grounded theory, a systematic means of developing data-driven theory. The thematic analysis required the identification of themes, which are described by the respondents either implicitly or explicitly (Guest et al., 2012). Themes were created based on questions that were developed a priori, as well as on emergent topics that came up during the course of the focus groups. Since qualitative analysis is both an inductive and iterative process, themes and coding categories were compared across focus groups and build upon one another (Thomas, 2006; Corbin & Strauss, 2007). Similar themes were grouped according to shared concepts and direct quotes were selected to demonstrate identified concepts. No theoretical models were generated from the focus group data; however, a final review of the data confirmed that all identified themes and categories were content-driven.

Results

Participant Characteristics

Forty-five BCa survivors were screened for participation in the study, 33 of whom participated in one of the five focus groups. Non-participation was primarily due to
scheduling conflicts, although one individual was unable to attend because of illness. Participants ranged in age from 39 to 74 years (mean = 57; SD=8.8). The majority of participants were either African-American (42%) or White (42%); employed full-time (52%), married (64%), college educated (55%), and had a household income greater than $75,000 (45%) (Table 2.2). A majority of participants were diagnosed with Stage I cancer (30%), not currently receiving BCa-related treatment (79%), and active members of a BCa support group (70%) (Table 2.3). Finally, five main themes were identified from the five focus group sessions; they include: 1) thoughts about PA and health, 2) factors that enhance survivors’ perceptions of using a DVD-based exercise program, 3) factors that serve as barriers to use of a DVD-based exercise program, 4) time points of receptivity to a DVD-based exercise program, and 5) HCP involvement in PA education and DVD-based exercise program dissemination.

**Screening Results**

During the screening process, 18% of participants reported being familiar with the 2008 Physical Activity Guidelines for Americans (U.S. Department of Health & Human Services [USDHHS], 2008) and 9% reported being familiar with the American College of Sports Medicine’s exercise guidelines for cancer survivors (Schmitz et al., 2010a). Twenty-seven percent of participants disclosed that their oncologist had not spent time discussing PA with them during their clinic visits. Although participants unanimously self-reported that PA was an important part of their lives and 61% reported engaging in leisure-time activity often, 97% were classified as insufficiently active based on their responses to the Godin Leisure-Time Physical Activity Questionnaire administered prior
Table 2.2. Focus Group Participants’ Demographic Characteristics.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n=33</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean (SD)</td>
<td>57</td>
<td>8.8</td>
<td></td>
</tr>
<tr>
<td>range</td>
<td>39-74</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age at Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean, SD</td>
<td>50</td>
<td>9.2</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>14</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>14</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latina</td>
<td>4</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>17</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>Part-time</td>
<td>4</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>2</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>6</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>3</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>21</td>
<td>64%</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>7</td>
<td>21%</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS/GED or less</td>
<td>4</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>7</td>
<td>21%</td>
<td></td>
</tr>
<tr>
<td>College degree</td>
<td>18</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>&gt; College degree</td>
<td>4</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $25,000</td>
<td>9</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>$25,000-$49,999</td>
<td>5</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>$50,000-$75,000</td>
<td>2</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>&gt; $75,000</td>
<td>15</td>
<td>45%</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>2</td>
<td>6%</td>
<td></td>
</tr>
</tbody>
</table>
Table 2.3. Focus Group Participants’ Illness-related Characteristics.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n=33</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer Stage at Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0</td>
<td>5</td>
<td>(15%)</td>
</tr>
<tr>
<td>Stage 1</td>
<td>10</td>
<td>(30%)</td>
</tr>
<tr>
<td>Stage 2</td>
<td>9</td>
<td>(27%)</td>
</tr>
<tr>
<td>Stage 3</td>
<td>4</td>
<td>(12%)</td>
</tr>
<tr>
<td>Stage 4</td>
<td>1</td>
<td>(3%)</td>
</tr>
<tr>
<td>No response</td>
<td>4</td>
<td>(12%)</td>
</tr>
<tr>
<td><strong>Surgery Type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>21</td>
<td>(64%)</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>11</td>
<td>(33%)</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>(3%)</td>
</tr>
<tr>
<td><strong>Currently receiving Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>(21%)</td>
</tr>
<tr>
<td>No</td>
<td>26</td>
<td>(79%)</td>
</tr>
<tr>
<td><strong>BCa Support Group Membership</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>23</td>
<td>(70%)</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>(30%)</td>
</tr>
</tbody>
</table>

to the focus group sessions. Next, main themes that resulted from the focus group sessions are reported. The first theme explores survivors’ thoughts about PA and health.

*Thoughts about Physical Activity and Health*

Post-diagnosis, survivors conveyed an increased awareness regarding the health benefits of PA, which – in part – positively influenced their PA beliefs and behaviors. The majority of participants cited at least one benefit of being physically active including having more energy, better circulation, improved flexibility, stronger bones, improved appearance, tension relief, reduced pain, better sleep, and weight loss. Mental benefits of activity discussed included improved mood and outlook, heightened focus, reduced stress, meeting new people, and being social. Additional benefits to being physically active, such as greater productivity, also were mentioned. Moreover, some participants
became physically active after treatment by joining a gym, walking, or participating in activities for increased muscle and tone. Participants also acknowledged the negative effects of being sedentary. Exhaustion and soreness were identified as drawbacks of being active, although they were described in a positive context. For example, participants discussed how they felt better when they exercised, even if it meant being sore:

*I feel so much better when I exercise. I sleep better. Um, I think my mind is more alert and more focused. And, um, I make better use of my day when I exercise.*

*So I got to walk where I’m going. And it’s all right. I don’t care about it. I may be a little sore afterwards or whatever, but it’s all good. It’s for a good purpose.*

*...I had a double mastectomy and I was blessed that I was able to move to my sister’s house and she took care of me, but I was very conscious about walking and nobody had to push me.*

Post-diagnosis, many participants spoke of an increased awareness of the benefits of being active, including reduced risk of cancer recurrence and swelling as well as improved bone health and mortality. While participants agreed with the health benefits, some participants challenged the notion that being physically active reduced the risk of cancer given their cancer diagnosis; however, this negative view was challenged by participants who believed an active lifestyle lessened the severity of their cancer, as well as improved the body’s response to treatment and helped to speed recovery, even when there was a recurrence. Here is the dialogue of two survivors who exemplified these opposing views:

*I said, ‘Lord, if exercise kept cancer from reoccurrence, I wouldn’t have had it four times, you know, since 2008.’ And I’m an active person.*
But flip it. Had you not been as physical as you are, maybe you’d be dead.

Finally, participants also discussed greater awareness of physical limitations after BCa surgery and its relation to their level of PA. A majority expressed concerns about continuing their physical activities, with many opting for lower intensity activities than prior to diagnosis, or modifying their regular activities to account for their physical limitations and prevent injury. One participant explained a slowing of activity only during treatment, while other participants expressed an inability to exercise due to treatment-related side effects, such as neuropathy. For example:

*I feel like I was more active before I was diagnosed…but now I have no strength and, like, I’m experiencing neuropathy really bad right now so I can’t do anything. I want to, but it’s like some days I can’t get out of bed.*

In sum, survivors were knowledgeable about the physical and mental health benefits of PA and aimed to maintain or increase their PA levels after diagnosis. Greater concern over physical limitations and injury risk led many survivors to modify their activities, while other survivors discontinued activity altogether as a result of debilitating treatment side effects. In the subsequent section, factors that enhanced BCa survivors’ perceptions of using a DVD-based exercise program are reviewed.

Factors Enhancing Perceptions of DVD Use

The convenience of a DVD-based exercise program was a recurring theme throughout the focus groups, regardless of what factors might be inhibitors to PA. For example, participants felt positively about being able to incorporate watching a DVD at home into a demanding schedule as well as being able to adjust their workout schedules when they
were experiencing treatment-related side effects. For instance, survivors talked about the challenge of leaving home to exercise when caring for young children, others spoke of fitting activity into a busy schedule, and yet others talked about trying to be active while dealing with their diagnosis. For example:

...when I had my surgery, I had three little kids, so I couldn’t very well get someone else to take them again, you know, while I went out for physical therapy someplace. That would’ve been a real, you know, imposition.

...it could fit into my day. Because every single day my schedule is different. So, I could adapt the DVD to my schedule.

I think when you’re first diagnosed, you don’t want to go out and really interact with people, so it needs to be something you can do at home.

Several participants also explained how the DVD exercise program could be a catalyst for becoming active again or regaining physical abilities over the course of the cancer continuum. One inactive survivor explained how the DVD could help get her to be active, while others expressed delight with the exercise resources available on the DVD exercise program. An example of this is:

...I think somebody like me who doesn’t exercise...it might encourage me, you know, to try those things, to start...So, you might continue and go on to bigger and better things.

I was so happy to see that [strength training] in there. Because I was always wondering, how can I get strength training in if I don’t go to the gym. I was like ecstatic to see that.

And that’s why I think this DVD is so great, because if you’re in the gym, you don’t know what to do. And, you know, you need to do it..., but you don’t have any other knowledge, input to really do it by yourself, and I think that’s where this [the DVD] is so excellent...
The majority of participants expressed appreciation that the DVD-based exercise program was tailor-made for BCa survivors. Most participants reported that addressing concerns specific to survivors, such as providing precautionary information and modified exercises, was essential for survivors engaging in PA. Participants were especially pleased to see information about lymphedema on the DVD and valued having survivors with similar physical challenges provide their personal stories and serve as models for exercise demonstrations. Moreover, the DVD was seen by some participants as a potential source of social support, especially post-surgery, whether used alone or in a group setting for a more social experience. In fact, some women stated:

_The other thing I did like was when they were demonstrating the exercises, they would show, if you couldn’t do it, stand; I also thought it was nice she would modify._

_I really liked that they addressed lymphedema. And that they addressed it that you can, you can lift more than five pounds. I mean, it’s like, I mean, for instance, I was doing today 115 pounds, well squats, and yeah, I mean I have lymphedema, but everyone tells me, oh no, no, don’t lift something more than five pounds. It’s like, that’s not true._

_It wasn’t a matter of seeing somebody in a really nifty little jumpsuit doing this and you’re thinking, how can I tone that down for myself to do at home._

_And maybe this video can be your buddy. You know, to get you,... you know, motivated. Yeah, because there’s a lot of us that, like, travel the journey alone. So, even just a video would be helpful, something, you know. That’s why I think this [the DVD] is really great._

_This is something that I would own and I could share in the house. Or if I had a bunch of women together at my house ...I could incorporate that [the DVD] into my spa day. Um, and I wouldn’t have to go out..._

For some survivors, exercise classes for the general population were too hard, too fast, or did not provide sufficient modifications for them. Survivors felt that, at times, exercise
instructors in the general population did not have the proper knowledge to specifically instruct BCa survivors. Many survivors recounted their experiences taking a general population exercise class, they are:

*Spin class was difficult, you know... And I remember the spin, you know, instructor, like, come on, you can do more than that. I was like, okay I just had a bilateral and I don’t need you in my face. And he was like, sorry. I’m like, it’s okay, I’m really sorry for yelling at you. But you can’t, you know.*

*I wouldn’t trust most fitness people to recognize. Unless there’s specific training for fitness people...like [name of instructor] I would trust because she’s a survivor and she knows what she’s doing. But, you know, the average person, I mean, are they going to relate to what the special issues are for breast cancer survivors or any cancer survivors?*

A DVD-based exercise program also was seen as easier to understand and follow than verbal and written instructions. Participants recounted being given written instructions or demonstrations, but then being unable to recall how to perform recommended exercises:

*Yeah, yeah because when you get a paper, it’s like, I don’t remember quite how to do that even if they demonstrated it. But if you have the DVD, then it’s like, oh okay, oh right...my shoulders were back, but now that I’m watching this woman. You know, let me get my shoulders back further, so...*

Survivors also talked about how a DVD was said to be a cost-effective alternative to other activity resources, such as exercise classes and physical therapy. Nevertheless, participants considered the DVD as a good compliment to other resources, whether as a follow-up to in-person exercise demonstrations or as a springboard for more advanced exercise classes. One survivor shared her opinion:

*I’ve had physical therapy....and I write everything down when they give me paper and I get home and say, now, was I supposed to do it this way or that way. And I think having the DVD would be a good refresher. Even if a person has physical*
therapy, the therapist could make sure they’re doing, you know, the same thing [on the DVD] or a modification of that; it would be a good review.

All in all, the DVD-based exercise program was well received given the convenience of having a BCa-specific, home-based program that could be incorporated into any schedule. The DVD also was considered cost-effective and user-friendly as compared to other exercise instruction resources. In the following section, factors that survivors viewed as barriers to using a DVD-based exercise program were reviewed.

Factors Serving as Barriers to DVD Use

While the DVD-based exercise program was positively received by a majority of participants, some perceived barriers to its use. Participants stressed that a number of factors, including surgery type, treatment types, age, pre-surgery fitness level, and mindset would collectively determine one’s readiness to be active, that the ideal time point for its use would vary, and that this information should be factored into the exercise program. One participant summarized much of these sentiments:

But the thing is too...we all had surgeries, but different types of surgeries. Some of us might have had lumpectomies, some of us might have had radical mastectomies, modified, simple, or whatever, and, and, lymph nodes taken out, so the CD [sic] didn’t address any of those issues. So, perhaps, they would do something that would be more, um, appropriate for us. You know, ’cause not everybody got neuropathy – some of us did, some of us didn’t. So, all if those things would have to be taken into consideration.

As a result of treatment-related side effects such as pain, numbness, anemia, neuropathy, and lack of energy, even low intensity and modified exercises were deemed by some participants to be too difficult. For most participants with this concern, these physical limitations were experienced immediately after surgery; however, other participants
continued to experience these limitations years after surgery. Specific to strengthening exercises, one participant was very vocal about her disinterest in weightlifting activities at age 70, with another survivor in her 40’s expressing a more general lack of interest in weightlifting altogether. For example:

...every bone in my body aches. I mean, all over I hurt. The first treatment – that’s the way I was. The second treatment, I couldn’t even stand for clothes to touch my flesh.

That one [strength training chapter] would not be, uh, important in my life... We regular folks didn’t need to lift weights.

Some participants who enjoy the social aspects of activity (i.e. group classes, meeting friends, etc.) felt that a DVD-based exercise program would not provide the same degree of motivation and social support as activities done with others. Similarly, a home-based resource was seen by some participants as questionable given the potential for distractions at home that could interfere with its use. Survivors explained their preference for group exercise classes and how staying home could work as a detractor to PA:

I’m not a DVD person, sorry, so I’m the wrong guy. I like to go to a class because I enjoy the motivation of a group.

So, at home, it’s like saying, okay I have to put everything aside because now I’m going to sit there or do these things [exercises]. Which is hard because there’s always, there’s always something to do. Versus at 10:00 o’clock on Wednesday morning, I show up at [an exercise class]... So, it’s a little different. I mean, I certainly need to schedule, but I don’t think I schedule equally the same because then the phone rings and other things.

In looking at possible barriers to the DVD, technical difficulties were considered a potential obstacle to using the DVD. However, most participants were able to operate the DVD-based exercise program with relative ease, with only a few participants reporting
technical difficulties. For example, one participant was unable to navigate through the chapters of the DVD-based exercise program, while four others had trouble accessing the exercise log that was included on the DVD. As one participant pointed out, older survivors might not be able to easily operate the program. Since most participants were able to use the program without any problems, this issue is not discussed further.

Regarding the costs of the program, only a few women expressed concerns over whether some survivors could afford the program given possible financial constraints. While these issues are noted for future study, the structure of the program as a barrier to use is reviewed further.

