Restoring Body Image after Breast Cancer through Exercise and Art Sculpture "RISE UP" after Breast Cancer: A Pilot Multi-Methods Study

by

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ABSTRACT

The purpose of this thesis was to explore and describe body image in survivors of breast cancer in the context of supportive care, with specific focus on resistance exercise training and art therapy. The overall purpose of this work was to inform current practice and offer an alternative approach to addressing body image in breast cancer survivors.

Manuscript 1. Scoping Review The first study (Chapter 2) is a scoping review on resistance exercise training and art therapy alone, and in combination as interventions to address body image in breast cancer survivors. This study revealed preliminary evidence of the benefits of resistance exercise and art therapy as single interventions to improve body image perception among breast cancer survivors.

Manuscript 2. Cognitive Interview Study. The second study (Chapter 3) is a qualitative study exploring the construct validity of the Body Image Scale in women with breast cancer using cognitive interview methods. Twelve breast cancer survivors participated in a cognitive interview while completing the Body Image Scale questionnaire. This study revealed several issues with construct validity, likely because the tool has remained unchanged despite the emerging field of body image. The findings of this study provide insight and suggestions on potential areas of questionnaire revision to improve the validity and relevance of the BIS for use with BCS.

Manuscript 3. Feasibility Study The final study (Chapter 4) presents a pilot feasibility study combining resistance exercise training with art sculpting to assess positive body image in breast cancer survivors. Participants were asked to attend a biweekly, 12-week, group resistance exercise program and a weekly, eight-week art sculpting class. The primary objectives of feasibility were assessed through the collection of recruitment, attendance, and completion rates,

cost tracking, and reporting of adverse events. Preliminary efficacy was determined by examining point estimates and measures of variability for objective and self-reported outcomes. The study outcomes reveal that a combination of resistance exercise training and art sculpting is feasible, and the secondary findings support preliminary efficacy for improving positive body image and body appreciation in breast cancer survivors.

To summarize, this thesis provided evidence that resistance exercise training and art therapy interventions are promising as interventions for improving body image in survivors of breast cancer separately (Chapter 2) and together (Chapter 4). However, more work is needed to find a tool that measures both the negative and positive aspects of body image (Chapter 3). Additionally, there is evidence to support that a combination of resistance exercise with art sculpting to promote body appreciation in breast cancer survivors is feasible (Chapter 4). As this thesis presents pilot research, the findings call for larger-scale trials to further investigate this alternative approach in addressing body image in breast cancer survivors.

PREFACE

This thesis is an original work by Corrie J Effa and Co-Authored by Dr. Margaret L. McNeely, Dr. Nancy Spencer, Dr. Lesley Pritchard, Naomi Dologoy, and Mona Al Onazi. This study received ethical approval from the Health Research Board of Alberta: Cancer Committee.

DEDICATION

To my parents, Allan and Karen Effa, for nurturing and demonstrating the importance of continual learning, while cheering me on throughout all of my life choices. To my sister (and my role model), Carmyn Effa, for always pushing me to think critically. Finally, to my love, Ian McKellar, for teaching me to have balance, for your listening ears, and providing me with so much support. I could not have done this without all your endless love and encouragement.

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Finally, a huge thank you to my participants who took part in the study. Your dedication and excitement for the project made me feel confident in what we created. All of you were so giving of your time, expending a lot of energy in both your artwork and in the exercise sessions. You all handled the changes to moving the study virtually with optimism and enthusiasm. I will always look back on this experience with fond memories.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

GLOSSARY OF TERMS

Cancer Related:

a) **Breast cancer** – A group of cancer cells (tumour) that destroys healthy tissue and are located in the breast.[1]

b) **Breast cancer survivor (BCS)** – Individuals who have had or are undergoing treatment for breast cancer. It is important to note that the term "survivor" can be contentious among some individuals, however this is the term that will be used for this thesis as there is currently a lack of a better word.

Breast Cancer Treatment:

a) **Radiation Therapy** – Radiation therapy uses external high energy rays to destroy cancer cells.[1]

b) **Chemotherapy** – Chemotherapy is a systemic therapy that uses cytotoxic drugs to destroy cancer cells.[1]

c) **Hormone Therapy** – Hormone therapy is used for breast cancer that is hormone receptor positive and is a treatment that adds, blocks, or removes hormones.[1]

d) **Surgery** – Surgery for breast cancer includes breast-conserving, mastectomy, and lymph node removal. The type of surgery is dependent on the size and location of the tumour, the size of breast, whether the cancer has spread to other lymph nodes, and if the individual already has had treatment for breast cancer.[1]

Body Image:

a) **Body Image** – "The mental picture of one's body, an attitude about the physical self-appearance, and state of health, wholeness, normal functioning and sexuality" (p.580).[2]

b) **Body Image Disturbance** – Persistent dissatisfaction of appearance, negatively affecting the individual from taking part in social activities, relationships with others, and occupational functioning.[3]

c) **Negative Body Image** – Having negative thoughts and feelings on the way one looks, often comparing one's own body to societal standards of what is considered beautiful.

d) **Neutral Body Image** – To have no association between a person's body and their worth.

e) **Positive Body Image** – An all-encompassing love and respect for one's body, which includes: a) appreciating the function of one's body; b) accepting one's body despite not matching societal ideals; c) feeling confident and happy with one's body; d) shifting

focus on one's assets rather than imperfections; e) being mindful of the needs of one's body; f) filtering information so that negative information is rejected and positive information is accepted.[4]

f) **Appearance Investment/Body Image Investment** – How much body image matters to an individual.[5]

g) **Self-Evaluation** – Relates to how the individual measures themselves up against societal and cultural beauty standards and their overall satisfaction or dissatisfaction with their image.[6]

Cognitive Interview Related:

a) **Cognitive Interview study** - A form of qualitative inquiry that collects and summarizes information on the functioning of a survey.[7]

b) **Construct validity –** Ability of a test to measure the construct it is intended to measure. A test is valid for measuring what it is intended to measure if: a) the construct exists; b) variations in the construct causally reflect variations in the outcome measure.[8]

Feasibility Intervention Related:

a) **Pilot feasibility study** – A pilot study is conducted at a smaller scale, typically administered prior to a future larger-scale study.[9] A feasibility study determines whether something can or should be done, and if so, how.[9] To combine both terms, a pilot feasibility study is a small study that provides useful information on important aspects for future larger trials, but has some flexibility in how it is administered.[9]

b) **Sculpting class** – A weekly class led by an artist who assisted participants in sculpting human form out of clay. A psychologist facilitated a half hour of each session to promote self-reflection, journaling, and group sharing.

c) **Resistance Exercise Training (RET)** – A biweekly 60-minute session that included a short cardiovascular warm-up followed by resistance exercise to major muscle groups. This consisted of:

   a. **Group circuit RET classes** – 60-minute circuit training classes using body weight, resistance bands, and free weight strengthening exercises to major muscle groups.

   b. **Wellspring individual RET sessions** – 60-minute sessions that were supervised by a Clinical Exercise Physiologist. The exercise included a short cardiovascular

warm-up followed by resistance exercise to major muscle groups using free weights, machines, and body weight.

d) **Virtual sessions** – Sessions were moved online through the platform Zoom once COVID-19 restrictions were in place.

e) **Multifocal/multidisciplinary approach** – An approach that considers and works to address the physical, psychological, behavioural, and social considerations of the issue.

Outcomes:

a) **Recruitment rate** – The number of participants eligible and consenting divided by the total number of participants that meet the eligibility criteria.

b) **Retention rate** – The number of participants that completed the study divided by the number of participants starting the study.

c) **Adherence to protocol** – The total number of sessions attended divided by the total number of sessions scheduled for RET and art therapy sessions.

d) **Cost tracking** – An approximate record of the costs expended in order to administer the study.

e) **Adverse Events** – Any unintended or unfavourable event that occurred as a result of the study.

   a. **Major physical adverse event** – Any serious injury as a result of the resistance exercise program that resulted in immediate medical attention.

   b. **Major psychological adverse event** – Any serious emotional or traumatic response that the psychologist observed as needing further psychological attention.

Questionnaires:

a) **The Physical Readiness Questionnaire for Everyone (PAR Q+)** – A form designed for pre-participation screening and risk stratification to determine whether an individual is safe to exercise, or whether they need further doctor approval.[10]

b) **Body Appreciation Scale 2 (BAS 2)** – A survey that is rooted in positive psychology that measures body appreciation.[11]

c) **Body Image Scale for Cancer (BIS)** – A common survey used to assess body image change within oncology.[12]

d) **Functional Assessment of Cancer Therapy-General** (FACT-G) – An oncology specific health-related quality of life measure that has questions related to Physical Well-Being, Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being.[13, 14]

e) **Physical Activity Stages of Change Questionnaire** – This questionnaire asks questions regarding whether the participant is currently active to determine where they fall in the stages of change (precontemplation, contemplation, preparation, decision/action, or maintenance).[15]

f) The Self-Reported Physical Activity Questionnaire (GODIN) – A survey used to determine how often one engages in mild, moderate, and strenuous activity for more than 15 minutes at a time over an average week.[16]

Study Acronym:

RISE UP: *R*estoring Body *I*mage after Brea*s*t Cancer through *E*xercise and Art Sc*ulp*ture

CHAPTER 1: INTRODUCTION

1.0 A BRIEF REVIEW OF THE TOPIC

1.1.1 Body Image

Body image is multifaceted, impacting one's identity, sexuality, relationships, mental health, and overall quality of life.[17] There is no clear consensus on the definition of body image; however, the following definitions have been proposed. The National Cancer Institute defines the construct as the way a person thinks about their body and how it appears to others;[18] whereas the National Eating Disorder Association defines it as how a person sees themselves in the mirror or in their mind, which encompasses appearance assumptions, self-evaluation, and how the person feels as they move in their body.[19] Specifically in breast cancer, body image is defined as "the mental picture of one's body, an attitude about the physical self-appearance, and state of health, wholeness, normal functioning and sexuality" (p.580).[2]