Regarding the structure of the DVD exercise program, participants suggested that an ideal content structure would provide essential BCa-related information, exercise demonstrations, and varied aerobic activities. Participants suggested that these segments be placed in separate sections that would allow viewers to revisit the exercise segments without repeating introductory and informational sections. Additionally, to improve use, participants also suggested providing time requirements and equipment needs at the start of each exercise section. As survivors explain:

So yeah, they could have the initial part...a shorter form for the education. And they say, okay here are the, now we're going to show you the exercises. Here, we're showing them to you and now here this is. Look at this section and you can do it together.

I can tell you where I felt it [the DVD] dropped the ball was in the area of aerobics. They got people on a bicycle, and I'm all getting ready to do some aerobics or something or some Cumba dancing or something. And then they were showing the people. Well, I'm not going to ride a bicycle for aerobic or whatever. But, um, you know, a little segment on there would be nice...salsa dancing, or whatever. Because dance is, dance is good as an exercise and that would engage us, uh, probably.
Two participants who were younger and physically active prior to diagnosis expressed a desire for additional DVDs (i.e. a progressive series) with advanced exercises that would be more challenging and faster paced.

In sum, negative side effects associated with surgery and treatments received, as well as older age, could impede survivors’ use of a DVD-based exercise program. Survivors also reported being less likely to use a DVD-based exercise program if they were not yet mentally ready, if they were already physically active, or if they preferred being physically active in a social setting with others. Next, survivors’ opinions regarding the best time during the cancer continuum to receive a DVD-based exercise program are discussed.

*Time Points of Receptivity to a DVD-based Exercise Program*

We asked participants when they would want to receive the DVD-based exercise program, either at diagnosis or after surgery. Participants were largely divided on when the best time was to receive the DVD. Many BCa survivors wanted the DVD at diagnosis because they were interested in having important information from the educational component, especially regarding lymphedema. They felt that having that information right away would help them be prepared for what lay ahead. Also, the tone of the DVD was seen as calm and unintimidating, which was believed to be appropriate for the time of diagnosis. Yet, other participants preferred to delay the receipt of the program until after diagnosis despite stressing the importance of using the DVD. They felt they were not ready to receive the information at diagnosis. For those participants wanting to wait until after diagnosis to receive the DVD, they expressed not being mentally ready to think
about exercise as they were feeling overwhelmed with information at diagnosis. However, despite the delay in receiving the exercise program, they agreed that it was important to not wait too long and risk suffering from worsening muscle function. For instance:

*I think it still would be more motivation if you would’ve had it [the DVD] before the surgery. Because then you already know what to expect; you’re not afraid of it.*

*I would want to know that I needed to exercise right after surgery. You can’t wait until after the surgery to give me that DVD because it’s already too late. You know, I want to know ahead so I can plan my schedule and… I wish I would’ve had it before. Because I didn’t know anything and I wasn’t told anything.*

*This type of thing [the DVD] would be just, it’s wonderful. Because, because it was, it would, I don’t want to say slow moving, but it was very gradual. So, when you first get diagnosis… that’s what you want. Because you’re paying, you’re listening to everything everybody says. So the pace is great because it grabs your attention. And you’re listening to it and you’re like, okay, alright, you know. I can do this.*

...you’ve just gotten a diagnosis that you’ve had a life threatening disease. And you want me to exercise? Come on now. I’m trying to live, you know, take care of my family, cross things off my bucket list. Because you’re not going to tell me to exercise now.

*You don’t hear anything except… You’re in total… Only because you are bombarded with so much information. You go from doctor to doctor to doctor and the last thing at that point you’re thinking about is exercising. I mean, you just have to get through surgery, through chemo, through, you know; all this stuff. So, maybe after you have your treatment plan.*

*I agree, too – right away [after surgery], because the longer you wait, that your muscles are getting stiff.*

Further, some participants suggested waiting until much later, that is, after treatment (e.g. after drains are removed; second or third visit to the oncologist) as a more realistic time
to receive the DVD. They believed that the treatment itself was exhausting and chemotherapy took all of their energy. For example:

[To get through the day] was all I could do after, when you’re doing chemo. But the chemo, you know, you sit up, you know, in the morning. You sit there for a few minutes, you’re sweating, you always take a shower and then I gotta lay down again for a few minutes and I get up so it’s all you can do.

...the relevancy of certain types of surgeries we had, and whether or not after surgery we had chemo and radiation....because chemo and radiation tend to make you tired. And, even though you feel, you know, even if you want to commit to it, you just don’t have the strength or tolerance. Even if the doctor tells you...

Overall, survivors had differing opinions about the ideal time to receive a DVD-based exercise program. Survivors who wanted a DVD at diagnosis were eager to educate and prepare themselves, while those wanting delay receipt were either not yet mentally ready for exercise information or were not yet capable of being active in light of surgery- and treatment-related side effects. In the subsequent section survivors’ experiences and thoughts concerning their healthcare providers’ role in dispensing exercise information and resources is reviewed.

Healthcare Provider Involvement

Whether BCa survivors wanted their health care providers (HCP) involved with the distribution of health and exercise information was also of interest. Participants reported receiving contradictory information about exercise and PA from their health care providers. Some participants received recommendations to walk, stretch, or avoid activity, while a majority did not receive any information about PA. In fact, one participant had a physical therapist overturn a physician directive to stay inactive. As the women show, there does not seem to be a consistent message about exercise:
Yeah, my primary care was the doctor. She’s the one that insists that I exercise. She said, half hour each day.

You know, you just go home and feel better. There was nothing about exercising whatsoever; it was almost like it was discouraged. Well, and even, the thing that the American Cancer Society was doing, you weren’t allowed [to lift weights].

See, that’s what I was told. Don’t do this, don’t do that... And then, yeah, as I have gotten some physical therapy and they were telling me, oh, but they should’ve told you during the radiation part that you should be moving your arms as much as possible.

Regardless of their experiences, a majority of participants conveyed a preference for receiving PA information from HCPs, and believed that HCPs should play a larger role in PA promotion. HCPs were seen as trust-worthy, reliable sources that could provide survivors with peace of mind and confidence concerning the accuracy of PA information. One participant appreciated having a HCP on the DVD, while two others explained the desire to have greater HCP involvement:

Yeah, all of them [surgeon, oncologist, general practitioner, therapist]. You should be hearing from all of these people. It should be a total thing.

I like to hear, you know, from a very reliable source and that particular doctor [on the DVD] seemed very astute to the rehab of breast cancer.

Because you were saying that just if they [HCP] give it [the DVD] to you, you may not go home and watch it. But if they give you a little introduction, you know, I mean, that would help.

Additionally, HCP offices also were seen as an ideal location for distributing resources like a DVD-based exercise program. Participants suggested having patients watch the introduction while at a clinic visit and then discussing it with their HCP at their visit, as well as at subsequent visits. One survivor suggested receiving a DVD at her HCPs office.
If HCPs are unable to take a more active role in PA education, participants recommended playing the DVD continuously in waiting rooms as well as distributing the program via BCa organizations, such as the American Cancer Society, BCa support groups, and the internet. For example:

*Maybe it should be promoted in the doctor’s, surgeon’s office and given away there... It should be handed to you; it should be encouraged so. This is, this is what you can do. This is what you need to do.*

In sum, although survivors received inconsistent messaging regarding PA, they wanted their HCPs to be more involved in PA instruction, including the dissemination of a DVD-based exercise program. Overall, the BCa survivors provided insight into how PA could or should be incorporated into the survivorship arena. As a general rule, the women mainly provided positive feedback on the use of a DVD-based exercise program that can be done in the home, regardless of their personal PA levels.

**Discussion**

Despite the increasing benefits of physical activity (PA) for breast cancer (BCa) survivors, particularly strength training, results suggest there are low adherence rates for PA which is consistent with previous research (Segar et al., 1998; Irwin et al., 2003; Stevenson et al., 2007; Cheema et al., 2008; De Backer et al., 2009; Mustian et al., 2009; Schmitz et al., 2009; Speck et al., 2010; Loprinzi & Cardinal, 2011; Sabiston & Brunet, 2011). Although focus group (focus group) participants considered PA an important part of their lives and a majority reported being physically active on a regular basis, only one participant was considered sufficiently active. Few participants were aware of general PA guidelines, and fewer still were aware of cancer-specific PA guidelines. These findings
suggeset a need to better educate BCa survivors about PA, recommended guidelines, and how to incorporate it into their lives.

The results of this qualitative study suggest that a DVD-based exercise program is an acceptable method for delivering PA information and instruction to BCa survivors. This finding is supported by previous research detailing BCa survivors’ preferences for home-based exercise programming due to its ability to overcome barriers to being active, such as lack of time and transportation (Denmark-Wahnefried et al., 2000; Jones & Courneya, 2002). Beyond overcoming general barriers to activity, our results suggest that the flexibility of a DVD also affords survivors the comfort and convenience of being active at home as well as the ability to adjust workout plans with respect to treatment-related side effects. For instance, survivors can easily reschedule activity to days when pain or fatigue are not a hindrance or opt to engage in activity late at night when unable to sleep. In contrast, Emslie and colleagues (2007) described BCa survivors as having difficulties motivating themselves to be active at home. In the current research, this view was shared by a minority of participants who expressed a preference for other forms of exercise programming or a lack of interest in exercise overall.

Findings also illustrated that the tailored nature of the DVD was a critical characteristic of the exercise program. Focus group participants wanted BCa-specific information that addressed their concerns about recurrence and lymphedema, offered shared experiences from other survivors, and provided exercise modifications to overcome limitations and prevent injury. This finding is consistent with survivors’ needs that have been previously identified (Ashing-Giwa et al., 2004; Emslie et al., 2007). Other exercise resources, such as written instructions and non-BCa-specific group
exercise classes in gym settings, were found lacking in their ability to provide the adequate support and expert instruction needed by many survivors.

Nevertheless, focus group participants offered several recommendations for enhancing a DVD-based exercise program. These suggestions included keeping information and exercise segments separate, listing equipment and time needs, and ensuring not only racial diversity, but also sensitivity to survivors of varied economic statuses, geographic location, activity preference (i.e. Salsa, Zumba), and physical abilities. Some focus group participants who were active prior to their diagnosis and found returning to activity and regaining physical functioning much easier than survivors who were not previously active expressed a need for more advanced versions of the DVD that would provide additional exercise instruction and modeling. A series of DVD-based exercise programs would not only allow for gradual improvements in PA level and physical functioning, but could also reflect the changing mindset of a survivor over time, moving from a soothing tone to a more upbeat and empowered tone.

One drawback to the exercise program under study was that some survivors felt it could not provide the same degree of support as other exercise opportunities. For example, some participants were also interested in forming friendships and exchanging information with other survivors. This finding is consistent with previous research detailing the value women put on exercising with other survivors (Ashing-Giwa et al., 2004; Emslie et al., 2007). However, survivors expressing this viewpoint were either able to locate BCa-specific exercise classes or took it upon themselves to modify exercises while participating in non-BCa-specific group exercise classes. Many of the participants did not have access to these types of activities outside the home.
Focus group participants did not come to any consensus regarding when survivors should receive a DVD-based exercise program, but they did agree that readiness would vary depending on a number of factors, including mindset, surgery type, and treatments received. Denmark-Wahnefried and colleagues (2000) identified diagnosis as a time when survivors expressed high desire for health promotion programming. This finding is partially supported in the current study by a number of survivors who preferred the DVD at the time of diagnosis in an effort to be better informed and prepared for dealing with their illness. These survivors felt the emotionally supportive aspects of the DVD, including a calm tone, reassuring information, and unintimidating encouragement to be active and return to pre-surgery functioning, were appropriate and valuable messages to receive at the time of diagnosis. Yet, other survivors were not mentally ready to receive a DVD at that time. This finding also is supported by Rees and Bath (2001), who reported information avoidance behaviors among BCa survivors among those too overwhelmed by their diagnosis or overburdened by the volume of information provided to them at diagnosis. Similarly, focus group participants that experienced severe side effects (i.e. fatigue, neuropathy) as a result of undergoing more invasive surgeries and greater amounts of BCa-specific treatments expressed an inability to use a DVD until these side effects had abated. Based on these findings, one solution may be to have a DVD-based exercise program in place with time points marked for when a patient might be interested in receiving PA and educational information. Survivors can make their own decisions about when they are mentally ready to hear information on PA. It may be that some patients will want information right away and accept the DVD at diagnosis, while others will be more receptive further along the cancer treatment continuum. In this way, the
exercise program is a part of the recovery process, but the decision as to when to receive this information can be patient-centered.

Lastly, these findings demonstrate that a higher level of involvement from HCPs was seen as an important component of PA promotion among BCa survivors. As previous literature suggests, focus group participants considered HCPs a reliable and trusted source of information (Bilodeau and Degner 1996; Fridfinnsdottir 1997; Kantsiper et al. 2009). BCa survivors also believed HCPs should provide information about the benefits of being active, disseminate DVD-based exercise programs, and continue to follow up about their activity level over time. The preference for greater HCP involvement presents a challenge in itself, given many focus group participants’ accounts of receiving misinformation or no information at all about PA or strength training. Nonetheless, reports from focus group participants that did received PA recommendations from their HCPs demonstrate that HCPs can adequately provide PA information to their patients. HCPs are in an ideal position to be aware of and address BCa survivors’ needs, including when to recommend PA, and a DVD-based exercise program can aid HCPs with the delivery of this information. As mentioned in the previous paragraph, because this study did not demonstrate consistent and accurate delivery of PA information to BCa survivors, the timing of when to receive that information should be subjective. Likewise, focus group participants were comfortable receiving information from alternative sources as well, including BCa support groups and BCa advocacy organizations.

Study findings should be viewed with caution in light of several limitations. First, the qualitative nature of this study prevents generalizability. For example, a majority of participants were members of a BCa support group, which could lead to bias as BCa
survivors who actively participate in support groups may have differing views as compared to those who do not. Nonetheless, a wide range of views were expressed in the current focus groups, suggesting that participants felt comfortable enough to express dissenting opinions. Second, there is also a likelihood of self-selection bias in which BCa survivors that are more interested in PA were more likely to volunteer to participate in the focus groups. The study sample was unanimous in reporting that PA was important; whereas, other BCa survivors may not have felt that PA was a priority. Third, given the small sample size, it was not possible to stratify the focus groups by BCa survivors’ characteristics, such as age, race, ethnicity, surgery type, treatments received, or fitness level, which may provide a clearer understanding of the basis for differing perceptions of a DVD-based exercise program.

Despite these limitations, this study provides important insights that demonstrate how an exercise program might play a productive role in educating and instructing BCa survivors. Benefits include essential information and easy-to-follow instructions regarding PA and strength training. Second, while a DVD-based exercise program may not satisfy all BCa survivors’ needs for social support, the DVD can play a significant role in providing emotional and practical support as the DVDs are created with testimonials from BCa survivors. Benefits of participating in an exercise program such as this for BCa survivors may be greater for those individuals who were not previously active or who underwent more extensive surgeries. Third, not all BCa survivors will be ready to receive a DVD-based exercise program at the same time point. HCPs should ensure their patients are aware of PA benefits and recommendations, but also should work with their patients to integrate PA, through a DVD-based exercise program, into
their lives as they are become ready to receive the information and guidance. Fourth, it is important that exercise programs are tailored to accommodate the evolving and differing needs of BCa survivors. There cannot and should not be a one size fits all approach. For instance, in addition to providing basic information, DVDs could provide advanced exercises and culturally-appropriate aerobic workout segments as well as settings and exercise models that demonstrate varied ethnicities, economic backgrounds, and physical abilities. Ickes and Sharma (2012), in a review of physical activity interventions among Hispanic adults, suggest that activity preferences may vary by cultural group, and that these preferences should be incorporated into PA interventions.