Although not always mentioned in the breast cancer field, it is important to note that the level of body image concern is impacted by both one's appearance investment and self-evaluation.[6] Appearance investment relates to how the individual prioritizes appearance and the level of importance appearance is to them.[6] Whereas self-evaluation relates to how the individual measures themselves against societal and cultural beauty standards and their overall satisfaction or dissatisfaction with their image.[6] The long history of women's bodies being objectified – meaning that they are objects to be looked at and their looks evaluated as a measure of worth – has created numerous negative psychosocial and sociopolitical issues for women in Western society.[20] These sociocultural pressures are often internalized by girls and women (self-objectification theory),[20] and have been found to negatively impact body image perception.[20, 21] The Western world views the breast as a symbol of femininity, sexual desirability, and attractiveness; this cultural symbol of the breast complicates acceptance particularly in breast cancer survivors (BCS), as they must deal with a changed appearance and new reality of how they see themselves as women.[22]

1.1.2 Body Image in Breast Cancer

Breast cancer is the most common cancer among women, with an expected 27,400 Canadians to be diagnosed with the disease in 2020.[1] Unfortunately, a diagnosis of breast cancer and the subsequent anti-cancer treatments – including radiation, chemotherapy, surgery, and ongoing

medical management – have many physical and psychological effects that can have a lasting impact on a person's life. Breast cancer treatments can cause changes such as hair loss, loss of skin elasticity, scarring from treatment, overall fatigue, weight changes, cessation of menstruation, hot flashes, sexual complications, lymphedema (chronic swelling), neuropathy (numbness in various areas of the body), and loss or significant changes to one or both breasts.[21, 23-27]

Body image concern, or disturbance (in more severe cases) is a side effect associated with breast cancer treatment.[28, 29] Body image disturbance is defined as persistent dissatisfaction of appearance, negatively affecting the individual from taking part in social activities, relationships with others, and occupational functioning.[3] Having a negative perspective of one's body image or having body image disturbance is associated with reduced quality of life, low self-esteem and higher rates of depression.[30, 31]

The 5-year survival rate for breast cancer is around 88%.[1] As a result, many breast cancer survivors are living with the long-term side-effects from treatment and may be struggling with higher psychological distress and body image concerns. There is a large variance in the reported prevalence of body image concern ranging from 30-88%.[2, 32] This variance is likely due to difference in both the chosen survey tool and criteria to determine body image concern among studies. Moreover, at present, there is no established clinical cut-off for body image disturbance.[33]

1.1.3 Breast Cancer and Positive Body Image

It is important to note, that a minority of BCS may experience a positive attitude towards themselves, as the survivor may be proud that their body has withstood the challenge of treatment, may have a lower appearance investment, or increased self-compassion than prior to diagnosis.[22, 29, 34] Additionally, negative body image and positive body image are not two extremes on a spectrum, rather separate constructs, as BCS may experience both negative body image and positive body image.[4] Positive body image is defined as loving and respecting one's body, which includes: a) appreciating the function of one's body; b) accepting one's body despite not matching societal ideals; c) feeling confident and happy with one's body; d) shifting focus on one's body assets rather than imperfections; e) being mindful of the needs of one's

body; f) filtering information so that negative information is rejected and positive information is accepted.[4]

1.2 STATEMENT OF PROBLEM

While advances in addressing body image in BCS have been made, there are several gaps that will be addressed in this thesis. Over the last two decades, selecting a body image measure for clinical and research settings has become increasingly challenging due to the magnitude of surveys available, the various dimensions of body image that can be measured, and the complexity of the construct.[35] Some of these tools cannot be applied to the breast cancer population, as the questions have a disproportionate focus on weight rather than body image concerns relevant to breast cancer.[34] While tools such as the Body Image Scale for Cancer (BIS) have been developed and show strong validity and reliability,[12] they have remained unchanged for almost 20 years despite advances in cancer treatments, changes in societal standards, and progress within the body image field.

Second, body image research originated from studying eating disorders and as a result, there is a disproportionate amount of research that focuses on reducing negative body image.[36, 37] Reducing negative body image without considering how to promote positive body image has limited the understanding and progress of body image in both research and clinical interventions.[4] Research on body image should incorporate a measure of body appreciation to better understand the separate constructs of negative body image and positive body image.[38] Additionally, interventions should not only work to reduce negative body image, but also encourage BCS to adopt a positive body image, which may produce a longer lasting treatment effect.[38]

The third gap in the literature is the need for clinical research to adopt a multidimensional approach to addressing body image concerns in breast cancer.[37] The current unidimensional disease-focused approach is primarily concerned with reducing breast cancer symptom-related body image concerns.[39] For example, BCS can be given wigs to manage discomfort with hair loss, and can have reconstruction surgery to maintain physical appearance after having a mastectomy.[40] A multidimensional approach is needed to consider the interactions between the disease, the individual, and the sociocultural context on body image perception.[39] Chapter 4

introduces the interdisciplinary intervention looking at the feasibility and preliminary efficacy of combining resistance exercise training (RET) with art sculpture to improve body image in BCS. The RET portion will target the perceptual component of body image in providing opportunities for BCS to improve their physical strength, which may in turn improve confidence and body appreciation. Whereas the art sculpting portion will target the psychosocial aspect of body image, allowing participants to slow down, reflect, and share their experiences with one another.

1.3 THESIS OBJECTIVES

1.3.1 Scoping review (Chapter 2)

The purpose of this scoping review was to explore the research on RET and art therapy alone, and in combination as interventions to address body image in BCS. The aims of this review were to:

1) Explore the nature, characteristics, and extent of the literature examining RET or art therapy on body image in BCS.

2) Examine how body image is defined and measured across the studies.

1.3.2 Qualitative Objective (Chapter 3)

The objective of this study was to explore the construct validity of the Body Image Scale in women with breast cancer using cognitive interview methods.

1.3.3 Quantitative Objective (Chapter 4)

To determine the feasibility and preliminary efficacy of combining resistance exercise training with art sculpting on positive body image in BCS.

1) Feasibility of the processes:

- Recruitment rate (the number of consenting participants divided by the total number of participants asked to join project).
- Attendance to protocol by looking at the attendance at all sessions (RET sessions, and art therapy sessions).
- Completion rates (number of participants that completed the study divided by the number of participants that started the study).
- Cost tracking of the interventions (costs associated with running of the program eg. personnel, equipment costs)

- Safety of the interventions (reporting of any minor or major physical and/or psychological adverse events)

2) Secondary Objectives: assess the preliminary efficacy of the intervention

- Changes in body image questionnaires (BAS-2)
- Changes in health-related quality of life (FACT-G)
- Changes in anthropometric test (weight) and fitness tests (sit-to-stand, plank endurance test)

1.3.3 Hypothesis related to feasibility

The primary hypothesis was that the combined intervention of RET with art sculpting would be feasible and safe for BCS experiencing negative body image. A combined intervention of RET with art sculpting will demonstrate an overall attendance rate of 80%.

1.3.4 Hypothesis related to preliminary efficacy

A combined intervention of RET and art sculpting will demonstrate a trend towards improved body image and body appreciation post-intervention.

1.4 DELIMITATIONS

1. The design was a single group pilot feasibility study that combined RET (twice per week for 12 weeks) and art sculpture (one per week for eight weeks). No planned follow-ups were scheduled after the intervention ended.
2. Positive body image was measured using the Body Appreciation Scale-2 (BAS-2) scale.
3. Health-related quality of life was measured using the Functional Assessment of Cancer Therapy (FACT-G) survey.
4. Fitness testing outcomes were measured using the 1 Rep-Max test of bench press and leg press, sit-to-stand test, grip strength, and the plank endurance test. Anthropometric measures of height, weight, hip, and waist circumference were also taken.
5. Only one round of cognitive interviewing was administered.

1.5 LIMITATIONS

1. Sample size: N=13
2. Participants in the study were volunteers who had completed the Alberta Cancer Exercise program.

3. COVID-19 affected the delivery of the study and as a result, the study intervention was delivered virtually for the last four weeks of the 12-week program. As such, post-intervention testing was done virtually and there were several tests that were not able to be administered in the virtual environment.
4. All but one of the participants in this study were white women. This lack of racial and ethnic diversity limits the generalizability of the findings.

1.6 SIGNIFICANCE OF THE RESEARCH

Chapter 3 is the first known study to administer cognitive interviews to BCS using the BIS tool. I wanted to see if the BIS captured the experiences of BCS and whether the participants interpreted the questions similarly or differently to one another.

Chapter 4 is the first known intervention that combines RET with art sculpting to address body image concerns in BCS. This is the first known study to also assess body appreciation using the BAS-2 scale in a clinical intervention with BCS.

CHAPTER 2: RESISTANCE EXERCISE AND ART THERAPY ON BODY IMAGE IN BREAST CANCER: A SCOPING REVIEW

Accepted for Publication: Women's Health Reports

Authors: Corrie J. Effa, Naomi D. Dolgoy, and Margaret L. McNeely

2.1 ABSTRACT

Background: Treatments for breast cancer are invasive, causing visible changes such as loss of the breast, body weight change, and hair loss. These changes in conjunction with the pressure for women to conform to societal beauty standards may lead to body image disturbance in breast cancer survivors. The aims of this scoping review were to explore the nature, characteristics and extent of the literature examining resistance exercise or art therapy on body image in BCS; and examine how body image is defined and measured across the studies.

Methods: We searched the literature up to January 2020, which included conducting electronic searches of three major databases and checking references of screened articles.