While this study helps to inform future efforts, additional research is needed to advance this area of study. Qualitative studies with HCPs would help to determine how best to integrate and disseminate DVD-based exercise programs into the healthcare setting. Exercise interventions can be used to confirm the acceptability and effectiveness of using this form of technology to engage BCa survivors in regular PA and strength training at any time point over the cancer treatment continuum. Lastly, consideration should be given to future work that expands the use of DVD-based exerciser programs to non-English speaking patients and patients with other types of cancer. In conclusion, DVD-based exercise programs can be an effective method for providing BCa survivors with much needed exercise instruction and encouragement to help restore physical functioning and quality of life.
Chapter 3
Maximizing Recruitment Efforts in a Clinical Setting

Background

Recruitment and retention of adequate subjects to effectively test scientific hypotheses are an essential component of a well-executed human subjects research study. Optimizing statistical power and the ability to detect a significant intervention effect are dependent upon enrolling a pre-determined number of participants (Lovato et al., 1997). Careful planning can maximize the likelihood of achieving recruitment goals; however, recruitment continues to be a significant challenge, whether as a result of overestimation of available enrollees or an inability to make adjustments to recruitment strategies, that often leads to study extensions and unrealized recruitment goals (Bhanushali et al., 2014; Donovan et al., 2002; Lovato et al., 1997; Spilker et al., 1992). Within the clinical setting, a review of 114 randomized trials revealed that less than one-third achieved their original recruitment goals and one-third had to extend their recruitment period (Campbell et al., 2007). Protracted recruitment can result in added costs or premature study closure (Lemieux et al., 2008).

Provider- and patient-level barriers may help explain recruitment challenges in the clinical setting. Many healthcare providers lack time and staff support to participate in research investigations, they receive little to no reward or recognition for their participation in research, and may be concerned about the influence of recruitment efforts on their provider-patient relationships (van Staa et al., 2014; Rendell et al., 2007; Pringle & Churchill, 1995). Likewise, patients may not satisfy study eligibility criteria, be hesitant to commit to the time demands of study participation, or show reluctance about
being randomized to a placebo arm (Park et al., 2014; Heiney et al., 2010; Ellis, 2000). BCa patients are no exception, as they are less likely to participate in research as a result of feeling stressed and vulnerable after their cancer diagnosis and when dealing with treatment side effects (Lemieux et al., 2008; Ellis et al., 2001; Ellis, 2000). Nonetheless, previous research has demonstrated that the clinical setting is a viable location for the recruitment of patients, including BCa survivors (Bhanushali et al., 2014; van Staa et al., 2014; Gorman et al., 2014; Lemieux et al., 2008; Goodwin et al., 2000). More research is needed to determine what factors are associated with poor enrollment and what factors encourage greater participation in clinical trials (Byrne et al., 2013; Lemieux et al., 2008; McDaid et al., 2006).

This paper describes the recruitment of post-operative BCa survivors, regardless of current treatment status, to a pilot study assessing the effects of a home-based strength training intervention. The objective of this paper is to develop a better understanding of how to enhance patient recruitment strategies in a clinical setting. Modifications to the recruitment process and lessons learned during the recruitment phase of the study are discussed, with recommendations to assist future studies with their recruitment efforts.

**Methods**

*General Study Design*

The research team conducted a pilot study assessing the effect of a DVD-based exercise program on upper body strength of post-operative BCa survivors. Women were originally recruited to participate in the study if they met the following criteria: 1) were currently a patient at the partnering cancer center; 2) received a BCa diagnosis (stages I-
III); 3) were 50-80 years of age; 4) were English-speaking; 5) had undergone BCa surgery at least four weeks prior, but no more than two years prior to study enrollment; 6) received oncologist clearance to participate; and 7) had access to a television and DVD player in their home. Women were excluded if they: 1) had contraindications for unsupervised exercise, including recent myocardial infarction, uncontrolled congestive heart failure or angina, breathing difficulties requiring oxygen use or hospitalization, use of mobility aids other than a cane, plans to have hip or knee surgery, musculoskeletal injuries, or other conditions (i.e. fibromyalgia, scoliosis, fractures, and herniated discs); 2) had plans for reconstructive surgery during the study period; 3) planned to move or engage in extended travel during the study period; or 4) met national strength training guidelines (performing a minimum of one set of 8-10 exercises that conditioned the major muscle groups at least 2 days per week). BCa survivors were not excluded based on previous, current, or planned BCa treatments.

Study participants were stratified by surgery type (lumpectomy versus mastectomy) and randomized to one of two groups: 1) a strength training group that was assigned to watch a DVD-based exercise program designed to engage women in progressive, upper body strengthening exercises twice weekly, or 2) a health education attention-control group assigned to watch one health-related DVD per week. The duration of the study intervention was 12 weeks. All participants were asked to attend a baseline and a post-intervention appointment at the university-affiliated wellness centers, while all other study activities took place in the participants’ homes. Written informed consent was
obtained prior to the start of each baseline appointment. The study was conducted with approval from the University of Miami’s Institutional Review Board.

Recruitment Procedures

The research team identified and recruited oncologists at the university-affiliated comprehensive cancer center to assist with the study. Three oncologists were selected based on their willingness to provide patient access and promote the study to their BCa patients. To avoid unnecessary burden, participating oncologists and their support staff (i.e., nurses and physician assistants) were provided with a small, defined role in the recruitment process, including review of electronic medical records (EMR) and providing final clearance for patients’ study participation.

Clinical staff of the participating oncologists was provided with a brief introduction to the study, including the study design and objectives, inclusion and exclusion criteria, and their role in the recruitment process. Given that investigator-initiated phone calls to BCa patients were not permitted by the sponsoring IRB, study staff met bi-weekly with the oncologists’ support staff to review the EMR of BCa survivors to identify potentially eligible patients who had upcoming oncology appointments. The appointment times of the patients who appeared to satisfy the initial eligibility criteria (i.e., age, surgery date) were recorded so that study staff could be present for an in-person introduction at their next clinic visit. At this clinic visit, oncologists or members of their support staff introduced the study staff to the patients who then provided the patient with a brief introduction to the study. After providing verbal consent, interested patients were either screened in-person or via telephone at a later date to determine study eligibility.
Oncologists were asked to provide final clearance for their patients to participate in the study only if potential contraindications for unsupervised exercise were identified during the screening process. Eligible BCa survivors were then scheduled for a baseline appointment. Patients who were hesitant or not immediately interested in participating were given a study flyer and encouraged to contact the study staff if they wished to participate at a later date. Notes were made to contact patients who were ineligible at the time of the screening, but would later become eligible to participate (i.e., after reconstructive surgery or completion of travel).

The study recruitment goal was to enroll 40 BCa survivors. The anticipated enrollment rate was to recruit 1-2 participants per week to the study. A period of six months was deemed necessary to recruit the desired sample size.

Recruitment Monitoring

Study staff maintained electronic recruitment logs detailing all interactions with potential participants. Recorded information includes the number of eligible patients identified by the oncology staff, upcoming oncology appointment dates and times of potentially eligible patients, the number of the in-person introductions, whether a study flyer was provided, all screenings conducted with interested patients, and the final eligibility status of all screened patients. The research team held weekly meetings to review the progress of study recruitment and ongoing efforts to reach out to interested patients not yet eligible (i.e., upcoming reconstructive surgery or travel plans) or who were not screened at the time of their appointment. Study staff also discussed the status of potentially eligible patients, including efforts to schedule baseline appointments.
**Results**

*Oncologist and Support Staff Barriers*

Study recruitment took place between February 2013 and March 2014, extending seven months longer than initially planned. During this time, participating oncologists reported seeing an average of 75 new and returning BCa patients per week. One hundred and twenty seven unique BCa survivors scheduled for an upcoming oncology appointment were identified as meeting age and cancer stage eligibility requirements based on EMR review by support staff. Of these women, 62 were both present at their scheduled appointment and agreed to be screened. Thirty-seven BCa survivors were eligible to participate, 23 of whom were enrolled in the study resulting in an attainment of 57.5% of the initial recruitment goal. A summary of the recruitment process is outlined in Figure 3.1.

Despite the high volume of patients seen by the three initial participating oncologists, only one participant was enrolled during the first four months of recruitment. Two strategies were implemented to improve participant recruitment numbers. First, study inclusion criteria for age and cancer stage at diagnosis were expanded. Support staff reviewing the EMR had identified several upcoming oncology appointments with women who were 40-49 years of age who would have otherwise been eligible to participate in the study. Likewise, one participating oncologist, who primarily interacted with stage IV BCa patients, recommended that study eligibility criteria be expanded to include them. These changes led to the inclusion of seven additional BCa survivors over the course of
Figure 3.1. Intervention Study Flow.

Chart Review (n=127)

Excluded (n=65)
☐ Not meeting inclusion criteria (n=24)
☐ Declined to participate (n=10)
☐ Other reasons (n=31)

Screening (n=62)

Excluded (n=39)
☐ Not meeting inclusion criteria (n=21)
☐ Declined to participate (n=10)
☐ Other reasons (n=8)

Enrolled (n=23)

Randomized (n=23)

Allocated to strength training intervention (n=12)
Completed post-assessments (n=10)

Allocated to health education intervention (n=11)
Completed post-assessments (n=10)
the study. Second, four additional oncologists were recruited to collaborate in the study, one of whom was stationed at a satellite cancer center location. Nine of the 23 study participants were patients of these newly added oncologists. Final recruitment numbers varied, ranging from zero to eight patients recruited from each participating oncologist.

Study staff faced several challenges during study recruitment. Meetings with the oncologists’ support staff to review EMRs were periodically postponed or canceled as a result of their demanding schedules. Interruptions in communication between study staff and support staff occurred during 10 different occasions throughout the study. It is unknown how many eligible patients were missed as a result of these lost opportunities; however, the number of weekly study introductions ranged from two to 10 on a given week. To limit these missed patient introductions, participating oncologists and their support staff were asked to provide potentially eligible BCa patients with a flyer when study staff could not be present at clinic for in-person introductions. Over the duration of the study, support staff contributed an estimated total of five hours each of their time towards study efforts, while participating oncologists contributed a maximum of three hours each.

**Patient-Specific Barriers**

Several patient-specific factors were identified as preventing or delaying study enrollment of eligible BCa patients. These factors included clinic cancellations, as well as exclusions based on other eligibility criteria. For instance, 26 of the patients identified for in-person introductions cancelled or rescheduled their clinic appointments. Fifty-one patients were ineligible for various reasons, including not being able to speak English,
being excluded by their oncologist because they were either new patients or were not considered emotionally stable, and living outside of the immediate study area. Table 3.1 provides a summary of the reasons for study exclusion. Among the 20 women who expressed they were not interested in participating in the study, the two main reasons cited for not wanting to participate were being too busy with cancer treatment and lacking time due to their transition back to work.

<table>
<thead>
<tr>
<th>Table 3.1. Reasons for Study Exclusion (n=104)</th>
<th>n</th>
<th>(%)</th>
</tr>
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<tbody>
<tr>
<td>Appointment rescheduled</td>
<td>26</td>
<td>(25.0)</td>
</tr>
<tr>
<td>Not interested in participating</td>
<td>20</td>
<td>(19.2)</td>
</tr>
<tr>
<td>Non-English speaking</td>
<td>19</td>
<td>(18.3)</td>
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<tr>
<td>Plans for reconstructive or other surgery</td>
<td>9</td>
<td>(8.7)</td>
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<tr>
<td>Oncologist exclusion</td>
<td>8</td>
<td>(7.7)</td>
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<tr>
<td>Already adequately physically active</td>
<td>6</td>
<td>(5.8)</td>
</tr>
<tr>
<td>Traveling during study period</td>
<td>5</td>
<td>(4.8)</td>
</tr>
<tr>
<td>Injury preventing exercise</td>
<td>3</td>
<td>(2.9)</td>
</tr>
<tr>
<td>Study staff unavailable for study introduction</td>
<td>3</td>
<td>(2.9)</td>
</tr>
<tr>
<td>No BCa surgery</td>
<td>2</td>
<td>(1.9)</td>
</tr>
<tr>
<td>Oncologist withheld clearance after screening</td>
<td>1</td>
<td>(1.0)</td>
</tr>
<tr>
<td>BCa surgery &gt; 2 years</td>
<td>1</td>
<td>(1.0)</td>
</tr>
<tr>
<td>Study staff not given access to patient (busy clinic)</td>
<td>1</td>
<td>(1.0)</td>
</tr>
</tbody>
</table>

BCa=breast cancer

Table 3.2 shows demographic and cancer-specific characteristics of screened women by enrollment status. BCa survivors enrolled in the study were 43 to 69 years of age with a mean age of 56.0, a majority were married (69.6%), college educated (73.9%), employed full-time (56.6%), and non-white (52.2%). On average, participants were nearly 10 months post-BCa surgery, with 39.1% receiving one or more types of BCa-related treatment (e.g. radiation, chemotherapy, hormone therapy) during the study period. Although only two participants reported a lymphedema diagnosis, 60% of all
Table 3.2. Baseline Characteristics of Screened Women by Enrollment Status.*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Enrolled (n=23)</th>
<th>Not enrolled (n=39)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), year</td>
<td>56.0 (8.2)</td>
<td>53.7 (8.2)</td>
<td>0.299</td>
</tr>
<tr>
<td>Age at Diagnosis, mean (SD), year</td>
<td>55.2 (8.3)</td>
<td>52.7 (8.4)</td>
<td>0.269</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>1 (4.4)</td>
<td>0 (0.0)</td>
<td>0.390</td>
</tr>
<tr>
<td>Some college</td>
<td>5 (21.7)</td>
<td>7 (18.0)</td>
<td></td>
</tr>
<tr>
<td>≥ College</td>
<td>17 (73.9)</td>
<td>32 (82.1)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>11 (47.8)</td>
<td>11 (28.2)</td>
<td>0.341</td>
</tr>
<tr>
<td>Black</td>
<td>4 (17.4)</td>
<td>9 (23.1)</td>
<td></td>
</tr>
<tr>
<td>Other**</td>
<td>8 (34.8)</td>
<td>19 (48.7)</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>13 (56.6)</td>
<td>20 (51.3)</td>
<td>0.990</td>
</tr>
<tr>
<td>Part-time</td>
<td>3 (13.0)</td>
<td>5 (12.8)</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>2 (8.7)</td>
<td>5 (12.8)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>2 (8.7)</td>
<td>4 (10.3)</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>3 (13.0)</td>
<td>5 (12.8)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>1 (4.4)</td>
<td>2 (5.1)</td>
<td>1.000</td>
</tr>
<tr>
<td>Married/Partnered</td>
<td>16 (69.6)</td>
<td>27 (69.2)</td>
<td></td>
</tr>
<tr>
<td>Divorced/Widowed</td>
<td>6 (26.1)</td>
<td>10 (25.6)</td>
<td></td>
</tr>
<tr>
<td>Cancer stage†</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>stage 1</td>
<td>8 (34.8)</td>
<td>1 (2.6)</td>
<td>0.317</td>
</tr>
<tr>
<td>stage 2</td>
<td>9 (39.1)</td>
<td>19 (48.7)</td>
<td></td>
</tr>
<tr>
<td>stage 3</td>
<td>4 (17.4)</td>
<td>12 (30.8)</td>
<td></td>
</tr>
<tr>
<td>stage 4</td>
<td>2 (8.7)</td>
<td>7 (18.0)</td>
<td></td>
</tr>
<tr>
<td>Time since surgery, mean (SD), months</td>
<td>9.8 (4.7)</td>
<td>11.0 (6.9)</td>
<td>0.453</td>
</tr>
<tr>
<td>No. nodes removed, mean (SD)</td>
<td>9.26 (9.7)</td>
<td>5.7 (8.0)</td>
<td>0.454</td>
</tr>
<tr>
<td>Diagnosed with Lymphedema</td>
<td>2 (8.7)</td>
<td>2 (5.1)</td>
<td>0.623</td>
</tr>
<tr>
<td>Currently Receiving Treatment††</td>
<td>9 (39.1)</td>
<td>10 (25.6)</td>
<td>0.393</td>
</tr>
</tbody>
</table>

*Data are presented as count (%) unless otherwise specified. Percentages may not sum to 100 due to rounding. **Includes Asian and Hispanic. †The staging system used was from the American Joint Commission on Cancer and refers to the extent of the cancer in the body. †† Current treatment status includes one or more of the following: chemotherapy, radiation, hormone therapy, and targeted therapy. SD=standard deviation; No.=number.
participants self-reported experiencing one or more lymphedema symptoms. Bi-variate analyses show baseline characteristics were not significantly different among women who were screened, but not enrolled in the study.