Results: Ninety-three articles were identified, 28 underwent full-text screening, with eight studies eligible for inclusion in the review. Five randomized controlled trials, one hybrid effectiveness-implementation trial, and two single group studies were found. All studies showed significant within-group difference in body image scores, with two studies showing a between-group difference in favour of resistance exercise. No studies were found combining resistance exercise and art therapy. None of the studies defined the aspect of body image they wished to measure, and only one used theory to inform their research.

Discussion: Preliminary evidence supports the benefit of resistance exercise and art therapy as single interventions to improve body image perception among breast cancer survivors. Findings suggest the need for closer attention to the delivery format of interventions. Future research is needed that is theory-informed, with a clear definition of the aspect of body image of interest, and with body image as the primary outcome.

Keywords: *Body image, breast cancer, art therapy, resistance exercise, positive health*

2.2 INTRODUCTION

2.2.1 Breast Cancer and Body Image

Breast cancer is the third most frequently diagnosed cancer in Canada, and it is estimated that 27,400 Canadians will be diagnosed with the disease in 2020.[1] Treatments for breast cancer are invasive, often resulting in visible changes in physical appearance, which can lead to body image concerns and psychological distress in breast cancer survivors (BCS).[41,39] Treatment of breast cancer typically involves surgery, followed by radiation, chemotherapy, and hormonal treatments.[41] Surgery involves removing part of the breast (lumpectomy), the entire affected breast (mastectomy), or both breasts (double mastectomy), which may cause BCS to feel mutilated, resulting in an immediate negative impact on their body image.[41] Moreover, amputation of a breast is often associated with pain, swelling in the breast or limb (lymphedema), and changes in sensation to the breast and chest wall.[22] As a result, the BCS may feel less feminine, less sexually attractive, and experience increased anxiety and depression.[41]

Radiation therapy is an adjuvant treatment involving high doses of radiation to destroy any remaining cancer cells in the region of the primary cancer.[27] Chemotherapy is a common systemic treatment that uses pharmaceutical agents to kill cancer cells, reducing the risk of cancer returning or spreading.[27] Physical effects that occur from radiation and chemotherapy treatment include weight gain, hair loss, skin irritation, skin discolouration, and hot flashes from early onset menopause.[23, 26] Hormonal treatment—which is treatment that blocks hormones to slow the growth of cancer cells—has also been known to impact sexual dysfunction.[23] Many BCS experience profound fatigue from treatment, which can limit the social and physical activities they engage in.[24] The compounding effect of the diagnosis, adjusting to the negative effects of cancer treatments on their bodies, and the impact of fatigue on everyday activities may be overwhelming for the BCS, reducing their overall quality of life.[21]

2.2.2 Resistance Exercise Training (RET) and Art Therapy on Body Image

Both resistance exercise training (RET) and art therapy have the potential to improve body image concerns among BCS. Current research points to the benefits of RET on body image perception among the adult general population.[42] While the mechanism of change is still unclear, there is evidence to suggest that for women, both subjective perceptions (self-efficacy, confidence), and objective improvements in fitness play a role in improving body image.[43] Art therapy aims to

influence the mind and body, which can be used to promote health and well-being.[44] Current research within oncology, points to art therapy as an intervention that creates space for self-expression that may be otherwise too painful to verbalize.[45] Additionally, art therapy can be used as a means for cancer survivors to redefine their priorities and personal identity so that they are more involved in self-care practices.[44]

2.2.3 Context and Purpose

While there is evidence to show that RET positively influences body image in the general population and that art therapy has improved psychological outcomes among cancer survivors, more research is needed to determine specifically if body image perception improves among BCS. The potential of combining RET and art therapy came from the authors' experience at Wellspring Edmonton—a non-profit centre that offers supportive programs to meet the psychological, emotional, and educational needs of individuals and families living with cancer in Edmonton, Canada. Anecdotally, we noticed that BCS taking part in our RET program twice weekly, along with an art therapy class hosted at the center, appeared to report fewer body image related concerns when compared to BCS participating in the resistance exercise program alone. The purpose of this scoping review was to explore the research on RET and art therapy alone, and in combination as interventions to address body image in BCS. The aims of this review were to: 1) explore the nature, characteristics, and extent of the literature examining RET or art therapy on body image in BCS; 2) examine how body image is defined and measured across the studies.

2.3 MATERIALS AND METHODS

A scoping review was performed to explore the literature broadly. The methodology utilized was based on the 5-step procedure created by Arksey and O'Malley.[46]

A librarian was consulted at the University of Alberta to help identify relevant studies, through an effective search strategy. The searches were run on the databases CINAHL, PsychInfo, and Medline up to, and including January 2020. (See Appendix A for details.)

Articles were considered eligible if they involved women with breast cancer in both the intervention and control group (if they had a control group), involved RET or art therapy interventions, included body image as a primary or secondary outcome, and were available in

English with accessible full texts. Articles were excluded if they were review articles, involved single case studies, or involved qualitative research with a sample size of two or less. Title and abstract screening were completed by one author (CE), and full text screenings were completed by two authors (CE, MM). When conflicts were identified, the authors (CE, MM) achieved consensus through discussion.

Upon selecting the articles, we abstracted the following elements: author, year, country; study design and sample size; objectives related to body image; intervention details; program design; the body image tools used; fitness testing measured (if applicable); and study results; and any other considerations reported by study authors. For collating, summarizing, and reporting the details, we examined the type of study, the intervention approach and the chosen outcome measures. We further expanded on the concepts surrounding body image relevant to the following: whether the study involved body image as a primary outcome; how the study defined body image; any theory or theoretical framework used to inform the research; the rationale or justification for the intervention; data supporting intervention fidelity; whether the study reported or controlled for confounding factors such as age, surgery and other cancer treatments, timing since diagnosis, BMI, and lymphedema. These listed concepts allowed us to further explore the nature of the body image studies in BCS.

2.4 SCOPING REVIEW RESULTS

The search resulted in 115 articles. Once duplicates were removed, 93 articles were included for initial screening. Of the 93 articles, 28 were deemed potentially eligible and were selected for full-text review. Following formal screening, seven articles met all inclusion criteria. One study had a primary objective focussed on self-esteem as measured by the Physical Self-Perception Profile (PSPP).[47] As the PSPP has questions related to "attractive body," the study was included in the review.[47] The references list of the seven articles were reviewed, which identified an additional study, for a total of eight papers (Figure 1). Of the eight papers, seven examined the effect of RET alone,[47-53] and one made use of art therapy alone as an intervention.[54] No studies were found combining both RET and art therapy.

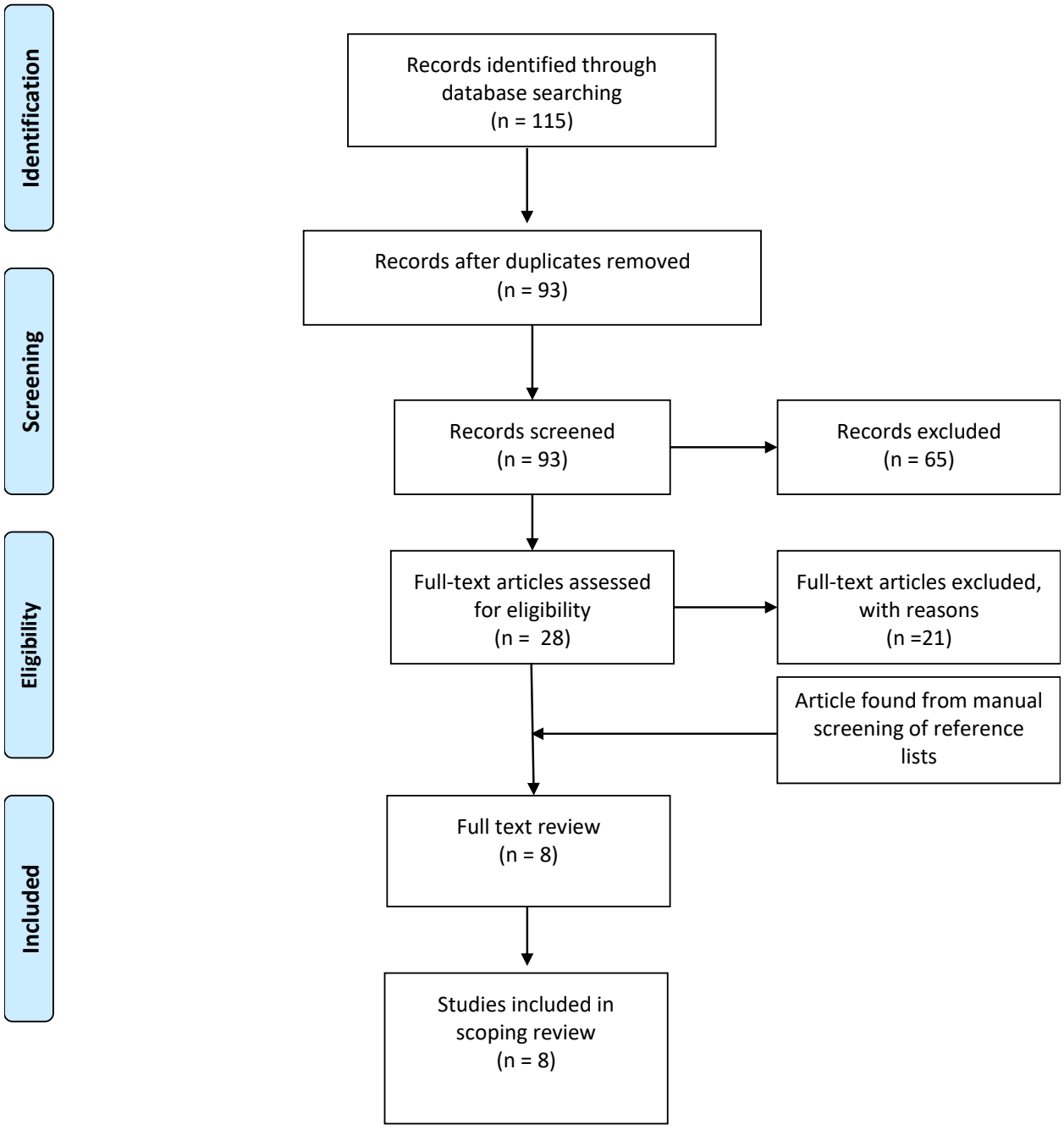

Figure 1: *Flow Diagram*

2.4.1 Study Design

Of the seven eligible articles involving RET, a variety of study designs were used. Four were randomized control trials,[47, 48, 51, 53] one was a hybrid effectiveness-implementation trial,[49] and two were non-randomized trials.[50, 52] Sample sizes ranged from 15 to 234. The single art therapy study was a randomized control trial with a sample size of 41.[54] Body image was a primary outcome in two RET studies,[48, 50] and a secondary outcome in the other six studies.[47, 49, 51-54] See Table 1 for a description of the included studies.

Table 1: *Characteristics of Included Studies*

Author/Year/Country	Study design sample size	Objectives related to body image	Intervention details	Program Design - Individual or Group	Body image tool used and Fitness Measures	Study results	Considerations
Speck, R.M., Gross, C.R., Hormes, J.M., Ahmed, R.L., Lytle, L.A., Hwang, W., Schmitz, K.H. 2010/USA (48).	•RCT n=234 breast cancer survivors with or without lymphedema. •Treatment group n=113 •Control group n=121.	Examine the effects of weight training on body image in Physical Activity and Lymphedema (PAL) trial (primary objective).	•1-year weight-lifting 2x/week at the YMCA 13 weeks supervised and then the rest unsupervised. •Control group on a 1-year waiting list.	Small groups (2-6 people) for first 3 months. Individual and unsupervised for remaining 9.	•Body image and relationship scale (BIRS) •Baseline and 12-month •Anthropometry, 1-RM bench and leg press; •Strength measurements: 10RM chest press and 1RM leg press.	•Significant between group difference in BIRS by 12% after 1-year in favour of intervention group compared to 2% increase in the control group ($p < 0.0001$); •Significant improvements in 1 RM bench press and leg press ($p<0.0001$) after 1-year; •No significant change in quality of life.	•Also measured general QOL (SF-36). •No association observed between lymphedema status and lower BIRS values.
Beidas, R.S., Paciotti, B., Barg, F., Branas, A.R., Brown, J.C., Glanz, K., DeMichele, A., DiGiovanni, L., Salvatore, D., Schmitz, K.H. 2014/USA (49).	Hybrid Type 1 effectiveness-implementation trial n=84. With or without lymphedema.	•Determine if modifying the Physical Activity and Lymphedema trial (PAL) would still prove to be effective and safe for survivors. •Qualitatively assess barriers and facilitators to implementing this design by interviewing key stakeholders.	4 small group training sessions led by a physio therapist and 2x/week strength training at home.	4 supervised small-group training sessions, the remaining unsupervised individual.	•Body image and relationships scale (BIRS); •1-RM bench and leg press.	•Significant within-group improvement in body image from baseline to 12 months ($p < 0.001$). •Significant within-group improvement in muscular strength ($p<0.001$).	Used the same measures as the PAL trial.

Benton, M.J., Schlairet, M.C., Gibson, D.R. 2014/USA (50).	•Nonrandomized 8-week trial n=20 •n=12, ages 40-59 group (YRT) •n=8, ages 60-80 group (ORT).	To evaluate the effect of age on changes in body image and overall QOL after a resistance training program (primary objective).	Both YRT and ORT groups 2x/week for 8 weeks identical supervised resistance training sessions.	Individualized supervised exercise program.	•Body image and relationship scale (BIRS); •Arm-curl test, 30 second chair-stand test, 10-RM bench press, 1-RM leg press.	•Significant within group improvement in BIRS total scores ($p<0.001$) •Significant between group difference in BIRS total scores, with a greater improvement in the YRT group compared to the ORT group ($p<0.01$). •Within group improvements in strength and function ($p<0.001$).	•The program brought awareness to functional decline in older participants but was too short in duration to show improvements and benefits of being active. •The ORT group were less susceptible to noticing improvements in fitness compared to the YRT group.
Musanti, R. 2012/USA (47).	•Prospective RCT 12-weeks duration with or without lymphedema. •Flexibility n= 12; •Aerobic n = 10; •Resistance n = 9; •Aerobic & Resistance n = 11.	To determine which exercise modality has the most significant impact on self-esteem (attractive body is a component measured).	Participants were assigned to a home based 12-week exercise program either A 3x/wk, R 3x/wk, AR 4-5x/wk, or F as the control.	Individualized home-based exercise program.	•Physical Self-perception profile (PSPP) measure of self-esteem has a component measuring attractive body. •Submaximal Bruce protocol treadmill test, 6-RM chest press and leg press, YMCA bench press, and shoulder/hip flexibility.	• Significant within-group improvement in attractive body in Resistance group only ($P<0.000$). •Significant within-group improvements in muscular strength (chest press $p=0.032$ and curls $p=0.013$ in Resistance, Aerobic & Resistance, and Flexibility groups)	•Did not report between-group differences for body image scores. •Other measures include: Rosenberg Self-Esteem Scale, Piper Fatigue Scale and Hospital Anxiety and Depression Scale to measure fatigue and mood.

Paulo, T.R.S., Rossi, F.E., Viezel, J., Tosello, G.T., Seidinger, S.C., Simoes, R.R., de Freitas Jr, R., and Freitas Jr, I.F. 2019/Brazil (51).	•RCT n=36 post-menopausal women between ages 50-80. •Resistance and aerobic group n=18 •Control group n=18.	Evaluate exercise program on QOL of breast cancer survivors aged 50-80 years undergoing aromatase inhibitor therapy (body image is a component of QOL).	•Supervised resistance and aerobic exercise 3x/week for 9 months & health education session 1x/month; •Control group invited to participate in stretching and relaxation 2x/week for 45 minutes for 9 months.	Supervised group exercise.	European Organization for Research and Treatment -QOL questionnaire and breast cancer specific module (EORTC QLQ BR23).	•Significant within-group improvement in body image in both exercise and control groups after 3 months compared to baseline ($p<0.001$) and after 6 months compared to 3 months.	•Used other QOL measures (EORTC QLQ-C30, SF-36). •Did not measure physical changes in fitness.
Stan, D.L., Rausch, S.M., Sundt, K., Cheville, A.L., Youdas, J.W., Krause, D.A., Boughey, J.C., Walsh, M.F., Cha, S.S. & Pruthi, S.2012/USA (52)	Prospective, interventional, one-arm, open-label study n=15 with or without lymphedema.	•Assess feasibility of Pilates exercises after mastectomy (primary outcome). •Changes in shoulder range of motion, neck flexibility, posture, lymphedema, height, QOL, mood and body image (secondary outcome).	36 45-minute sessions of Pilates mat classes over a 12-week period.	Participants could choose to come into the exercise facility and do a group class or do a DVD at home.	Multidimensional Body-Self Relations Questionnaire (MBSRQ).	•Statistically significant within-group improvements in health evaluation ($p=0.049$) and body area satisfaction ($p=0.017$). •Shoulder mobility significantly improved in abduction ($p=0.002$) and internal rotation ($p=0.028$).	

Eyigor, S., Karapolat, H., Yesil., H., Uslu, R., & Durmaz, B. 2010/Turkey (53).	•RCT n=52 without lymphedema •Hospital exercise program n=27 •Control group home exercise program n=25.	Determine the effect Pilates has on breast cancer survivors' functional capacity, flexibility, depression and QOL (body image as a component of QOL).	•Supervised Pilates exercise 1 hour 3x/week for 8 weeks. •Control group was instructed to do home exercises that were given to everyone in a handout.	Group Pilates class.	• European Organization for Research and Treatment -QOL questionnaire and breast cancer specific module (EORTC QLQ BR23). •6 minute walk test (MWT), and modified sit and reach test.	• Significant within-group improvement in body image as BR23 functional scores significantly improved in exercise group from pre to post values ($p<0.05$). •Significant between-group improvement in 6 MWT in exercise group compared to control ($p=0.00$).	Additional psychological measures: Beck Depression Test, Brief Fatigue Index, EORTC QLQ 30.
Svensk, A.C., Öster, I., Thyme, K.E., Magnusson, E., Sjödin, M., Eisemann, M., Åström, S., Lindh, J. 2009/Sweden (54).	•RCT n=41 •Art therapy n=20 •Control group n=20.	Evaluate art therapy intervention on self-rated QOL among breast cancer survivors (body image as a component of QOL).	•Randomized into art therapy 1x/wk for 5 weeks or control group, which had no art therapy. •QOL assessments before intervention, 2 and 6 months later.	Individual sessions with art therapist.	European Organization for Research and Treatment -QOL questionnaire and breast cancer specific module (EORTC QLQ BR23).	•Significant within-group improvement in art therapy group for body image between baseline and 6 month measurement ($p=0.027$).	•Additional Measures: QOL measures: WHOQOL-BREF (Swedish version).
Legend: RCT - Randomized Control Trial QOL - Quality of Life 1 RM – 1 Repetition Maximum							

2.4.2 Intervention Details: RET

The RET interventions involved either two to three sessions per week, with the length of program ranging from eight weeks to one year. Programs varied considerably, with one home exercise program,[47] two supervised group sessions,[51, 53] one supervised one-on-one sessions,[50] one study with a combination of home and group sessions,[52] and two studies with a combination of supervised small-group sessions and individual unsupervised sessions.[48, 49] The control groups were either wait-list control, or followed an intervention involving walking or flexibility training.