Discussion

The current pilot study offers several insights into the feasibility of recruiting post-operative BCa patients from a clinical setting. Enrollment of the desired number of participants was not achieved due to several unforeseen factors. However, several important considerations for the design of future clinic-based studies to maximize recruitment efforts were identified and are explored in greater detail herein.

Obtaining institutional support and correctly estimating the sample frame are essential preliminary actions (Betram et al., 2011; Rogerino et al., 2009; Ott et al., 2006). To gain institutional support, the research team first presented the study protocol to, and secured the support of, the cancer center’s BCa tumor oncology board. Second, the research team met individually with cancer center medical oncologists to solicit their help. To assess the sample frame, study staff consulted with participating oncologists and collectively determined that the pool of potentially eligible participants attending clinic appointments was sufficient. Despite taking these steps, the research team was unable to achieve the established recruitment goal. Accurate assessment of the sampling frame may have required a more detailed evaluation of eligible patients, including a preliminary review of patients’ EMRs from past appointments over an appropriate time frame.
Another important preparatory step is the identification of recruitment limitations and resources within the clinical setting. The research team was initially unaware of concurrent studies that were simultaneously recruiting BCa patients. Two participating oncologists added to the protocol later in the recruitment period were initially unable to collaborate with the research team due to their participation in one of these concurrent studies. Moreover, as with previous studies with BCa survivors, study staff was not permitted to directly contact patients without prior approval from their oncologist (Befort et al., 2014; Cadmus Betram et al., 2011; Snyder et al., 2009; Irwin et al., 2008). Although in-person introductions were time-consuming, they yielded a much shorter screening-to-randomization time than mail-based recruiting strategies used in previous studies (Cadmus Betram et al., 2011; Irwin et al., 2008), suggesting that they may not be a recruitment limitation for studies with sufficient study personnel. With regards to recruitment resources, newly available research support services, designed to assist with patient recruitment, were identified well into the study, but would have benefited recruitment efforts greatly if used at the study’s onset. A more accurate assessment of available resources and limitations could have potentially increased the overall number of participants recruited to the study.

The recruitment of BCa survivors from this particular setting following BCa surgery presented unique challenges. Side effects experienced post-surgery, initiation of various BCa-related treatments, and plans for reconstructive surgery made recruitment difficult at this time point. Previous research, which recommends recruiting BCa survivors at least 12 weeks after diagnosis, surgery, or treatment end to bolster recruitment success,
supports this finding (Lemieux et al., 2008). Likewise, the current study was conducted in South Florida where non-English-speaking and international patients are prevalent, suggesting that a multilingual intervention may be more appropriate for BCa survivors in this specific setting. Factors hindering recruitment that were out of the research team’s control included numerous rescheduled appointments and lack of interest in study participation among many BCa survivors.

Previous researchers have discussed the importance of minimizing clinician’s time commitment and study workload, delineating clear roles and responsibilities, and providing support staff to assist them with study tasks in order to avoid interference with daily clinic operations (Donovan et al., 2014; van Staa et al., 2014; Fletcher et al., 2012; Lemieux, 2008; Bowen et al., 2007; Campbell et al., 2007; Pringle & Churchill, 1995). At the same time, several studies also have championed the active involvement of clinicians (Bhanushali et al., 2014; van Staa et al., 2014; Bowen et al., 2007). The current study highlights the benefits and drawbacks of minimizing clinician involvement and leaving more time-consuming tasks, like introducing the study, performing eligibility screening, and conducting the informed consent, to the study staff.

Participating oncologists were receptive to participating in the study, as well as enthusiastic about involving their BCa patients; although, the extent and type of participation varied by oncologist. For example, some oncologists eagerly encouraged their eligible patients to participate in the study and personally introduced them to the study staff, while others took a more hands-off approach, relying instead on support staff to complete study-related tasks. Standardization of oncologists’ study involvement may
not always be possible; however, allotting more time for formal study training may have promoted a more uniform recruitment process across oncologists.

With the more limited role that several oncologists played in the study, the assistance provided by their support staff became very important in recruitment efforts. While the role of the support staff was kept to a minimum, there were times when their clinical duties kept them too busy to assist the research team with reviewing EMRs and identifying potentially eligible patients. One solution to these challenges would be to give study staff access to EMRs in order to review upcoming appointments. Using the EMR proved to be an invaluable, time-saving tool for identifying potentially eligible patients to approach about participating in the study and has successfully been used for patient recruitment in earlier work (van Staa et al., 2014; Bhanushali et al., 2014; Heiney et al., 2010; Bowen et al., 2007). Preliminary review of EMRs by study staff could reduce the time burden placed on support staff (Rogerino et al., 2009). Additionally, study staff’s ability to monitor appointments in real time and identify rescheduled or delayed appointments also would be time-saving given that study staff spent a substantial amount of time waiting for appointments that did not take place at the scheduled time.

Despite time limitations, support staff involvement in the recruitment process proved to be advantageous in a number of ways. Support staff was familiar with returning patients, making it possible for them to identify patient information not included in the EMRs, such as language preference and place of residence, which was needed to determine eligibility. Likewise, study introductions provided by support staff may have garnered greater interest and been perceived as more trustworthy than those given by
study staff who were strangers to the patients. Greater involvement of the support staff could have also limited idle time spent by study staff waiting to conduct study introductions at the clinic, as well as prevented missed recruitment opportunities when study staff, who could not be stationed within the clinic, was unable to attend identified oncology appointments. Provided that support staff is able to assume a larger study role, steps should be taken to formally include them in the design and study protocol.

This study, coupled with findings from previous work, supports the idea that there is not likely a one-size-fits-all means of maximizing recruitment in a clinical setting (Lemieux et al., 2008; McDaid et al., 2006). Success of recruitment strategies may vary by differing types of clinics (i.e., academic versus private), just as they may vary between similar types of clinical settings (Bhanushali et al., 2014; Ott et al., 2006). Fletcher and colleagues’ (2012) use of qualitative research to assess the recruitment activity of clinicians in randomized controlled trials can inform future efforts. Qualitative assessments of target populations and key stakeholders can aid researchers in determining which recruitment barriers are most relevant to their work and how best to address them. For example, qualitative work with clinical staff conducted prior to the current study may have helped to determine the amount and types of involvement clinic staff was able to contribute to the study (Fletcher et al., 2012; Bowen et al., 2008).

Building flexibility and contingency plans into a study design also can help to account for unforeseen barriers and aid in efforts to promote successful recruitment (Bhanushali et al., 2014). In the current study, two contingency plans (i.e., broadening of inclusion criteria and addition of participating oncologists) were utilized early in the recruitment
phase to boost enrollment numbers. However, these initial contingency plans were not sufficient to overcome additional recruitment challenges, necessitating additional actions, such as the extension of the study period and the recruitment of additional participating oncologists. Extending the recruitment period led to additional challenges, such as imposing a greater time commitment from participating oncologists and their support staff, and may have contributed to some degree of support staff burnout. Several holidays and oncology conferences within the extended time period also interrupted or halted recruitment efforts at times throughout the study.

In sum, recruitment of BCa survivors to a pilot study from a clinical setting of a major cancer center proved to be more challenging than anticipated. Several strategies, such as using EMRs for initial pre-screening and minimizing clinician involvement, were appropriate for this clinical setting; however, there were numerous other challenges to enrolling the desired number of participants. Key lessons learned include the importance of meticulously assessing the available sampling frame and recruitment resources, as well as associated limitations. Qualitative study of key stakeholders can augment recruitment efforts by aiding in the identification of unique site-, patient-, and clinician-specific characteristics and their impact on recruitment, just as a flexible study design that incorporates contingency plans can also bolster recruitment efforts in the face of unforeseen challenges. Finally, the dissemination of publications detailing important lessons learned during study recruitment, particularly in more challenging populations, is essential. Researchers should make use of the shared experiences presented in this and previous studies when tailoring their work to their chosen setting and population.
Chapter 4
A Home-Based, DVD Strength Training Program Increases Upper Body Strength and Range of Motion among Post-Operative Breast Cancer Survivors

Background

Breast cancer (BCa) is the most common type of cancer diagnosed among women in the United States. In 2014, there were 232,670 estimated new cases of BCa among American women, accounting for more than one-quarter of all incident cases (Siegel et al., 2014). BCa is also the second leading cause of cancer mortality, with an estimated 40,000 annual deaths (Siegel et al., 2014). Fortunately, advances in cancer detection and treatment have led to improved survival among women diagnosed with BCa, as five-year relative survival rates are now greater than 90% (American Cancer Society, 2010; Stevinson, 2010). With larger numbers of women living as BCa survivors, focus has shifted towards addressing the adverse physiological and psychological effects associated with BCa and its treatments (e.g. surgery, chemotherapy, radiation, hormone therapy) (Markes et al., 2009; Reiger et al., 2009; Schneider et al., 2007; Albert et al. 2006; Bicego et al., 2006; Visovsky et al., 2006; Blomqvist et al., 2004; Courneya et al., 2003). Potential sequelae of cancer treatments, including fatigue, weight gain, psychological distress, lymphedema, loss of muscle strength, and impaired functional capacity can be debilitating and negatively affect quality of life (QOL) (Markes et al., 2009; Reiger et al., 2009; Schneider et al., 2007; Albert et al. 2006; Bicego et al., 2006; Visovsky et al., 2006; Blomqvist et al., 2004; Courneya et al., 2003).

Evidence supports regular physical activity (PA) as an effective means of managing the negative side effects of BCa treatments and improving health-related QOL (Loprinzi et al., 2011; Speck et al., 2010; De Backer et al., 2009; Mustian et al., 2009; Cheema et
al., 2008). However, attention has been primarily given to aerobic activity with less focus on other types of PA, such as strength training. Whereas aerobic activity is essential for maintaining good health and reducing cancer reoccurrence and mortality (Sabiston et al., 2011), strength training is of particular importance for BCa survivors who experience muscle wasting and functional limitations associated with BCa treatments (Loprinzi et al., 2011; Sabiston et al., 2011; Smoot et al., 2010; Sweeney et al., 2006; Shamley et al., 2007). Previously, recommendations advised BCa survivors to limit the use of their affected arm to reduce lymphedema risk (Schmitz et al., 2009; Kent, 1996). In contrast, recent studies have shown strength training to be both safe and effective for decreasing the occurrence of lymphedema exacerbations and symptoms (Kwan et al., 2011; Schmitz et al., 2010b; Johansson et al., 2005). Improved muscular strength also aids in the performance of activities of daily living, can prevent injuries associated with disuse of the upper body, and improves body composition and bone health (Strasser et al., 2013; De Backer et al., 2009; Stevinson et al., 2007). Despite the proven benefits of strength training, only 20.7% of middle-aged women in the general population are meeting recommended guidelines of performing strengthening exercises at least twice weekly, with rates of participation dropping further with age (Strasser et al., 2013; U.S. Department of Health and Human Services, 2012; Physical Activity Guidelines Advisory Committee, 2008). Whereas the prevalence of strength training among BCa survivors is currently unknown, comparable trends in aerobic activity would suggest that the rates of strength training among BCa survivors are lower than general population estimates and decrease further post-diagnosis (Stevinson et al., 2007; Irwin et al., 2004; Irwin et al., 2003). Lack of time and transportation, as well as cancer-related barriers like fatigue and
lack of energy, may help to explain why PA levels are low and decline post-diagnosis (Stevinson, 2010; Stevinson et al., 2007; Irwin et al., 2004; Irwin et al., 2003).

Given their positive influence on cancer patients, healthcare providers (HCP) have been considered strong advocates for the promotion of PA and strength training recommendations (Karvinen et al., 2010). Cancer survivors who have a discussion about exercise with their oncologist report greater frequency and more total minutes of exercise than survivors whose oncologists did not initiate exercise discussions (Jones et al., 2002; Segar et al., 1998). Nevertheless, an insufficient number of HCPs recommend PA to BCa survivors, with more recent studies showing that between 56-64% of HCPs report discussing PA with their patients (Karvinen et al., 2010; Daley et al., 2008; Jones et al., 2002; Denmark-Wahnefried et al., 2000; Segar et al., 1998; Young-McCaughan et al., 1991). Several barriers, including providers’ lack of time and unfamiliarity or uncertainty regarding the benefits of various types of PA for cancer patients, have been reported and may help explain this phenomenon (Karvinen et al., 2010; Stevinson et al., 2007; Jones et al., 2005). New methods of delivering educational information and exercise programming that can be used by HCPs in a way that overcomes provider-specific barriers and helps facilitate BCa patients’ uptake of strength training are needed.

Approaches that take BCa survivors’ preferences into consideration are ideal as they are likely to maximize adherence. Jones et al. (2002) surveyed predominantly BCa survivors (n=299) to determine their exercise programming preferences. The majority of cancer survivors preferred exercising unsupervised, at home, and alone in a program that would start before treatment. Among BCa survivors, home-based programs often are preferred over in-person, clinic-based programs given that they help to eliminate barriers
such as lack of time and transportation (Rogers et al., 2008; Denmark-Wahnefried et al., 2000). Previous research in this population has demonstrated the efficacy of home-based PA interventions on outcomes such as aerobic PA levels, fatigue, and QOL (Mustian et al., 2009; Matthews et al., 2007; Pinto et al., 2005; Segal et al., 2001).

Home-based PA interventions that utilize video- or DVD-based exercise programs for BCa survivors are beginning to receive greater attention and may present HCPs with a trustworthy resource they can provide to their BCa patients (Ingram et al., 2010; Haines et al., 2010; Kilgour et al., 2008; Mock et al., 2005). Focus groups conducted with BCa survivors highlighted a preference for DVD-based exercise programming over verbal and written exercise prescriptions, and that such programming would be well received if provided by HCPs (unpublished work). For example, Haines and colleagues (2010) found that a combined aerobic and strength training program using DVD instruction among 89 BCa survivors undergoing chemotherapy effectively improved QOL and physical functioning at 3-months, although these improvements were not maintained at 6-months. Current studies, however, have focused primarily on psychosocial outcomes and typically include multimodal or aerobic-only training. Further study of home-based strength training exercise programs using DVD instruction that have a primary focus on strength training for BCa survivors and can be easily disseminated in a clinical setting is needed. Therefore, the aim of this study was to evaluate the effects of a 12-week home-based exercise program on the upper body strength of post-operative BCa survivors.
METHODS

The study was a 12-week, home-based randomized controlled pilot trial assessing the effects of a DVD-based exercise program on post-operative BCa survivors’ upper body strength. Recruitment of post-operative BCa patients took place in a clinical setting, while study interventions were home-based. Participants were randomized to one of two groups and asked to view DVDs specific to their intervention. Assessments, including physiological and psychosocial measures, took place at baseline and upon completion of the 12-week study intervention.

Participants

BCa patients were recruited from February 2012 through March 2014. Eligible women had a history of BCa (stages I-IV); had undergone BCa-related surgery four weeks to two years prior to study entry; were between the ages of 40 and 80; were current patients at the University-based comprehensive cancer center; received medical clearance to participate from their oncologist; had access to a television and DVD player at home; spoke English; and provided informed consent. Women meeting these criteria were eligible regardless of current or past BCa-related treatments. BCa patients were excluded if they had plans to move or engage in extended travel during the study period, were already meeting PA guidelines for strength training, or had contraindications for unsupervised exercise, including recent myocardial infarction, uncontrolled congestive heart failure or angina, breathing difficulties requiring oxygen use or hospitalization, use of mobility aids other than a cane, and musculoskeletal injuries, as well as other conditions, including fibromyalgia, scoliosis, polio, fractures, and herniated discs.
Study staff partnered with oncologists and their support staff (i.e., physician assistant and nurses) from a University-based comprehensive cancer center in South Florida to recruit post-operative BCa patients. Study staff met bi-weekly with clinic staff to review the electronic medical records (EMRs) of BCa survivors who had upcoming oncology appointments to identify potentially eligible patients. Identified patients were provided with an in-person introduction to the study and asked if they were interested in participating. Interested patients were screened during their oncology appointment or later by telephone to confirm eligibility. Patients who were uncertain about participating were given a study flyer and encouraged to contact study staff at a later date if interested. Baseline assessment appointments were made with those patients who were deemed eligible and wished to participate in the study. Potential study participants provided verbal consent prior to being screened, and written informed consent at the start of their baseline appointment. This study was conducted with the approval of the University of Miami’s Institutional Review Board and the cancer center’s Protocol Review Committee.

Participants were asked to complete a battery of physiological and psychological assessments at baseline that were repeated after the 12-week intervention period. After baseline measurements were taken, BCa survivors were stratified by surgery type with a classification of either lumpectomy or mastectomy, and then randomly assigned to one of two study groups, either a Strength Training (ST) or Health Education (HEI) intervention, via a computer-generated list of random numbers (GraphPad QuickCalcs, 2012). Block randomization was used to maintain balance across groups throughout recruitment.
Strength Training Intervention

Participants in the ST intervention received a copy of *Strength & Courage* (S&C), a commercially available DVD-based exercise program, and a set of hand weights consisting of pairs of weights ranging from one to five pounds (Strength & Courage, 2007). The S&C DVD contained five chapters that consisted of postural and post-operation exercises, flexibility, and strength training, as well as aerobic exercise guidelines designed to help BCa survivors regain flexibility and upper body strength post-surgery. A certified personal trainer led the exercises in Chapters 1 and 2, while an American College of Sports Medicine Health Fitness Specialist with an American Cancer Society cancer exercise trainer certification modeled exercises in Chapters 3 and 4. Bonus features of the S&C DVD include a section about strength training and lymphedema, as well as a printable exercise log. A description of the S&C DVD chapters, including the recommended activity frequencies and progressions for the ST intervention, is provided in Table 1.1.

Over the 12-week study period, participants were instructed to view the S&C DVD at home and follow along with the demonstrated strengthening exercises found in Chapter 4 at least twice weekly for a total of approximately 30 minutes per session on nonconsecutive days. The DVD encouraged participants to gradually progress through the chapters, moving to subsequent chapters as they mastered each set of exercises. Participants were asked to complete Chapters 1 through 3 prior to beginning Chapter 4 to ensure that they were capable of safely completing the assigned strengthening exercises. Participants slowly increased repetitions and weight as tolerated, documenting weekly activity in an exercise log provided to them. Precautionary information and exercise
modifications were provided throughout the DVD to ensure safe participation. Study staff communicated with study participants, via telephone, on a weekly basis to monitor safety and intervention adherence.

Health Education Intervention

The HEI served as an attention control group. Participants randomized to the HEI received a series of health education DVDs covering a wide array of topics unrelated to strength training (e.g. sleep, alternative medicine, depression, Alzheimer’s, sleep, neuroscience, and healthy eating). Participants were instructed to watch one DVD per week, lasting approximately 120 minutes, and record their thoughts about the topic in a study log provided to them. Study staff communicated via telephone with HEI participants on a weekly basis to encourage their continued participation and to assess their adherence to the intervention. At the conclusion of the study period, HEI participants were given a copy of the S&C DVD for their personal use.

Measurements

Medical Screening. The Physical Activity Readiness Questionnaire (PAR-Q) was administered during study eligibility screening to determine whether participation in exercise was safe (Chisholm et al., 1978). Participants also took the Hospital Anxiety and Depression Scale at the baseline assessment (HADS; Zigmond et al., 1983). Participants not meeting a predetermined cut-off were excluded from the study and given a referral to the cancer center’s psychological services. Participating oncologists provided final clearance for all study participants, especially if any concerns were identified during the screening process.
Demographic and Clinical Characteristics. Self-reported demographic characteristics, cancer history, and treatment history were recorded at baseline. Demographic characteristics included age, race and ethnicity, education level, marital status, and employment status. Cancer history consisted of cancer stage, age at diagnosis, type of BCa-related surgery (lumpectomy or mastectomy), date of surgery, and number of lymph nodes removed. Treatment history was comprised of the types of BCa-related treatments (radiation, chemotherapy, and hormone therapy) received and the time frame of their administration.

Study Outcome Measures. Measurements were obtained from all participants at baseline and upon completion of the study intervention by trained staff using standardized methods. Anthropometric measures included height (baseline only), weight, and waist circumference. Height was measured using a wall-mounted stadiometer (Lohman et al., 1988). Body weight was measured using a calibrated digital scale with participants wearing street clothing and no shoes. Body mass index (BMI) was calculated as weight in kilograms divided by height in meters squared (kg/m²). Waist circumference was measured at the narrowest part of the torso between the xiphoid process and the umbilicus after a normal expiration.

The primary study outcome was upper body muscular strength as measured by a one-repetition maximum test (1-RM); the maximum amount of weight that can be lifted once performed on a chest press machine. The 1-RM is the standard method of evaluating changes in muscular strength, and is considered safe for most populations when properly supervised (Schmitz et al., 2009; Barnard et al., 1999). Participants were led through a
series of upper body stretches and then asked to rate the level of difficulty of a warm-up set of five repetitions at five pounds on the chest press. Weight then was added accordingly until the participant was unable or unwilling to progress to a heavier weight, or until they exhibit improper biomechanical form (Schmitz et al., 2009).

Additional measurements were taken to assess functional capacity and physical functioning, shoulder range of motion, PA levels, fatigue, distress, and QOL. Functional capacity was measured using the 6-minute walk test (ACSM, 2006; Solway et al., 2001). Physical functioning was assessed using the Disabilities of the Arm, Shoulder, and Hand (DASH) Outcome Measure (Hudak et al., 1996). Shoulder flexion and abduction were measured on both sides of the body using standard goniometry procedures in a standing position (Trombly, 1989). Current PA levels were assessed using a self-report 7-day PA recall questionnaire (7-day PAR) in which metabolic equivalent (MET) values of all sleep and moderate- to vigorous-intensity activities were summed, multiplied by current weight in kilograms, and divided by seven to yield kilocalories per day (Johnson-Kozlow et al., 2006; Blair et al., 1985). Fatigue severity and interference were evaluated using the Fatigue Symptom Inventory (FSI), while distress was assessed using the National Comprehensive Cancer Network’s (NCCN) Distress Thermometer (NCCN, 2013; Donovan, 2010). The Medical Outcomes Study Short Form 36 Health Survey (SF-36) and the Functional Assessment of Cancer Therapy – Breast (FACT-B) survey were used to assess QOL (Tomich et al., 2002; Rowland et al., 2000; Ganz et al., 1999; Ware et al., 1996; Ware et al., 1992).

Safety Assessments. Several measures were used to evaluate participants’ safety over the course of the study, including pain and lymphedema symptoms. The short-form Brief
Pain Inventory (BPI) was used to assess the severity and impact of pain on daily functioning (Tan et al., 2004; Price et al., 1983; Downie et al., 1978; Revill et al., 1976). The Norman Lymphedema Survey was used to evaluate the self-reported presence and degree of lymphedema, as well as the number of lymphedema symptoms experienced (Norman et al., 2001). During weekly calls with participants, study staff asked participants to report any study-related pain or safety concerns, if applicable. At the post-intervention assessment, participants completed an additional injury history survey form to assess whether any strength training-related injuries were experienced during the study period.

**Study Adherence.** ST intervention participants were considered compliant if they completed two sets of all eight strengthening exercises demonstrated in the S&C DVD twice per week, while HEI intervention participants were considered compliant if they watched one assigned health education DVD per week. Adherence rates for ST intervention participants consisted of the percentage of strength training sessions completed throughout the study period. HEI intervention participants’ adherence rates were comprised of the percentage of health education DVDs watched over the study period. Study staff collected adherence data during a weekly call to participants.

**Statistical Analysis**

Descriptive statistics for baseline variables included counts, percentages, means and standard deviations. Baseline characteristics were compared between study groups using Fisher exact tests for categorical variables and Student *t*-tests for continuous variables. Repeated measures analysis of variance (ANOVA) was used to evaluate unadjusted
group changes in mean upper body muscular strength from baseline to 12-weeks in ST participants as compared to HEI participants. Repeated measures analysis of covariance (ANCOVA), adjusting for baseline measures of upper body muscular strength, time since BCa surgery, and current treatment status, were used to evaluate individual changes in strength. Similar analyses were conducted for secondary outcomes including measures of physical functioning, weight, arm circumference, and shoulder range of motion, as well as self-reported measures of distress, pain, fatigue, lymphedema symptoms, and QOL. Finally, a repeated measures ANOVA analysis was used to evaluate the impact of adherence on the primary outcome in ST group participants. All analyses were conducted using SAS, version 9.3 (SAS Institute, Cary, North Carolina).

The sample size calculation was based on the primary outcome of the study, assessing the effects of the intervention on upper body muscular strength as measured by the 1-RM chest press. To achieve a statistical power of 80%, assuming a significance level of 0.05, an effect size of 0.25, and a loss to follow-up of 20%, an overall sample size of 40 participants was desired. Previous research findings have demonstrated an effect size ranging from 0.93 to 2.25. However, the effect size in the current study was decreased to account for the proposed intervention period being of significantly shorter duration (i.e., 12-weeks versus 6- to 12-months) and taking place during the treatment period of the cancer continuum when intervention effects are muted in comparison to interventions occurring after completion of cancer treatment (Schmitz et al., 2010a; Schmitz et al., 2009; Ahmed et al., 2006). G*Power freeware was used to calculate the sample size (Faul et al., 2007).
RESULTS

One hundred and twenty seven unique BCa survivors were identified as meeting age and cancer stage eligibility requirements based on EMR review. Of these women, 62 were present at their scheduled appointment and agreed to be screened. Thirty-seven BCa survivors were eligible to participate based on screening, 23 of whom were enrolled in the study. Two participants (8.7%) did not complete the study due to cancer metastasis and hospitalization for pneumonia, while a third was lost to follow-up. Figure 3.1 illustrates the flow of participants through the study. Participant retention was 83.3% in the ST group (n=10) and 90.9% in the HEI group (n=10). Mean adherence among study completers was 72.7% and 75.0% within the ST and HEI groups, respectively.

Table 4.1 displays descriptive data of the participants at baseline. Participants were 43 to 69 years of age with a mean age of 56.0, a majority were married (69.6%), college educated (73.9%), employed full-time (56.6%), and non-white (52.2%). On average, participants were nearly 10 months post-BCa surgery, with 39.1% receiving one or more types of BCa-related treatment (e.g. radiation, chemotherapy, hormone therapy) during the study period. Although only two participants reported a lymphedema diagnosis, 60% of all participants self-reported experiencing one or more lymphedema symptoms. Bi-variate analyses show baseline characteristics were distributed similarly across study groups as well as between study completers and non-completers (data not shown).

Unadjusted data for upper body strength, functional capacity, anthropometry, and shoulder range of motion among study completers showed no significant between-group
### Table 4.1. Baseline Characteristics of the Intervention Study Sample.*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All participants (n=23)</th>
<th>Strength Training (n=12)</th>
<th>Health Education (n=11)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), year</td>
<td>55.96 (8.2)</td>
<td>53.42 (6.9)</td>
<td>58.73 (8.9)</td>
<td>0.123</td>
</tr>
<tr>
<td>Age at diagnosis, mean (SD), year</td>
<td>55.17 (8.3)</td>
<td>52.58 (7.1)</td>
<td>58 (8.8)</td>
<td>0.118</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ High school</td>
<td>1 (4.4)</td>
<td>1 (8.3)</td>
<td>0 (0.0)</td>
<td>0.227</td>
</tr>
<tr>
<td>Some college</td>
<td>5 (21.7)</td>
<td>4 (33.0)</td>
<td>1 (9.0)</td>
<td></td>
</tr>
<tr>
<td>≥ College</td>
<td>17 (73.9)</td>
<td>7 (58.0)</td>
<td>10 (91.0)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>11 (47.8)</td>
<td>6 (50.0)</td>
<td>5 (45.0)</td>
<td>0.504</td>
</tr>
<tr>
<td>Black</td>
<td>4 (17.4)</td>
<td>3 (25.0)</td>
<td>1 (9.0)</td>
<td></td>
</tr>
<tr>
<td>Other**</td>
<td>8 (34.8)</td>
<td>3 (25.0)</td>
<td>5 (45.0)</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>13 (56.6)</td>
<td>7 (58.0)</td>
<td>6 (55.0)</td>
<td>0.325</td>
</tr>
<tr>
<td>Part-time</td>
<td>3 (13.0)</td>
<td>2 (17.0)</td>
<td>1 (9.0)</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>2 (8.7)</td>
<td>1 (8.3)</td>
<td>1 (9.0)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>2 (8.7)</td>
<td>2 (17.0)</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>3 (13.0)</td>
<td>0 (0.0)</td>
<td>3 (27.0)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>1 (4.35)</td>
<td>0 (0.0)</td>
<td>1 (9.0)</td>
<td>0.810</td>
</tr>
<tr>
<td>Married/Partnered</td>
<td>16 (69.6)</td>
<td>9 (75.0)</td>
<td>7 (64.0)</td>
<td></td>
</tr>
<tr>
<td>Divorced/Widowed</td>
<td>6 (26.1)</td>
<td>3 (25.0)</td>
<td>3 (27.0)</td>
<td></td>
</tr>
<tr>
<td>Cancer stage†</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 1</td>
<td>8 (34.8)</td>
<td>4 (33.0)</td>
<td>4 (36.0)</td>
<td>0.682</td>
</tr>
<tr>
<td>Stage 2</td>
<td>9 (39.1)</td>
<td>4 (33.0)</td>
<td>5 (45.0)</td>
<td></td>
</tr>
<tr>
<td>Stage 3</td>
<td>4 (17.4)</td>
<td>2 (8.7)</td>
<td>2 (18.0)</td>
<td></td>
</tr>
<tr>
<td>Stage 4</td>
<td>2 (8.7)</td>
<td>2 (8.7)</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>Time since surgery, mean (SD), months</td>
<td>9.77 (4.7)</td>
<td>8.00 (3.3)</td>
<td>11.71 (5.3)</td>
<td>0.055</td>
</tr>
<tr>
<td>No. nodes removed, mean (SD)</td>
<td>9.26 (9.7)</td>
<td>8.83 (10.1)</td>
<td>9.73 (9.7)</td>
<td>0.831</td>
</tr>
<tr>
<td>Diagnosed with lymphedema</td>
<td>2 (8.7)</td>
<td>1 (8.3)</td>
<td>1 (9.1)</td>
<td>1.000</td>
</tr>
<tr>
<td>Lymphedema symptoms, no.</td>
<td>2.57 (3.2)</td>
<td>3.17 (4.0)</td>
<td>1.91 (2.1)</td>
<td>0.359</td>
</tr>
<tr>
<td>Currently receiving treatment††</td>
<td>9 (39.1)</td>
<td>5 (42.0)</td>
<td>4 (36.0)</td>
<td>1.000</td>
</tr>
<tr>
<td>Physical activity level, mean (SD), kcal/day</td>
<td>672.29 (143.9)</td>
<td>672.38 (85.6)</td>
<td>672.18 (193.7)</td>
<td>1.000</td>
</tr>
<tr>
<td>Anxiety score, mean (SD)</td>
<td>4.17 (3.1)</td>
<td>4.92 (3.1)</td>
<td>3.36 (2.7)</td>
<td>0.220</td>
</tr>
<tr>
<td>Depression score, mean (SD)</td>
<td>3.17 (2.4)</td>
<td>2.83 (2.1)</td>
<td>3.55 (2.8)</td>
<td>0.494</td>
</tr>
</tbody>
</table>

* Data are presented as count (%) unless otherwise specified. Percentages may not sum to 100 due to rounding.