The exercise programs all had a component of strength training; however, the chosen intervention protocol varied considerably between studies. Two of the studies did Pilates exercise,[52, 53] four studies used free weights, weight machines, or a combination of the two,[48-51] and one study used resistance bands.[47]

2.4.3 Intervention Details: Art Therapy

The art therapy study involved one hour of supervised one-on-one sessions per week for five weeks.[54] The individual art therapy sessions were led by one of two art therapists.[54] The following supplies were available at each session: paper, oil pastel and paints, paintbrushes tempera fluid, pencils, charcoal, tape, and scissors.[54]

2.4.4. Defining Body Image and Corresponding Outcome Measures

None of the eight studies defined body image nor provided detail of what aspect of body image they were aiming to measure (Table 2). Of the eight studies, the instruments chosen to measure body image varied substantially, with four different scales used: The Body Image and Relationships Scale (BIRS), the European Organization for Research and Treatment of Breast Cancer Quality of Life Questionnaire (EORTC QLQ-BR23), Multidimensional Body-Self Relations Questionnaire (MBSRQ), and the Physical Self-Perception Profile (PSPP).

Three studies used the BIRS, which has components of strength and health, social barriers and appearance, and sexuality.[48-50] The BIRS is a disease-specific measure, where the questions are specific to the changes and potential issues that BCS face.[55] The tool has 32-items, where five responses are possible (1= disagree strongly to 5= agree strongly).[55] The higher the score, the greater number of issues the BCS experiences.[55]

Three studies,[50, 52, 53] including the art therapy paper, used one of EORTC QLQ-BR23, which has questions related to body image, sexual functioning, sexual enjoyment, and future perspective.[56] Similar to the BIRS, this 23-item tool is also a disease-specific measure, where five responses are possible, ranging from 0 (not at all) to 4 (very much).[56] Scoring higher on the symptom-oriented questions indicate increased symptoms, and scoring higher on the functioning scales represent higher levels of functioning.[56]

One study used the MBSRQ,[52] which measures attitudes related to evaluative, cognitive, and behavioural components of body image.[57] The full version of this tool is 69 items, consisting of ten subscales.[57] One unique aspect of this tool is that it has a section measuring one's attitude towards fitness and health, which is advantageous for those doing RET interventions.[57] While the tool was designed for adults and adolescents aged 15 years or older, it has yet to be validated for breast cancer.[58]

One study used the PSPP,[47] which measures four subdomains of self-esteem: perceived body attractiveness, sport competence, physical strength, and physical conditioning.[59] The respondent selects one of two opposing statements that they relate to the most and consequently choose if it is "sort of me" or "really true of me".[47] The attractive body component was the component relevant for this review. This tool has also not yet been validated for BCS.[47]

2.4.5 Use of Theory

Upon reviewing all studies, only one paper was theoretically informed (Table 2).[47] The Self-Esteem Model was applied to help explain the connections between the exercise modality and physical self-esteem in BCS.[47]

2.4.6 Summary of Findings: RET

All of the RET studies using the BIRS tool showed statistically significant improvements in overall scores within the intervention group.[48-50] Speck and colleagues was one of two papers to report a significant between-group difference in the BIRS scale in favor of the intervention group (12% improvement) when compared to the control group (2% improvement) at twelve months.[48] The second paper, Benton and colleagues, had two groups doing the same exercise intervention—one with younger BCS (40-59 years) and the other with older cancer survivors (60-80 years).[50] While both groups showed significant improvement on the BIRS scale after the

intervention; the younger group demonstrated a significant larger improvement compared to the older group, suggesting that age may be a factor in the response to RET in terms of body image perception.[50] The remaining studies in this review reported significant within-group improvements only.[47, 51-53] Musanti et al reported significant improvements in the "attractive body" component of the PSPP from baseline to post-intervention in the RET group.[47] Similarly, Stan et al showed a significant improvement in the "health evaluation" and "body area satisfaction" subscales of the MBSRQ only.[52] Finally, Eyigor et al showed significant within-group improvements in body image in the EORTC QLQ-BR23 "functional" score category, while the "symptom" category remained unchanged.[53]

The four RET studies that measured muscular strength before and after the intervention all showed significant improvements in strength.[47-50] One study did not include fitness testing as an outcome in their protocol, which was the primary reason for not meeting the intervention fidelity requirement in Table 2.[51]

2.4.7 Summary of Findings: Art Therapy

The art therapy trial showed significant improvements in quality of life in the intervention group compared to the control group, however there were no clinically significant differences between groups for body image as measured by the EORTC QLQ-BR23.[54] Both the art therapy and control group were found to improve in body image; however, the only statistically significant improvement in body image was found in the art therapy group at the six-month follow-up.[54]

Table 2: *Analysis of Interventions*

	Primary Outcome	Body Image Definition	Theoretically Informed	Rationale/Justification for Intervention	Intervention Fidelity	Control of Confounders
Defining Parameters	Whether body image was considered a primary outcome of the study.	Whether the study defined body image, or explicitly stated what aspect of body image planning to measure, aside from talking about the tool.	Whether the study used theory to explain mechanism of change in body image perception in breast cancer.	Whether the study provided justification and rationale for conducting the intervention, highlighting the gap in literature.	Whether the control group was comparable to the intervention, the appropriate measurements administered, and adherence to protocol.	Whether the study controlled for the following confounding variables: lymphedema, age, BMI, time since surgery, and treatment type.
Authors						
Speck, R.M., Gross, C.R., Hormes, J.M., Ahmed, R.L., Lytle, L.A., Hwang, W., Schmitz, K.H.	+	-	-	+	+	+
Beidas, R.S., Paciotti, B., Barg, F., Branas, A.R., Brown, J.C., Glanz, K., DeMichele, A., DiGiovanni, L., Salvatore, D., Schmitz, K.H.	-	-	-	+	+	-
Benton, M.J., Schlairet, M.C., Gibson, D.R.	+	-	-	+	+	-
Musanti, R.	-	-	+	+	+	-
Paulo, T.R.S., Rossi, F.E., Viezel, J., Tosello, G.T., Seidinger, S.C., Simoes, R.R., Reitas, R.D., and Reitas, I.F.	-	-	-	+	-	-
Stan, D.L., Rausch, S.M., Sundt, K., Cheville, A.L., Youdas, J.W., Krause, D.A., Boughey, J.C., Walsh, M.F., Cha, S.S. & Pruthi, S.	-	-	-	+	+	-
Eyigor, S., Karapolat, H., Yesil., H., Uslu, R., & Durmaz, B.	-	-	-	+	-	-

Svensk, A.C., Öster, I., Thyme, K.E., Magnusson, E., Sjödin, M., Eisemann, M., Åström, S., Lindh, J.	-	-	-	+	+	-

Legend:
+ Present in the paper according to parameters set.
- Lacking in the paper according to parameters set

2.5 DISCUSSION

2.5.1 Nature, Characteristics and Extent of the Literature

While this scoping review provides preliminary evidence that RET can influence body image in BCS, continued research is indicated to evaluate the effectiveness of art therapy, as only one study, with a small sample size, was found. Although the studies provided adequate rationale and intervention fidelity for carrying out their respective interventions, several key issues arose in our scoping review. These issues, along with resulting research considerations from our two aims are depicted in Figure 2. To start, only one of the five RCT papers showed a significant between-group difference in body image scores,[48] while the remaining four reported a within-group difference.[47, 51, 53, 54] Svensk et al, posit that improvements in body image may be related to the 'response shift' phenomenon.[54] This phenomenon occurs when the cancer survivor recalibrates their personal values and internal standards over time as they cope with their disease, thus reporting lower instances of distress or concern despite their symptoms remaining unchanged.[60] Consequently, the within-group improvements may have resulted in part or entirety from this phenomenon, rather than due to the intervention itself. Studying the response shift phenomenon in body image among BCS is complex, as in the context of surgery alone, the shift depends on body image investment prior to diagnosis, the type of surgery, and post-surgical complications.[5, 61] Further RCTs are needed to control for this phenomenon, and to better evaluate the effectiveness of the intervention.

Most of the studies in this review included body image as a secondary outcome, resulting in less control of potential confounding variables; as baseline body image levels were not considered in the study inclusion/exclusion criteria, which may influence the results of body image outcomes. Additionally, only one study controlled for the surgery type,[54] and only two studies controlled for time since surgery,[47, 48] despite the fact that both the type of surgery and time since surgery are known to impact BCS' body image perception.[61, 62] One study examined the impact of age on body image in BCS participating in RET[50] and only one study controlled for age.[48] Similar to studies in the general population, further research is needed to determine if RET is helpful in improving body image among older women.[42] The study by Speck and colleagues controlled for the greatest number of confounding variables, and serves as an example for future studies.[48]