** Includes Asian and Hispanic. † The staging system used was from the American Joint Commission on Cancer and refers to the extent of the cancer in the body. †† Current treatment status includes one or more of the following: chemotherapy, radiation, hormone therapy, and targeted therapy. SD=standard deviation; No.=number; kcal=Kilocalories.
Table 4.2. Adjusted Strength, Functional Capacity, Anthropometry, and Range of Motion Change Scores by Study Group. ‡

<table>
<thead>
<tr>
<th>Variable</th>
<th>Change between Baseline and 12 Weeks</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health Education mean±SE</td>
<td>Strength Training mean±SE</td>
</tr>
<tr>
<td>Chest press (lb)</td>
<td>1.8±3.2</td>
<td>13.2±3.1</td>
</tr>
<tr>
<td>6-minute walk test (m)</td>
<td>26.4±13.0</td>
<td>24.7±12.9</td>
</tr>
<tr>
<td>Weight (lb)</td>
<td>1.3±1.1</td>
<td>-0.5±1.1</td>
</tr>
<tr>
<td>BMI</td>
<td>0.1±0.2</td>
<td>0.0±0.2</td>
</tr>
<tr>
<td>Waist circumference (cm)</td>
<td>-0.2±0.2</td>
<td>-0.3±0.2</td>
</tr>
<tr>
<td>Shoulder flexion (°)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>right</td>
<td>-3.1±1.9</td>
<td>7.1±1.9</td>
</tr>
<tr>
<td>left</td>
<td>-2.7±2.7</td>
<td>8.9±2.7</td>
</tr>
<tr>
<td>Shoulder abduction (°)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>right</td>
<td>3.5±2.9</td>
<td>12.5±2.8</td>
</tr>
<tr>
<td>left</td>
<td>1.5±2.5</td>
<td>15.8±2.4</td>
</tr>
</tbody>
</table>

† BMI=Body mass index, the weight in kilograms divided by the square of height in meters. ‡ Adjusted for baseline data, time since surgery, and current treatment status. SE=standard error.

Figure 4.1. Upper Body Muscular Strength by Adherence Level Among Strength Training Participants.

1-RM=one repetition maximum.
differences at baseline, with the exception of shoulder flexion of the right arm (data not shown). Adjusted analysis controlling for baseline strength, time since surgery, and treatment status demonstrated that women in the ST group had significantly greater increases in upper body strength compared to women in the HEI group (13.2 ± 3.1 vs. 1.8 ± 3.2 lbs; p=0.019; Table 4.2). Figure 4.1 shows mean upper body muscular strength data by adherence level, using mean adherence as the cut-point for low and high adherence. ST group participants with high levels of adherence experienced a 57.5% increase in muscular strength compared to an 18.8% increase among ST group participants with lower levels of adherence (15.8 vs. 8.0 lbs; data not shown). However, the impact of adherence level on muscular strength did not reach statistical significance (p=0.214; data not shown). Significant improvements also were observed for shoulder flexion (right arm: 7.1 ± 1.9 vs. -3.1 ± 1.9°, p=0.001; left arm: 8.9 ± 2.7 vs. -2.7 ± 2.7°, p=0.006) and abduction (right arm: 12.5 ± 2.8 vs. 3.5 ± 2.9°, p=0.037; left arm: 15.8 ± 12.4 vs. 1.5 ± 2.5°, p<0.001) in ST participants. Changes in weight, waist circumference, and functional capacity measures were not significantly different between the two groups.

Unadjusted baseline and post-intervention data for subjective measures of upper body disability, distress, fatigue, QOL, and self-reported PA levels showed no significant between-group differences at baseline (Table 4.3). Only role limitations due to emotional concerns in HEI participants significantly improved after the 12-week intervention (p=0.024). Adjusted analyses revealed a significant between-group difference in distress level after the 12-week intervention (ST = -1.24 vs. HEI = 1.31, p=0.003; Table 4.4). HEI participants reported a significantly greater reduction in fatigue disruption (p=0.005) and significant improvements in general health (p=0.029), role limitations due to physical
health (p=0.002), and emotional problems (p=0.0024) than ST participants. No other significant between-group differences were found among the subjective measures.

**Table 4.3. Unadjusted upper body disability, distress, fatigue, quality of life, and physical activity level data at baseline and 12-weeks by study group.**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline</th>
<th>12 Weeks</th>
<th>Change between Baseline and 12 Weeks</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health Education mean±SE</td>
<td>Health Training mean±SE</td>
<td>Health Education mean±SE</td>
<td>Health Training mean±SE</td>
</tr>
<tr>
<td>DASH</td>
<td>10.4±4.2</td>
<td>16.6±4.2</td>
<td>9.3±3.8</td>
<td>14.5±3.8</td>
</tr>
<tr>
<td>Distress</td>
<td>3.2±0.8</td>
<td>2.6±0.8</td>
<td>4.1±0.8</td>
<td>1.7±0.8</td>
</tr>
<tr>
<td>FACT-B</td>
<td>79.5±4.3</td>
<td>82.9±4.3</td>
<td>83.3±4.4</td>
<td>84.6±4.4</td>
</tr>
<tr>
<td>FSI Disruption</td>
<td>12.6±3.8</td>
<td>15.1±3.8</td>
<td>5.9±3.5</td>
<td>13.6±3.5</td>
</tr>
<tr>
<td>FSI Severity</td>
<td>12.3±2.5</td>
<td>9.6±2.5</td>
<td>8.3±2.5</td>
<td>9.9±2.5</td>
</tr>
<tr>
<td>SF-36 Emotional</td>
<td>75.5±5.1</td>
<td>81.5±5.1</td>
<td>73.0±5.9</td>
<td>80.5±5.9</td>
</tr>
<tr>
<td>SF-36 Energy</td>
<td>65.0±5.4</td>
<td>62.5±5.4</td>
<td>68.8±6.4</td>
<td>63.1±6.4</td>
</tr>
<tr>
<td>SF-36 General</td>
<td>58.5±5.6</td>
<td>57.6±5.6</td>
<td>66.5±3.4</td>
<td>58.0±3.4</td>
</tr>
<tr>
<td>SF-36 Physical</td>
<td>78.5±6.6</td>
<td>68.5±6.6</td>
<td>79.0±7.7</td>
<td>69.5±7.7</td>
</tr>
<tr>
<td>SF-36 Role Limitations, Emotional</td>
<td>83.3±6.9</td>
<td>82.5±6.9</td>
<td>92.5±6.2</td>
<td>74.2±6.2</td>
</tr>
<tr>
<td>SF-36 Role Limitations, Physical</td>
<td>68.8±7.5</td>
<td>66.3±7.5</td>
<td>81.9±7.3</td>
<td>65.0±7.3</td>
</tr>
<tr>
<td>SF-36 Social</td>
<td>73.8±7.4</td>
<td>77.5±7.4</td>
<td>81.3±7.3</td>
<td>75.0±7.3</td>
</tr>
<tr>
<td>7D PAR (kcal/day)</td>
<td>624.9±33.6</td>
<td>681.9±33.6</td>
<td>740.7±74.4</td>
<td>759.3±74.4</td>
</tr>
</tbody>
</table>

* Between-group difference at 12-weeks, p<0.05. SE=standard error. DASH=Disabilities of the Arm, Shoulder, and Hand; FACT-B=Functional Assessment of Cancer Treatment-Breast; FSI=Fatigue Severity Inventory; SF-36=Medical Outcomes Survey Short Form Health Survey; 7D PAR=7-day Physical Activity Recall; kcal=Kilocalories.

Measures of safety, including pain and lymphedema symptoms, were not significantly different between groups in the unadjusted analyses (data not shown). Adjusted analyses showed similar results for lymphedema symptoms, although significant between-group improvements for overall pain (-3.04 vs. 17.7, p=0.005) and pain severity (0.31 vs. -1.1, p=0.002) were found among HEI participants (Table 4.5). No strength training-related adverse events were reported throughout the study period.
### Table 4.4. Adjusted Upper Body Disability, Distress, Fatigue, Quality of Life, and Physical Activity Level Data at Baseline and 12-Weeks by Study Group.‡

<table>
<thead>
<tr>
<th>Variable</th>
<th>Change between Baseline and 12 Weeks</th>
<th>Health Education</th>
<th>Strength Training</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>mean±SE</td>
<td>mean±SE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DASH</td>
<td>-2.2±1.8</td>
<td>-0.4±1.7</td>
<td>0.498</td>
<td></td>
</tr>
<tr>
<td>Distress</td>
<td>1.3±0.6</td>
<td>-1.2±0.6</td>
<td><strong>0.003</strong></td>
<td></td>
</tr>
<tr>
<td>FACT-B</td>
<td>1.9±2.1</td>
<td>3.4±2.1</td>
<td>0.624</td>
<td></td>
</tr>
<tr>
<td>FSI</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disruption</td>
<td>-7.8±1.7</td>
<td>-0.6±1.63</td>
<td><strong>0.005</strong></td>
<td></td>
</tr>
<tr>
<td>Severity</td>
<td>-4.0±1.7</td>
<td>0.1±1.16</td>
<td>0.102</td>
<td></td>
</tr>
<tr>
<td>SF-36</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional</td>
<td>-6.6±2.9</td>
<td>1.8±2.9</td>
<td>0.058</td>
<td></td>
</tr>
<tr>
<td>Energy</td>
<td>3.3±2.5</td>
<td>0.7±2.5</td>
<td>0.471</td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>7.4±2.1</td>
<td>0.6±2.0</td>
<td><strong>0.029</strong></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>0.7±2.9</td>
<td>-0.4±2.9</td>
<td>0.792</td>
<td></td>
</tr>
<tr>
<td>Role Limitations, Emotional</td>
<td>7.2±3.0</td>
<td>-7.3±2.9</td>
<td><strong>0.002</strong></td>
<td></td>
</tr>
<tr>
<td>Role Limitations, Physical</td>
<td>13.2±3.2</td>
<td>-2.2±3.2</td>
<td><strong>0.002</strong></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>5.5±4.1</td>
<td>-1.1±4.1</td>
<td>0.283</td>
<td></td>
</tr>
<tr>
<td>7D PAR (kcal/day)</td>
<td>119.5±49.6</td>
<td>73.5±49.2</td>
<td>0.529</td>
<td></td>
</tr>
</tbody>
</table>

‡ Adjusted for baseline data, time since surgery, and current treatment status. SE=standard error. DASH=Disabilities of the Arm, Shoulder, and Hand; FACT-B=Functional Assessment of Cancer Treatment-Breast; FSI=Fatigue Severity Inventory; SF-36=Medical Outcomes Survey Short Form Health Survey; 7D PAR=7-day Physical Activity Recall; kcal=Kilocalories.

### Table 4.5. Adjusted Pain and Lymphedema Data at Baseline and 12-Weeks by Study Group.‡

<table>
<thead>
<tr>
<th>Variable</th>
<th>Change between Baseline and 12 Weeks</th>
<th>Health Education</th>
<th>Strength Training</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>mean±SE</td>
<td>mean±SE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BPI</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain interference</td>
<td>0.45±0.25</td>
<td>-0.22±0.25</td>
<td>0.073</td>
<td></td>
</tr>
<tr>
<td>Pain severity</td>
<td>-1.10±0.28</td>
<td>0.31±0.28</td>
<td><strong>0.002</strong></td>
<td></td>
</tr>
<tr>
<td>SF-36 Pain</td>
<td>17.66±4.76</td>
<td>-3.04±4.70</td>
<td><strong>0.005</strong></td>
<td></td>
</tr>
<tr>
<td>NLS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphedema severity</td>
<td>0.26±0.43</td>
<td>-0.32±0.42</td>
<td>0.356</td>
<td></td>
</tr>
<tr>
<td>Lymphedema symptoms, #</td>
<td>-0.65±0.55</td>
<td>-0.85±0.55</td>
<td>0.809</td>
<td></td>
</tr>
</tbody>
</table>

‡ Adjusted for baseline data, time since surgery, and current treatment status. BPI=Brief Pain Inventory; SF-36=Medical Outcomes Study Short Form Health Survey; NLS=Norman Lymphedema Survey.
DISCUSSION

The current study evaluated the effects of a 12-week home-based exercise program on the upper body strength of post-operative BCa survivors. The results showed that strength training instruction provided via a DVD in a home setting can safely yield improvements in upper body strength as well as range of motion compared to a control condition. During the course of the intervention, ST participants also demonstrated a significant reduction in distress levels, while HEI participants experienced significant improvements in fatigue disruption, general health, and role limitations due to physical and emotional problems. These findings are discussed in greater detail below.

The ST group experienced significant improvements in their upper body strength, increasing their 1-RM by an average of 13.2 pounds (39.4%) at post-assessment. Previous studies assessing the impact of strength training among BCa survivors support our finding (Steindorf et al., 2014; Strasser et al., 2013; Kolden et al., 2002). These interventions, ranging between 12 to 52 weeks in length, led to a mean increase in upper body strength of approximately 15 lbs (range: 7-32.3 lbs). However, the majority of these studies were supervised programs that took place outside of the home setting or incorporated a home-based component after an initial period of supervision. Among home-based interventions with a strength training component, Ott et al. (2004) reported a significant mean increase of 6.1 lbs of overall weight lifted among BCa survivors four years post-treatment in an uncontrolled pilot with 23 women. However, to date, the majority of home-based interventions incorporating strength training have not found significant improvements in upper body strength (Haines et al., 2010; Mustian et al., 2009; Kilgour et al., 2008). Being that all of these home-based interventions concurrently
focused on multiple aspects of physical fitness, potential improvements in strength may have been diluted. In one other case, the aim of the intervention was to maintain, rather than increase, strength during the course of the study (Mustian et al., 2009). Furthermore, prior studies have used bands as opposed to dumbbells.

Changes in other physiological measures, such as functional capacity, PA level, weight, and waist circumference were, as expected, not significant given that they were not targeted in the intervention. Although shoulder range of motion also was not a primary focus of my study, ST participants demonstrated significant improvements in shoulder flexion and abduction. These improvements are consistent with previous interventions with strength training components, conducted both in and out of the home setting, that have shown significant increases in shoulder range of motion (Kilbreath et al., 2012; Louzada Petito et al., 2012; Kilgour et al., 2008). Post-operative pain and tightness can contribute to reduced range of motion among BCa survivors, which can be further exacerbated by protective tendencies to reduce movement and avoid injury (Lee et al., 2010). In turn, limited range of motion negatively impacts daily functional activities as well as QOL (Nesvold et al., 2010) highlighting the need to provide BCa survivors with opportunities to proactively regain shoulder range of motion following BCa surgery.

Results from the present study are also in agreement with previous findings that progressive strength training is safe for BCa survivors, both during and after BCa-related treatment (Strasser et al., 2013; Courneya et al., 2007; McKenzie et al., 2003), leading to the incorporation of strength training into national exercise guidelines for cancer survivors (Schmitz et al., 2010a). Similarly, home-based interventions assessing strength training also have been proven safe (Haines et al., 2010; Mustian et al., 2009; Kilgour et
The combined safety and effectiveness of a DVD-based strength training program that can be completed in an unsupervised, home setting shows great promise. Not only can BCa survivors benefit from a program that addresses common barriers to being physically active, as well as overcoming fears of exercise-induced lymphedema (Silva et al., 2010), but HCPs also can feel confident in promoting the use of such evidence-based programs to their BCa patients with minimal time requirement.

Mixed results were found for measures of well-being. Among ST participants, a significant decrease in distress level was found compared to HEI participants, while measures of fatigue, pain, and QOL did not show improvement. These findings are similar to a previous study in which a strength training intervention did not result in improvements in QOL or fatigue (Strasser et al., 2013). In contrast, Ohira et al. (2006) reported significant improvements in physical and psychosocial well-being among BCa survivors post-treatment following a 6-month strength training program. More recently, Steindorf et al. (2014) showed improvements in cancer-related fatigue and QOL among BCa survivors undergoing radiation after a 12-week group-based strength training program. It is unclear why these benefits from strength training-only interventions conducted in supervised settings did not extend to the current study. One possible explanation could be that larger doses of strength training were delivered in these other studies, which were double that of the current study’s requirements.

For HEI participants, significant improvements were observed for general health, pain, and role limitations due to physical and emotional problems as compared to ST participants. An explanation for these findings may be that the HEI participants benefited from the content of the health education DVDs they were asked to watch during the
While the HEI DVDs were selected to provide educational content not directly related to PA, other topics covered in these DVDs, including stress management and healthy sleep practices, have been successfully used in previous research to reduce cancer-related fatigue and improve QOL (Mustian et al., 2009; Osborn et al., 2006). Although HEI participants were asked only to view the health education DVDs, it is possible that they applied strategies that were presented in their DVDs that impacted their overall well-being.

One concern about home-based interventions is the potential for low levels of compliance that may result from a lack of direct supervision (Pinto et al., 2002). The adherence level seen in this study (72.7%) compares favorably to previous home-based interventions that have ranged from 21.0 - 94.4% (Haines et al., 2010; Mustian et al., 2009; Mock et al., 2005; Headley et al., 2004; Ott et al., 2004). In the current study, ST participants with high levels of adherence demonstrated a larger increase in upper body strength than those ST participants with low levels of adherence. The fact that this finding was not statistically significant may be attributed to insufficient statistical power to detect a difference between the two levels of adherence. This dose-response relationship highlights the need for continued efforts to improve intervention adherence, including weekly telephone contact and other facilitative strategies (Ott et al., 2004).

Several study limitations should be taken into consideration when evaluating these findings. Difficulties with recruiting resulted in a sample size that was smaller than anticipated. Larger than expected improvements in upper body strength among ST intervention participants made it possible to detect a significant intervention effect. However, this limited the ability to detect other effects of the study during secondary
analyses. The small sample size, as well as the study’s inclusion and exclusion criteria, also limit generalizability of these findings. Study subjects, although racially diverse, were largely well-educated, married, employed full-time, and English-speaking. Given that the S&C DVD is currently only available in English, we were limited in my recruitment of non-English speaking patients in a cancer center that serves a large population of Spanish-speaking BCa patients. Second, although the assignment of participants to an intervention took place after the baseline assessments, study staff was aware of the participants’ group assignment at the post-intervention assessment. To limit the potential for bias, study staff did not have access to baseline data prior to the post-intervention assessment appointments. Third, several study outcomes were based on participant self-report, which is susceptible to social desirability bias. Likewise, there may have been recall bias when assessing PA level via self-report.

Strengths of the current study include the use of a randomized controlled design, the use of standardized measures and methods of assessment, stratification by surgery type, and the incorporation of BCa survivors’ exercise preferences (i.e. home-based activity, receiving expert guidance) into the study design. Objective measurement of upper body strength using the 1-RM test was an improvement on previous home-based interventions that have used grip strength as a proxy measure for strength (Haines et al., 2010; Ingram et al., 2010; Kilgour et al., 2008). Moreover, the use of an attention control condition provided a more equivalent amount of time and attention to participants across both study groups.

To my knowledge, the present study is the first home-based intervention employing the use of a DVD to assess the effects of a strength training program on BCa survivors’
upper body strength. Previous research examining the effects of strength training on BCa survivors have either evaluated the effects of home-based training only after a period of supervised exercise or have assessed a combined intervention, concurrently looking at other modes of activity, including aerobics, balance, and flexibility (Haines et al., 2010; Schmitz et al., 2010b; Schmitz et al., 2010c; Schmitz et al., 2009; Kilgour et al., 2008; Ahmed et al., 2006; Ott et al., 2004). Future studies may wish to explore the independent effects of various modes of PA (e.g. strength vs. aerobic training) on physical and psychosocial measures of health and well-being as well as identify their mechanisms of action in the home setting. Tailoring DVD content to meet the needs (i.e. language, cultural, and physical ability) of BCa survivors also may encourage greater intervention compliance and inclusion of a wider range of survivors.

In conclusion, a twice-weekly, home-based strength training program delivered via DVD can improve post-operative BCa survivors’ upper body strength and range of motion. The S&C DVD provided effective exercise instruction in promoting safe participation in a progressive strength training program in an unsupervised setting. The continued development of home-based interventions, such as the S&C DVD that take into account BCa survivors’ preferences, reduce barriers to being physically active, ensure safe participation in unsupervised PA, and can be easily and cost-effectively disseminated by HCPs is an important area for future research that has the potential to positively impact how we care for post-operative BCa survivors.
Overview

PA is beneficial for BCa survivors post-surgery; however, rates of participation are lower than recommended levels (Strasser et al., 2013; Schmitz et al., 2010a). This study was designed to evaluate whether a DVD-based exercise program was an acceptable, safe, and efficacious medium for promoting strength training participation among BCa survivors. As such, focus groups were conducted to assess general acceptability followed by a randomized controlled pilot trial to determine the impact of the DVD-based exercise program on upper body strength of post-operative BCa survivors. In the subsequent discussion, the main findings of this study, the public health implications of this work, and future research directions will be reviewed.

Acceptability of a Strength Training DVD for Breast Cancer Survivors

Focus groups yielded a rich context in which to understand the PA knowledge, beliefs, and behaviors of BCa survivors. Across the focus groups, few participants were aware of national PA guidelines, and fewer still were aware of cancer-specific PA guidelines (Schmitz et al., 2010a). Nonetheless, focus group participants unanimously considered PA to be an important part of their lives and were able to list several physical and psychological benefits they enjoyed from being physically active. Types of physical activities that participants reported engaging in were largely aerobic, including walking, sports, yoga, and various forms of dance. Only three participants reported having engaged in strength training exercises in the past. These findings confirm my first hypothesis that BCa survivors believe that PA is important for their health and well-being.
and were more likely to engage in aerobic activity as compared to strength training. Despite the importance placed on PA, only one participant was considered sufficiently active in meeting aerobic PA recommendations for BCa survivors. These low PA participation rates are consistent with previous research in this population (Segar et al. 1998; Irwin et al. 2003; Stevinson et al. 2007; Cheema et al. 2008; De Backer et al. 2009; Mustian et al. 2009; Schmitz et al. 2009; Speck et al. 2010; Loprinzi & Cardinal 2011; Sabiston & Brunet 2011), and suggest a need to better educate BCa survivors about how to incorporate various forms of PA, especially strength training, into their lives given their appreciation for the physical and psychological benefits they gain from being active.

My findings also indicate that the S&C DVD is an acceptable means of delivering PA information and exercise instruction to BCa survivors. However, the complex interplay of age, PA level, and BCa treatment experience led to varied perceptions among participants that influenced their level of acceptance of the S&C DVD. Hypothesis 2, which suggested that there would be higher acceptance rates for using the DVD-based exercise program among BCa survivors who were older, currently inactive, and who had more recently undergone BCa surgery could not be confirmed, as study findings suggested only partial support. In terms of DVD use across different age groups, older participants, with the exception of one individual who reported being too old to complete some of the exercises provided on the S&C DVD, had fewer complaints regarding the DVD as compared to the youngest focus group participants. While the two youngest participants expressed more constructive criticisms of the DVD than their older counterparts, their level of acceptance was largely associated with their current level of PA, which they reported to be of greater intensity than exercises provided within the S&C DVD. On the
other hand, inactive BCa survivors found the DVD to be a helpful tool that provided needed information and guidance that answered their questions, eased their fears of, and increased their level of comfort with becoming physically active.

Focus group participants did not come to a consensus regarding the time point when they would be most amenable to receive a DVD-based exercise program, but there was agreement that their level of readiness would vary depending on a number of factors, including mindset, surgery type, and treatments received. Some investigators, such as Denmark-Wahnefried and colleagues (2000), have identified diagnosis as a time when survivors expressed high desire for health promotion programming. This finding is only partially supported in the current study by a number of survivors who preferred receiving the DVD at the time of diagnosis in an effort to be better informed and prepared for dealing with their upcoming treatment. These survivors felt the emotionally supportive aspects of the DVD, including the calm tone, reassuring information, and unintimidating encouragement to be active and return to pre-surgery functioning, were appropriate and valuable messages to receive at the time of diagnosis. Other survivors expressed that they were not mentally ready to receive additional information, such as the S&C DVD at the time of their diagnosis. This finding supports the work of Rees and Bath (2001) who reported information avoidance behaviors among BCa survivors who felt overwhelmed by their diagnosis or overburdened by the volume of information provided to them at diagnosis. Similarly, focus group participants that had experienced severe side effects (i.e. fatigue and neuropathy) from their BCa surgeries and related treatments, regardless of their level of acceptance, expressed an inability to use a DVD until these side effects had abated.
Given the likelihood of experiencing one or more negative side effects from BCa-related treatments, focus group participants appreciated the flexibility that a home-based DVD program afforded them. Participants emphasized the convenience of being able to adjust their workout plans when treatment-related side effects might prevent them from being active. Others expressed the convenience of not having to leave their home to be active, especially shortly after BCa surgery. Participants also endorsed the DVD for allowing them to incorporate activity into their daily schedules more easily which could help with overcoming barriers, such as childcare and other competing time commitments. Previous research describing BCa survivors’ preferences for home-based exercise programming support this finding (Denmark-Wahnefried et al., 2000; Jones & Courneya, 2002).

All participants, regardless of age and PA level, felt that the tailored nature of the DVD was a critical characteristic of the exercise program. For instance, focus group participants welcomed the S&C DVD’s inclusion of BCa-specific information that addressed their concerns about cancer recurrence and lymphedema, shared experiences from other survivors, and exercise modifications designed to overcome physical limitations while preventing injury. These needs, including the desire for BCa-related information and seeing other BCa survivors exercise, have been previously identified (Ashing-Giwa et al., 2004; Emslie et al., 2007). Lastly, focus group participants expressed a preference for the DVD over other forms of instruction, such as written instructions and non-BCa-specific group exercise classes in gym settings, which they deemed to lack the adequate support and expert instruction needed by many survivors.
Efficacy of a Home-based, DVD Strength Training Program

After confirming the acceptability of the S&C DVD-based exercise program, my next objective was to assess the efficacy of the DVD in a randomized controlled pilot intervention among a sample of BCa survivors. Specifically, I investigated the effects of the 12-week intervention assessing use of the S&C DVD in the home setting among post-operative BCa survivors. The results of the intervention showed that the DVD-based strength training program can yield improvements in upper body strength and range of motion compared to an attention control condition. During the course of the intervention, ST participants also demonstrated a significant reduction in distress levels, while HEI participants experienced significant improvements in fatigue disruption, general health, and role limitations due to their physical and emotional problems. These findings are discussed in greater detail below.

The ST group experienced significant improvements in their upper body strength, increasing their 1-RM by an average of 13.2 pounds (39.4%) relative to an average increase of 1.8 pounds seen in the HEI group over the course of the intervention. This finding supports Hypothesis 3, which proposed significantly greater increases in muscular strength from baseline to post-intervention among the ST group relative to the HEI group. Previous studies assessing the impact of strength training interventions among BCa survivors also have shown significant improvements in muscular strength (Steindorf et al., 2014; Strasser et al., 2013; Kolden et al., 2002). These interventions, ranging between 12 to 52 weeks in length, led to mean increases in upper body strength of approximately 15 pounds (range: 7-32.3 lbs.). However, the majority of these studies were supervised programs that took place outside of the home setting or incorporated a
home-based component after an initial period of supervised training. My results are impressive given that the strength improvements experienced by the ST group were achieved over a relatively short duration (12 weeks) and without the direct supervision of exercise professionals who were provided in these previous studies.

To date, the majority of home-based interventions incorporating strength training have not found significant improvements in upper body strength (Haines et al., 2010; Mustian et al., 2009; Kilgour et al., 2008). Only one home-based interventions with a strength training component, Ott et al. (2004), reported a significant increase of weight lifted (6.1 lbs.) among BCa survivors who were, on average, four years post-treatment. It is possible that because these home-based interventions concurrently focused on multiple aspects of physical fitness, potential improvements in strength may have been diluted. My results are even more impressive in light of the limited success previous home-based interventions have had with regards to improving upper body strength.

In addition to improvements in strength, ST participants demonstrated significant improvements in shoulder flexion and abduction. Although shoulder range of motion was not a primary focus of the intervention, ST participants had access to the full S&C DVD, which included stretching exercises designed to improve shoulder range of motion post-surgery. These improvements are consistent with previous interventions with strength training components, conducted both in and out of the home setting, that have shown significant increases in shoulder range of motion (Kilbreath et al., 2012; Louzada Petito et al., 2012; Schmitz et al., 2010; Kilgour et al., 2008). Post-operative pain and tightness can contribute to reduced range of motion among BCa survivors, which can be further exacerbated by protective tendencies to reduce movement and avoid injury (Lee et al.,
In turn, limited range of motion negatively impacts daily functional activities as well as QOL (Nesvold et al., 2010) highlighting the need to provide BCa survivors with opportunities to proactively regain shoulder range of motion following BCa surgery. As such, an added benefit of the DVD was the availability of stretching exercises that allowed ST participants to improve range of motion in concert with upper body strength post-surgery.