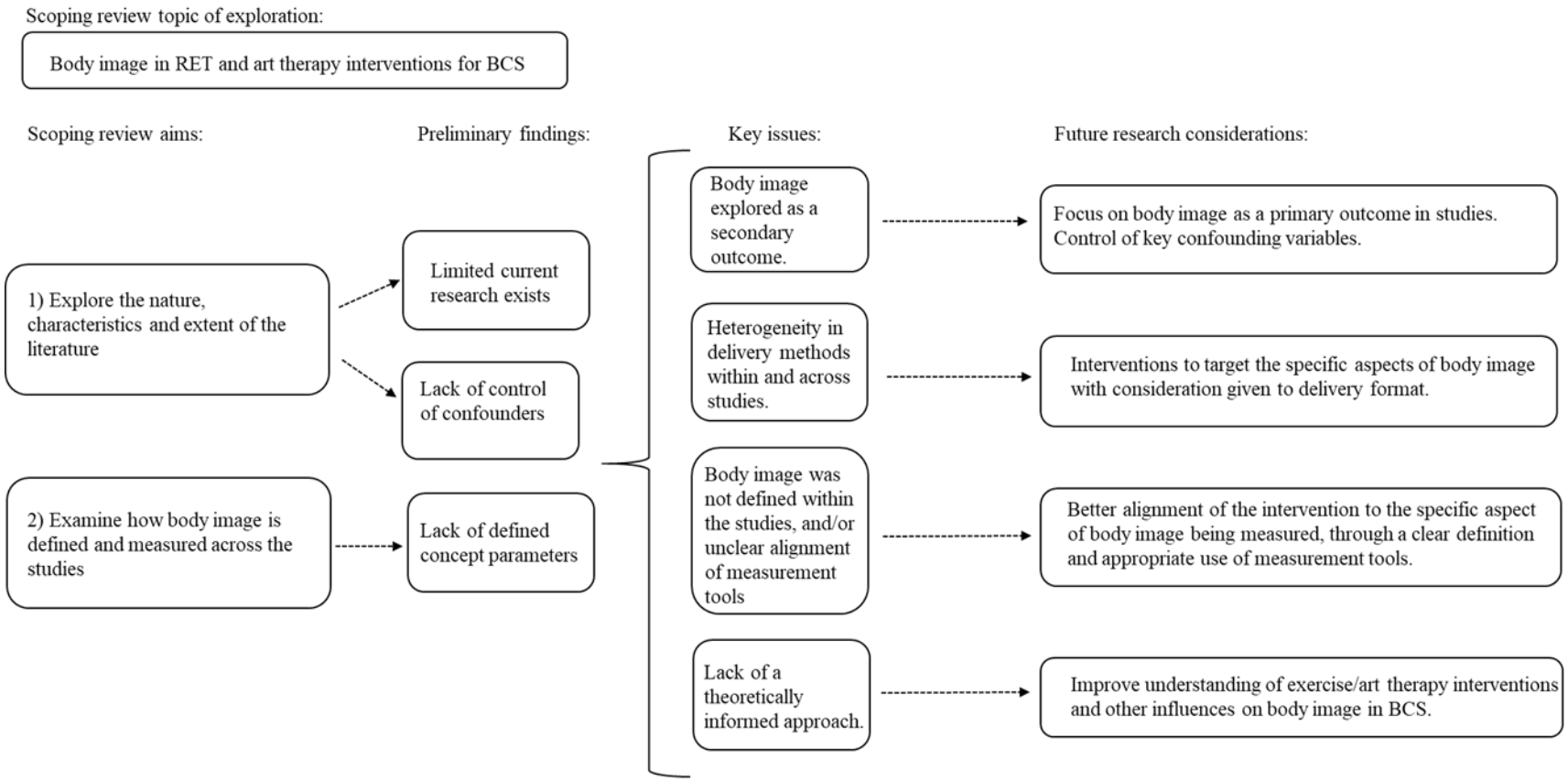

Figure 2. Key considerations of body image in resistance exercise training (RET) and art therapy interventions for breast cancer survivors (BCS)

Figure 2: *Key Considerations of Body Image in Resistance Exercise Training (RET) and Art Therapy Interventions for Breast Cancer Survivors (BCS)*

2.5.2 Delivery Formats

This scoping review found a wide range in exercise formats (i.e. group versus individual; home versus community) both across and within studies, providing a challenge to determine whether one delivery method was more effective than another. The authors of one study hypothesized that improvements in body image may have resulted from the group delivery format, concluding that the group environment provided opportunities for the BCS to share their experiences, without fear of feeling judged.[51] Similarly, research among the general population suggests the need for a placebo control group with a matched delivery format consistent with the intervention group.[42] Among the RET papers in this review, two of the seven papers used a wait-list control or had control participants follow an individualized home exercise program when the experimental intervention was delivered to participants in a group format.[48, 53] Ensuring that both the intervention and control groups have equal amounts of attention and group interaction is paramount in understanding the effect of the delivery format on outcomes. Thus, future research should consider not only the intervention, but also the delivery format.

2.5.3 Defining Body Image

Another significant finding of our review was that none of the studies defined body image, providing a challenge for the reader to understand the rationale for the intervention and choice in measurement tools. Similar to quality of life, body image affects the cognitive, physical, emotional, social, and behavioural health of the BCS, demonstrating the multidimensionality of the construct.[35] As such, specifically defining the aspect of body image of interest—whether it be all aspects or in the realm of positive body image psychology, subjective satisfaction, perceptual, affective, cognitive, or behavioural components of body image—will provide clarity on the selection of the measurement tool.[35] For example, the MBSRQ measures appearance satisfaction (an aspect of body image defined as the affective perceptions an individual has about their body)[34] and also measures appearance investment (which is a separate dimension that is not correlated with appearance satisfaction).[35] Appearance investment does not measure body image but rather measures how important physical appearance is to the individual, and whether cognition and actions are centred around physical appearance.[35] Along with a definition, future studies should consider alignment of the definition, study objectives, and chosen measurement tool, to facilitate better understanding of the meaning of the results.[35] To inform future research in the field, Table 3 lists key measurement tools and the aspect of body image being measured.

Table 3: *Body Image Tool and Corresponding Aspect of Body Image Being Measured*

Body Image Tool	Type of Instrument	Aspect of Body Image Measured	Summary of the Tool
Body Image and Relationship Scale (BIRS)	Global satisfaction measure specific to breast cancer	Self-perceptions of appearance, health, physical strength, sexuality, relationships and social functioning (48, 49, 50).	• Breast cancer specific; • A global view how body image affects psychological adjustment and functioning in daily life.
Physical Self-Perception Profile (PSPP)	Physical self-esteem	Measures perceptions of body attractiveness (47).	• Appearance satisfaction/dissatisfaction; • Whether a person views their body as attractive.
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Breast-Cancer Specific Module (EORTC QLQ BR23)	Quality of Life Measure specific to Breast Cancer	Five Scales: Body image, sexual functioning, sexual enjoyment, future perspective (functional scales), arm symptoms, breast symptoms, upset due to hair loss, and systematic side effects (symptom scales) (51, 53, 54).	• Breast cancer specific; • Based on ability to cope with changes from treatment.
Multidimensional Body-Self Relations Questionnaire (MBSRQ)	Global satisfaction measure	Measures appearance evaluation, appearance orientation, fitness evaluation, fitness orientation, health evaluation, health orientation (52).	Body image as a reflection of: • affective elements (feelings towards body); • cognitive elements (thoughts and awareness towards the body); • behavioural elements (behaviours connected towards the body).

2.5.4 Lack of Theory-Informed Research

Finally, the use of theory was lacking in the studies included this review, as only one study reported using theory to inform their research.[47] A recent systematic review examining the efficacy of psychosocial and physical activity-based interventions to improve body image among BCS similarly concluded that the lack of theory-informed research limits the understanding of the potential mechanisms behind the findings.[39] This issue is not unique to breast cancer studies, but is also seen with research involving the general population.[42] The benefit of using theory-informed research will not only help guide hypothesized causal pathways between the intervention (RET or art therapy) and the outcome measure (body image), but also facilitates consideration of the behavioural, social, and subjective implications of the construct.[63]

2.5.5 Limitations

There are several limitations of this scoping review that need to be highlighted. Only three databases were searched extensively, and as a result, some articles may have been missed. However, the three databases were carefully selected with the help of a librarian to ensure the searches were relevant and comprehensive. Despite the extensive search, only one study was found examining art therapy and no studies were found examining RET in combination with art therapy. The findings are further limited by the wide variability in the chosen assessment tools, objectives, and intervention protocols limiting our ability to make clear recommendations on the benefit of RET and art therapy on body image.

2.6 CONCLUSIONS

This review provides preliminary evidence showing that engaging in health-promoting activities—such as art or resistance exercise—have the potential to improve body image among BCS. To improve the quality of research examining body image in BCS, consideration should be given to the following: (1) incorporating body image as a primary outcome to better control confounding variables; (2) attending to the details of the intervention itself, with focus on delivery formats; (3) defining the aspect of body image that is of interest, and selecting the assessment tool that aligns best with the stated objectives; (4) using a theory-informed approach as a means to understand the influences of the RET or art therapy intervention on body image. We propose that adopting these recommendations will progress our understanding of supportive

interventions such as RET and art therapy on body image in BCS, potentially enhancing BCSs' wellness outcomes and quality of life.

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CHAPTER 3: EXPLORING THE VALIDITY OF THE BODY IMAGE SCALE WITH SURVIVORS OF BRESAT CANCER: A COGNITIVE INTERVIEW APPROACH

Submitted for Publication: Breast Cancer Research and Treatment

Authors: Corrie Effa, Mona Al Onazi, Nancy Spencer, Lesley Pritchard and Margaret McNeely

3.1 ABSTRACT

PURPOSE: The purpose of this study was to explore the construct validity of the Body Image Scale for Cancer Questionnaire (BIS) using cognitive interviews.

METHODS: Twelve breast cancer survivors participated in a cognitive interview while completing the BIS. Each participant was asked to think-out-loud while answering items and an interviewer asked probing questions corresponding to Tourangeau's question and answer model (comprehension, retrieval, judgement, response). Interviews were audio recorded, transcribed, and data were analyzed deductively and inductively.

RESULTS: Participants' interpretations of the questions varied significantly (comprehension category). Several participants perceived the phrasing of some questions to be leading. Within the retrieval category, participants were able to provide examples of how their physical, physiological, and body function affected their body image. Participants expressed positive attitudes towards, and gratitude for their body, which was not captured by the questionnaire. The judgement theme reflected participant uncertainty in how to respond appropriately to specific items. From a response perspective, participants found some items challenging to answer. Finally, the BIS included sensitive questions that elicited emotional reactions and discomfort for some participants.

CONCLUSION: The findings of this study provide insight into, and suggestions for potential questionnaire revisions that may enhance the validity and relevance of the BIS for use with breast cancer survivors.

3.2 INTRODUCTION

3.2.1 Body Image in Breast Cancer

Treatments for breast cancer involve surgery, chemotherapy, radiotherapy, and hormone therapy, all of which can result in physical changes to the body over a short period of time.[41] Body image concerns for breast cancer survivors (BCS) may develop due to the loss of the breast from surgery, resulting deformity, surgical scars, as well as other factors related to the disease and treatment process.[41, 64, 65] In BCS, body image disturbance has been associated with higher physical and psychosocial distress, and decreased quality of life.[66, 67]

Body image is a multidimensional construct that can be explored broadly or specifically.[35] The construct is dependent upon the interactions between the individual, the disease, and the sociocultural context.[39] Aspects related to the individual pertain to the person's own perceptual and affective thoughts of their appearance and function of their body;[37, 68] whereas the disease aspects comprise the physical side-effects or changes related to the disease and treatments. The sociocultural aspects are the broader influences within cultures and societies that shape peoples' thoughts, feelings and behaviors related to the body.[20, 22] The complexity of this construct is evident in the numerous tools developed to measure different aspects of body image such as body image satisfaction/dissatisfaction, body image behaviours, and investment in body image ideals.[69] As BCS often experience significant and sudden changes to their bodies, including amputation, hair loss, and scarring, a valid and reliable cancer-specific tool to clearly identify body image issues would be useful to better understand the relevant influences on body image, and overall impact of treatment.[34]

The BIS is a self-report instrument commonly used in clinical trials to measure body image in patients who have undergone treatment for cancer and has been translated for use into multiple languages (Appendix B).[12, 70] The BIS was developed to capture body image outcomes across cancer types and treatment modalities, and has questions that reflect affective, behavioural, and cognitive domains.[12, 70] The scale has been shown to have high reliability, clinical and discriminant validity, and sensitivity to change,[12] and the BIS total score has been found to be a predictor of quality of life in patients with breast cancer.[67] The BIS is a ten-item questionnaire, using a four level Likert scale ranging from 0 (not at all) to 3 (very much).[12] Global questionnaire scoring ranges from 0-30, with higher scores representing increased body image

concerns.[12] The BIS was developed almost 20 years ago; given advances in cancer treatments and our evolving understanding of the societal influences on body image, we were interested in exploring how more recent survivors of breast cancer interpreted and answered the questionnaire items.[71]

3.2.2 Cognitive Interviewing

Cognitive interviewing is a method used in questionnaire development and validation.[7, 72] Cognitive interviewing is a qualitative approach, where answers to questions are collected through participant interviews and analyzed to evaluate the respondent's cognitive processes when answering individual questions on a questionnaire. This information provides insight on how a questionnaire item may be interpreted, and can be used to detect issues that otherwise may be overlooked.[7, 72] Interview data are collected by using either a think-aloud approach, where participants are asked to express what they are thinking out loud as they answer a question, and/or through a verbal probing approach, where the interviewer asks questions to gather information on the respondent's cognitive processes.[7, 72] These qualitative data provide information on how the respondent mentally processes, understands, constructs their thoughts, and responds to the question presented to them.[72, 73] Multiple participant interviews on the same tool can then be analyzed critically, shedding light on whether the interpretation of the question is aligned with the questionnaire's intent,[73] essentially a form of construct validity.

3.2.3 Test response model

Cognitive interviewing is part of the Cognitive Aspects of Survey Methodology (CASM) The core principal of the CASM is that answering a survey question involves a series of complex cognitive processes that a respondent consciously and unconsciously undergoes to form an answer.[72] Tourangeau (1984) advanced the CASM field by proposing a four-stage model of survey response, comprised of comprehension, retrieval, judgement, and response.[74] Comprehension comprises the respondent's interpretation of the question and understanding of specific words or phrases in the question.[74] Retrieval involves the recall of relevant information the respondent draws upon from their long-term memory.[74] Judgement is the process by which the respondent gauges and evaluates accuracy of what they have retrieved.[74] Response involves the respondent choosing, reporting, and editing until they select a final answer.[74] Understanding this process is critical to demonstrating the construct validity of any questionnaire. While

definitions of construct validity have been debated, ensuring the knowledge processes underlying item responses reflect the construct of interest is necessary for demonstrating this type of validity.[8]

3.2.4 Purpose

The purpose of this study was to explore the construct validity of the BIS questionnaire using cognitive interview methods. Construct validity is defined as the ability of a test to measure the construct it is intended to measure.[8] We chose a mixed approach using both think aloud and verbal probing, to reveal issues related to the individual items, and to better understand the function of each item.[7, 72]

3.3 METHODS

3.3.1 Sampling and Participants

This cognitive interview study was part of a larger study exploring the Restoring Body Image after Breast Cancer through Exercise and Art Sculpture (RISE UP) program and represents work from within an interpretivist paradigm. All participants who met the eligibility criteria, and enrolled in RISE UP, also consented to take part in a cognitive interview (Appendix C). A criterion-based sampling strategy was used and participants who had completed the 12-week Alberta Cancer Exercise Program (ACE) were eligible if they met the following criteria:

1. Female at least 18 years of age;
2. Diagnosis of early stage breast cancer (Stage I-III);
3. Post-cancer treatment (with the exception of ongoing hormonal therapy);
4. Completed the 12-week Alberta Cancer Exercise program and identified issues with body image and/ or weight on the program intake form;
5. Cleared by an exercise physiologist for unrestricted activity;

Participants were excluded from the study if they had presence of active cancer or uncontrolled metastatic disease; other serious or uncontrolled disease or injury that would be deemed unsafe for exercise; had undergone breast reconstruction surgery; were unable to provide consent or to commit to and/or comply with the study testing or intervention due to personal reasons.

3.3.2 Procedures

Individual cognitive interviews were scheduled to coincide with the day of baseline assessment and exercise fitness testing for RISE UP. The interviews were held in a private space at the University of Alberta. Interviewers (MM, JY) followed a script that explained the purpose of the interview and asked the participant to think out-loud while answering each question. Probing questions corresponding to the four stages of the CASM question and answer model—comprehension, retrieval, judgement, and response—were systematically varied so that each participant was randomly assigned two of the four probes for each question (Appendix D).[75] The interviews were audio recorded and transcribed verbatim by two members of the research team (CE, KA). Interviews averaged 14.5 minutes (range 10 to 21 minutes). Participants pseudonyms are used in this manuscript to protect confidentiality and all identifying information was removed.

3.3.3 Analysis

The qualitative analysis involved a combined approach of both successive aggregation and collaborative analysis. Data analysis was performed independently by two researchers (CE, MAO), who met at set time points whenever a significant reduction in data occurred.[7] A top-down analysis was completed first, as classifying codes into the CASM model of comprehension, retrieval, judgement, and response was a pragmatic and prescriptive way to classify the themes.[7] Following the deductive analysis, the researchers also performed a thematic analysis using Braun and Clarke's framework, which generated the subthemes within each questionnaire response model.[76] Once subthemes were identified, the researchers met with the primary interviewer (MM) to discuss the findings and agree on final subthemes. Another meeting was subsequently scheduled with a member of the research team (NS) with previous cognitive interviewing experience,[75] who provided suggestions on consolidating and clarifying themes. Consensus was reached across all research members and the themes were finalized. Quotes were abstracted to further illustrate and support the chosen themes and subthemes.[7] Participant actual names were changed to pseudonyms to protect confidentiality and anonymity.

3.4 RESULTS

Twelve women (mean age; 59, standard deviation: 11.3 years) completed the interview. Additional information on participant characteristics is provided in Table 4. Approval for this

study was granted by the Health Research Ethics Board of Alberta: Cancer Committee (Appendix E).

The results are described below using Tourangeau's categories as primary themes, supported by the inductively derived subthemes. While we offer some examples within the descriptions below, Table 5 provides additional information on identified concerns across the BIS items. It is also important to note that while we identified subthemes within each CASM category, the categories are not mutually exclusive, but interconnected. Table 6 follows *Krista's* responses to item six, illustrating the connection of themes within a single participant's response. To read supplementary results, refer to Appendix F.

Table 4: *Demographic and Medical Variables*

Variable	Participants (N =12)
Age (years)	Mean: 59 (11.3)
BMI	Median: 31.2 (23.3-46.7)
Marital Status	Frequency
Never Married	(2) 16%
Married	(7) 58%
Divorced	(3) 25%
Education (highest level attained)	Frequency
Some High School	(1) 8%
Completed University/College	(8) 67%
Completed Graduate School	(3) 25%
Annual Family Income	Frequency
Between 20-59,999	(3) 25%
Between 60-99,999	(3) 25%
>100,000	(6) 50%
Current Employment Status	Frequency
Retired	(3) 25%
Part-Time	(5) 42%
Full Time	(4) 33%
Ethnic Origin or Ancestry	Frequency
Caucasian (White)	(11) 92%
East and Southeast Asian	(1) 8%
Stage of Cancer	Frequency
Stage 1	(5) 42%
Stage 2	(3) 25%
Stage 3	(3) 25%
Stage 4	(1) 8%

Type of Surgery	Frequency
Breast Conserving	(7) 58%
Radical Mastectomy	(5) 42%
Lymph Node Surgery & Lymphedema	Frequency
Axillary Lymph Node Biopsy	(9) 75%
Sentinel Lymph Node Biopsy	(3) 25%
Lymphedema	(3) 25%
Treatment	Frequency
Chemotherapy Only	(2) 17%
Radiation Only	(1) 8%
Chemotherapy and Radiation	(8) 67%
Biological	(1) 8%
Surgery	(12) 100%
Endocrine	(6) 50%
Currently on Treatment	Frequency
Chemotherapy + Endocrine	(1) 8%
Endocrine	(5) 42%
BIS Baseline Score	Median: 6 (4-19)