Results from the intervention study partially supported Hypothesis 4, which suggested that there would not be observable differences in safety measures between the ST and HEI groups from baseline to post-intervention. HEI participants experienced significant improvements in two measures of pain relative to ST participants; although, no significant increases in pain or lymphedema symptoms were observed, nor were any strength training-related adverse events reported by ST participants. These findings are in agreement with previous research showing that supervised, progressive strength training is safe for BCa survivors, both during and after BCa-related treatment (Strasser et al., 2013; Courneya et al., 2007; McKenzie et al., 2003). In fact, sufficient evidence has mounted to warrant the inclusion of strength training into the national exercise guidelines for cancer survivors (Schmitz et al., 2010a). Previous home-based interventions incorporating strengthening exercises have been proven safe, although these studies provided an initial in-person introduction to the assigned exercise program (Haines et al., 2010; Mustian et al., 2009; Kilgour et al., 2008). However, it is important to confirm that strength training can be safely completed in unsupervised settings through the use of DVD-based exercise programs that are not accompanied by in-person exercise instruction. Not only can BCa survivors benefit from professional guidance offered
through a DVD-based program, but a home-based program such as the S&C DVD also addresses common barriers to being physically active and may help survivors overcome fears of exercise-induced lymphedema (Binkley et al., 2012). The combined safety and effectiveness seen with the use of the S&C DVD program provides evidence that strength training can be completed in an unsupervised, home setting and shows great promise for future use of DVDs as a medium for delivering exercise programming to BCa survivors. Furthermore, HCPs also can feel confident in promoting the use of such evidence-based programs to their BCa patients in their clinic setting with a minimal time requirement.

Hypothesis 5, which suggested that ST participants would experience significant improvements in QOL as compared to the HEI group, was not supported by my findings. ST participants did experience a significant decrease in distress level, in comparison to HEI participants, while measures of fatigue and QOL did not show improvement. Two supervised strength training programs have reported improvements in various measures of QOL. Ohira et al. (2006) reported significant improvements in physical and psychosocial well-being among BCa survivors post-treatment following a 6-month strength training program, while Steindorf et al. (2014) showed improvements in cancer-related fatigue and QOL among BCa survivors undergoing radiation after a 12-week group-based strength training program. Only one previous study involving interventions with a strength training component that assessed psychosocial measures did not result in improvements in QOL or fatigue (Strasser et al., 2013). It is unclear why these benefits from strength training interventions conducted in supervised settings were not extended to the current study. One possible explanation could be that larger doses of strength training were delivered in these other studies, which were double that of the current study...
requirements. Another explanation could be that the face-to-face contact received in a supervised intervention may prove beneficial for BCa survivors’ QOL.

The significant improvements that were observed for general health, pain, and role limitations due to physical and emotional problems among HEI participants as compared to the ST group were unexpected findings. An explanation for these findings may be that the HEI participants benefited from the content of the health education DVDs they were asked to watch during the study. While the HEI DVDs were selected to provide educational content not directly related to PA, other topics covered in these DVDs, including stress management and healthy sleep practices, have been successfully used in previous research to reduce cancer-related fatigue and improve QOL (Mustian et al., 2009; Osborn et al., 2006). Although HEI participants were asked only to view their health education DVDs, it is possible that they applied strategies that were presented in their DVDs that impacted their overall well-being. This occurrence suggests that future DVD-based strength training programs may provide additional psychosocial benefits to BCa survivors by incorporating health education information to positively impact their overall QOL.

Participant adherence level in the intervention study (72.7%) compares favorably to previous home-based interventions that have ranged from 21.0-94.4% (Haines et al., 2010; Mustian et al., 2009; Mock et al., 2005; Headley et al., 2004; Ott et al., 2004). In the current intervention, although not statistically significant, ST participants with higher levels of adherence trended towards having larger increases in upper body strength than ST participants with lower levels of adherence. This dose-response relationship highlights the need for continued efforts to improve intervention adherence, including
weekly telephone contact and other facilitative strategies (Ott et al., 2004). Special strategies to enhance adherence levels, as well as encourage retention, also may be needed for post-operative BCa survivors who are experiencing discouraging side effects or are hesitant to engage in activity for fear of risking injury.

*Lessons Learned in the Recruitment of Breast Cancer Survivors from Clinical Settings*

In addition to maximizing adherence and retention efforts, recruitment of adequate subjects to effectively test scientific hypotheses is an essential component of a well-executed human subjects research study. Several strategies, such as using EMRs for the initial pre-screening and minimizing clinician involvement, employed during the recruitment phase of the intervention study proved to be appropriate for the clinical setting; however, there were numerous other challenges to enrolling the desired number of participants to the study. Key lessons learned include the importance of meticulously assessing the available sampling frame and resources, as well as understanding setting limitations (e.g. recruitment support limitations and sample frame characteristics). These steps can be further augmented by qualitative studies of key stakeholders to identify unique site-, patient-, and clinician-specific dynamics, as well as thoroughly assessing the extent to which clinicians are able to participate in research studies. A flexible study design that incorporates contingency plans to account for times when clinic or study staff is unable to fulfill assigned study responsibilities can also bolster recruitment efforts in the face of unforeseen challenges. Finally, the dissemination of more literature detailing important lessons learned during study recruitment, particularly in more challenging populations, is essential. Researchers should make use of the shared experiences
presented in this and previous investigations when tailoring their work to their chosen setting and population.

**Study Limitations and Strengths**

Results of this study should be considered within the context of several limitations. First, my qualitative findings, while encouraging, have limited generalizability among BCa survivors. A majority of the focus group participants were members of local BCa support groups, which could lead to bias as BCa survivors who actively participate in support groups may have differing views compared to those who do not participate in support groups. Nonetheless, a wide range of views was expressed suggesting that the sample was relatively heterogeneous and participants felt comfortable expressing dissenting opinions. Second, there is also the likelihood of self-selection bias in which BCa survivors that are more interested in PA were more likely to volunteer to participate in the focus groups. The study sample was unanimous in reporting that PA was important; whereas, other BCa survivors that declined to participate may place less importance on PA. Third, given the small sample size, it was not possible to stratify the focus groups by BCa survivors’ characteristics, such as age, race/ethnicity, surgery type, treatments received, or fitness level, which may have provided a clearer understanding of the differing perceptions of a DVD-based exercise program and its exact utility.

Limitations within the intervention study also warrant consideration. First, the intervention used a commercially-available DVD rather than creating a tailored program for the targeted sub-group of BCa survivors. The focus group results suggested potential improvements to the S&C DVD that could not be incorporated for use during the intervention study. Second, difficulties with recruitment resulted in a sample size that was
smaller than anticipated. I was able to detect a significant intervention effect for the primary outcome of interest given a larger than expected improvement in upper body strength among ST participants. However, the smaller sample size may have limited my ability to detect other effects of the study during secondary analyses. Additionally, the study’s inclusion and exclusion criteria limit the generalizability of my findings. Study subjects, although racially diverse, were largely well-educated, married, employed full-time, and English-speaking. Given that the S&C DVD is currently only available in English, recruitment was limited to English speaking patients in a cancer center that serves a large population of Spanish-speaking BCa patients. Third, although the assignment of participants to an intervention took place after the baseline assessment, study staff was aware of the participants’ group assignment at the post-intervention assessment, which may have unintentionally lead to observer-expectancy bias at this time point. Fourth, several study outcomes were based on participant self-report, which is susceptible to social desirability bias. Likewise, there may have been recall bias when assessing PA levels through self-reported activity recall.

Despite these limitations, the study also has several strengths worth noting. Collectively, the use of mixed methods confers greater benefits than conducting a solely qualitative or quantitative analysis (Johnson & Onwuegbuzie, 2004). Use of focus groups provided me with greater insight into BCa survivors’ perceptions of a DVD-based exercise program and whether DVDs are a viable format for delivering PA information and instruction than what would be possible in a quantitative analysis. The focus groups also helped to inform some aspects of the intervention study. Namely, the qualitative data provided a better understanding of which sub-group of BCa survivors was best targeted
by the S&C DVD, helping to shape the inclusion and exclusion criteria used in the study. Given that focus group participants who were already active were less likely to find the DVD helpful, BCa survivors already meeting PA guidelines were excluded from the study. Moreover, focus group results demonstrated that BCa survivors are likely to be experiencing negative side effects of BCa-related surgery long after their surgery date, which encouraged the broadening of the time-since-surgery inclusion criterion a maximum of two years post-surgery. Likewise, the intervention study was able to confirm several assertions made during the focus groups. For instance, the main findings of the intervention study, specifically the ST group adherence levels and corresponding improvements in upper body strength, support the notion that the S&C DVD would be acceptable and effective in a home setting.

Additional strengths of the intervention study include the use of a randomized controlled study design and the use of an attention control condition. Previous home-based interventions have primarily utilized usual care control groups, which fail to provide a comparable intervention experience, including equivalent time commitments for study tasks and similar levels of attention from study staff. Moreover, in addition to using standardized and validated assessment measures, the use of an objective measure of upper body strength (the 1-RM test) was an improvement on previous home-based interventions that have used grip strength as a proxy measure for strength (Haines et al., 2010; Ingram et al., 2010; Kilgour et al., 2008). Finally, the intervention incorporated BCa survivor’s previously reported exercise preferences (Rogers et al., 2008; Jones et al., 2002; Denmark-Wahnefried et al., 2000).
Public Health Implications

BCa Survivorship Care

DVD-based exercise programs, such as the S&C DVD, provide great promise for improving the BCa survivorship experience. While evidence continues to mount regarding the various benefits of PA for BCa survivors (Strasser et al., 2013; Sabiston et al., 2011; Schmitz, et al., 2010), finding ways to encourage and increase PA levels among BCa survivors continues to be a challenge in light of low participation levels (Irwin et al., 2004; Courneya et al., 1997). DVD-based exercise programs can be used in the home setting to provide unsupervised, home-based activity while maintaining the quality and consistency needed for proper instruction (Rogers et al., 2008; Jones et al., 2002; Denmark-Wahnefried et al., 2000). Likewise, use of a home-based program may encourage long-term strength training behaviors above and beyond supervised programs that are finite. This study, coupled with previous home-based interventions, demonstrate, that not only are DVD-based exercise programs are acceptable to BCa survivors, but that they also can be safely and effectively implemented in an unsupervised setting (Louzada-Petito et al., 2012; Ingram et al., 2010; Haines et al., 2010; Cadmus et al., 2009; Mustian et al., 2009; Kilgour et al., 2008; Matthews et al., 2007; Mock et al, 2005; Pinto et al., 2005; Headley et al., 2004; Ott et al., 2004; Segal et al., 2001).

This study further extends the literature by being the first of its kind to evaluate the effects of a DVD-based strength training program on BCa survivors’ upper body strength in the home setting. Previous research examining the effects of strength training on BCa survivors have either evaluated home-based training only after a period of supervised exercise, or have assessed a combined intervention, concurrently looking at other modes
of activity, including aerobics, balance, and flexibility (Haines et al., 2010; Schmitz et al., 2010; Schmitz et al., 2009; Kilgour et al., 2008; Ahmed et al., 2006; Ott et al., 2004). My assessment of a home-based, DVD strength training program provides evidence of the singular impact of home-based strengthening exercises on upper body strength. Coupled with the proven safety of using a DVD-based program in the home setting, these findings also suggest an opportunity for extending the use of DVD-based education to individuals with other types of cancer that may benefit from increased levels of PA.

**HCP Involvement in Physical Activity Promotion**

DVD-based exercise programs have the potential to augment the delivery of care to BCa survivors. BCa survivors consider HCPs a desirable, reliable, and trusted source of information, and want them to play a larger role in the promotion of PA (Binkley et al., 2012; Kantsiper et al., 2009; Fridfinnsdottir, 1997; Bilodeau & Degner, 1996). My findings highlight a significant opportunity for HCPs to provide PA information and resources to their patients through the use of similar DVDs. HCPs, with their limited time and exercise-specific knowledge, may be able to rely upon evidence-based, DVD-based exercise programs that are easily disseminated to complement the care they offer their patients. By providing a DVD-based exercise program to their patients, HCPs can help motivate them to be active and give them necessary information and guidance for beginning and progressing through a PA routine post-surgery. Furthermore, the use of a DVD-based exercise program in clinical practice may also encourage HCPs to promote and discuss PA behaviors with their patients, in addition to empowering their patients to do the same.
Future Research Directions

Development of DVD-based Exercise Programs

Results from the focus groups highlight desirable features of DVD-based exercise programs that satisfy BCa survivors’ preferences. Recommendations for future iterations of a home-based program include keeping information and exercise segments separate, listing equipment needs and time requirements at the start of each chapter, and ensuring not only racial diversity, but also sensitivity to survivors of varied economic statuses, geographic locations, languages, activity preferences, and physical abilities. This might include customizing the DVD for BCa survivors who have recently undergone surgery or who are experiencing negative physiological side effects to other BCa treatments. BCa survivors with fewer side effects or who were active prior to their diagnosis may progress through a basic exercise program more quickly, requiring the development of a more advanced DVD-based exercise program. A series of DVD-based exercise programs would not only allow for gradual improvements in PA levels and physical functioning, but could also reflect the evolving mindset of a survivor over time, moving from a soothing tone to a more upbeat and empowering tone. Lastly, although not discussed in focus groups, the importance of grounding DVD-based exercise programs in an evidence-based theoretical framework should be considered an essential component of future iterations.

DVD-based Intervention Studies in the Home Setting

The findings of the intervention study inspire several directions for future research that may merit further attention. First, given that the current study was a pilot study with
a small sample, a natural progression would be to conduct a similar intervention study on a larger scale to more conclusively evaluate the main effects of the intervention, explore the impact of different BCa survivor demographic and disease characteristics through sub-analyses, and to investigate the potential physical and psychological mechanisms by which BCa survivors experience physiological and psychological benefits of strength training. Second, modifications to the study design can also generate interesting research questions in need of evaluation. For instance, BCa survivors could be recruited to complete the intervention prior to, as well as after, BCa surgery to determine whether they recover more quickly than BCa survivors completing the intervention only after BCa surgery. Long-term follow up would also be desirable to assess the likelihood that BCa survivors would sustain strength training practices. Assessing both groups prior to BCa surgery would also provide a clearer understanding of the rate by which BCa survivors recover upper body strength and range of motion based on pre-surgery strength training levels. Third, modifications to the DVD could yield additional information regarding how DVD-based programs can be optimized to provide additional benefits to BCa survivors. For example, the dose of the intervention could be increased to match previous supervised strength training interventions that have demonstrated not only safety, but also significant improvements in QOL to assess whether a greater dose is also associated with QOL improvement in the home setting (Steindorf et al., 2014; Ohira et al., 2006). Conversely, health education information believed to improve QOL could be incorporated into a DVD-based exercise program. Another potential DVD adaptation would consist of developing culturally-tailored versions that provide strength training exercises to minority populations, including non-English speaking Hispanic BCa
survivors. Finally, the use of home-based DVD programs could be extended to individuals with other types of cancer. Strength training has been shown to be beneficial for other cancer survivors (Strasser et al., 2013), who may similarly benefit from customized, home-based programming designed to increase their physical activity levels.

Summary

In conclusion, DVDs are an acceptable medium for the delivery of home-based strength training programs to BCa survivors to improve the upper body strength and range of motion in BCa survivors post-surgery. The S&C DVD provided effective exercise instruction in promoting safe participation in a progressive strength training program in the home setting. The continued development of home-based interventions, such as the S&C DVD, that take into account BCa survivors’ preferences, reduce barriers to being physically active, ensure safe participation in unsupervised PA, and can be easily disseminated by HCPs is an important area for continued research that has the potential to positively impact how we care for post-operative BCa survivors.
References


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