Table 5: *Concerns with Each BIS Item*

Category	**Comprehension**		**Retrieval**			**Judgement**	**Response**	
Theme	**Differences in Interpretation**	**Leading Questions**	**Body Changes**	**Emotional Response**	**Questioning Relevance**	**Uncertainty**	**Accessibility**	**Sensitivity**
Parameter	When a participant had different interpretations of questions and terms	When the question was worded to assume the participant was better before diagnosis.	When a participant provided an example that was not related to breast cancer or physical appearance.	When a participant had a positive answer that could not be measured by the tool.	When a participant could not relate to the question.	When a participant was uncertain with their answer.	When a participant found the question challenging to answer, or was between 2 answers.	When a participant found the question to be emotionally triggering.
Questions:								
Q1: Have you been feeling self-conscious about your appearance?	✓	✓	✓	✓	-	-	✓	-
Q2: Have you felt less physically attractive as a result of your disease or treatment?	✓	✓	✓	✓	-	✓	✓	-
Q3: Have you been dissatisfied with your appearance when dressed?	-	✓	-	-	✓	-	✓	✓
Q4: Have you been feeling less feminine/masculine as a result of your disease or treatment?	✓	✓	✓	✓	✓	✓	✓	✓
Q5: Did you find it difficult to look at yourself naked?	-	-	✓	✓	✓	✓	✓	✓
Q6: Have you been feeling less sexually attractive as a result of your disease or treatment?	✓	✓	✓	-	✓	✓	✓	✓
Q7: Did you avoid people because of the	-	✓	-	✓	✓	✓	✓	-

way you felt about your appearance?								
Q8: Have you been feeling the treatment has left your body less whole?	✓	✓	✓	✓	-	-	✓	-
Q9: Have you felt dissatisfied with your body?	✓	✓	✓	✓	-	✓	✓	✓
Q10: Have you been dissatisfied with the appearance of your scar?	✓	✓	✓	✓	✓	✓	✓	-

Table 6: *Interconnectivity of Themes*

Deductive Theme	**Comprehension**	**Deductive Theme: Retrieval**		**Judgement**	**Response**
Inductive Theme	**Differences in Interpretation**	**Questioning Relevance**	**Emotional Response**	**Certainty**	**Sensitivity**
Krista's Response to item 6: "Have you been feeling less sexually attractive as a result of your disease or treatment?"	*"I mean, that all ties into the feeling attractive – physically attractive too, right? Umm, and it's worrying about other peoples' perceptions."*	*"… but like I said I haven't had a partner for decades now so it's like, well [laughs]. You know, if I ever get into a serious relationship where that's a problem, then we would have to go across a lot of obstacles and by that point I'd have to feel pretty safe with him".*	*"…but, you know I thought I was accepting, and this is where I'm at, this is the journey I went on. You know, everything considered I was lucky".*	*"Well, I'm debated if it was just a little bit or quite a bit. And when I talk about it more, then I go yeah, okay it doesn't actually bother me because I'm not just sitting there thinking about it very often, very much. So yeah, maybe I would waiver and say yeah, it bothers me a little bit…"*	*"Well I just don't – I feel uncomfortable – I'm of the generation where you really didn't talk about sex. So, uh, yeah. About the same as answering the other ones".*

3.4.2 Category 1: Comprehension

Differences in Interpretation. There were varying interpretations of the question items as well as specific terms across the interviews that led to confusion for participants. Table 7 displays the terms and questions that produced the most diverse interpretations with supporting quotes.

Table 7: *Conceptual Variability of Terms and Questions*

Interpretation of Terms	#1	#2	#3	#4
Q1: Self-conscious	**Self perception and social perception** *"… how I look towards other people, or even for myself." –Barb*	**Self perception** *"How I feel when I generally leave my house… And do I feel good about it?" – Natalie.*	**Social perception** *"…I am aware of somebody looking at me and I feel strange…" – Yvonne*	
Q2: Physically attractive	**Judgement of physical appearance from self** *"…feel their breasts and things like that are not as attractive…" –Mary*	**Judgement of physical appearance from others** *"…this would be how others perceive you – your level of attractiveness that other perceive you." –Sophia*	**Worthiness** *"So you know it's, it's a there's a value judgement and a and a feeling somehow less attractive means less worthy." –Krista*	**Self-esteem** *"…how has your self esteem lessened since you were diagnosed with your treatment…" – Laurie*
Q6: Sexually attractive	**Being found appealing to others or partner** *"It's whether somebody is finds me attractive." –Yvonne*	**Sexually active** *I: "Okay. So are you interpreting sexually attractive as being sexually active?" P: "Probably yeah… that's the way I interpret it." –Susan*	**Presenting as appealing for others** *It's worrying about other peoples' perceptions…" –Krista*	
Q8: Less Whole	**Functional changes** *"Like less of a well-functioning machine." –Sophia*	**Physical changes** *"…it is asking me if parts of my body have been taken out or changed in some way." –Natalie*	**Feeling incomplete/less purposeful** *"…maybe not as purposeful or your body is there's lacking." – Barb*	

Interpretations of Question	#1	#2	#3	#4
Q4: Do you feel less feminine/masculine as a result of your disease or treatment?	**Do the physical changes to your body bother you as a result of treatment?** *"…does it bother me because I don't have a boob?" –Susan*	**Do the breast cancer treatments change how you feel as a female?** *"…it's asking me how I feel as female" –Laurie*	**Do the breast cancer treatments make you feel less like a woman?** *"…did your breast cancer treatment um make you feel less like a woman?" –Sophia*	
Q9: Have you felt dissatisfied with your body?	**Are you dissatisfied with how your body functions?** *"…I'm dissatisfied with the way it works right now…" –Susan*	**Are you dissatisfied with your physical appearance/body shape?** *"…I am not happy with the way something looks" –Amy*		
Q10: Have you been dissatisfied with the appearance of your scar?	**Did your surgeon do a good job?** *"…maybe the surgeon wasn't as neat or tidy as he could have been?" –Alix.*	**How does the scar look?** *"Is my scar ugly?" –Yvonne*	**Do you have physical discomfort from the scar?** *"…feeling uncomfortable with it physically because they might feel pain from it sticking somewhere…" –Sandra*	**How does the scar make you feel?** *"…how do I feel about how the scar looks on my body" –Erin*

Leading Questions. Sentence structure, the phrasing of some questionnaire items, as well as the choice in terminology swayed some participants to answer in a particular way. For example, *Krista* expressed her concern with the phrasing of the question "less physically attractive", alluding that "it assumes that you had a point where you felt you were more physically attractive." She found these questions especially difficult as she disclosed that prior to her diagnosis she had other health concerns impacting her perception of her body image.

3.4.3 Category 2: Retrieval

Body Changes. Participants provided varying examples of changes that affected their physical and physiological selves, body function, and the cumulative effect all these changes on their body image demonstrating diversity in the type of information used to answer question items. While several participants spoke of breast cancer treatment-related changes to their body alone, others expanded to include examples of aging and early onset menopause, and others focused on the effect of cancer treatments on their body function. The most common appearance-related breast cancer concern was weight gain, however, participants also expressed concerns with uneven breasts, hair thinning, and menstrual changes. For example, *Susan* expressed her concern asserting, "not because I don't have a boob but because I'm too fat."

Emotional Response. Although the majority of participants had appearance and body image concerns, they also expressed gratitude towards, and acceptance for their changed body. This was evident in their responses of self-acceptance. *Krista* said, "this has kind of been a journey of acceptance." Using humour to make light of her situation, *Sandra* joked, "I know the medication ends in four years [laughter], so I want to take my meds to be around to celebrate stopping them." Looking ahead rather than back, *Yvonne* reflected, "life goes on." Finally, by adopting a broader perspective, *Mary* described, "you know, my health and my life were more important than having bigger boobs." Despite being asked to reflect upon negative experiences with their bodies, the responses were balanced with positivity and gratitude. This was not accounted for in the BIS.

Questioning Relevance. On several separate occasions, participants did not relate to specific questions. In fact, several participants indicated items four, five, six, and ten were not relevant to their experiences. Participants either discussed how the example did not relate to them, talked about another example that was somewhat related, or hypothesized an example in attempt to relate to the question. In response to item six (Have you been feeling less sexually attractive as

a result of your disease or treatment?), *Yvonne* stated, "I don't have a partner… I like living alone so I haven't dated." *Sandra* also did not relate this question and explained, "… you know my husband and I have been together for 48 years so worrying about being sexually attractive to each other went out the window 20 years ago [laughs]".

3.4.4 Category 3: Judgement

Uncertainty. When asked how sure participants were about their responses, for the most part they expressed confidence. However, moments of uncertainty were also evident. These uncertainties were not exclusive to the judgement category, but interwoven within the comprehension, retrieval, and response categories, demonstrating that the four categories of survey response are not linear and may overlap.[74] For example, some participants felt uncertain about their answers when they did not align with the scale falling between two options. In response to item two, *Amy* said, "well, it was kind of like a 'not at all' or 'a little', so pretty sure? But not, yeah" (response—accessibility). When unable to related to item five, *Natalie* confessed, "…so, I'm not sure how to answer this question" (retrieval—questioning relevance). *Susan* shared her uncertainty about what question nine was asking, she exclaimed, "I can't, that question just throws me I don't even know how to answer it!" (comprehension—differences in interpretation). Finally, when feeling confused about a time period, *Erin* said, "Okay that one I'm not sure about" (comprehension—differences in interpretation).

3.4.5 Category 4: Response

Accessibility. Participants' opinions were divided on whether the questions were easy or difficult to answer. As seen in the retrieval subtheme of questioning relevance, several participants struggled to relate to some of the questions and found it difficult to retrieve relevant examples. This subsequently challenged participants to come up with an answer to the question. When asked how hard it was to select an answer for item six, *Yvonne* who does not have a significant other, was unable to relate to the question and responded, "well, the answer wasn't there." In order to navigate answering this question, she decided to make a "not applicable" box on the survey tool and checked that off instead.

Krista also expressed her concerns with the accessibility of item nine by saying, "…dissatisfied covers so much territory and it's an emotional thing and a judgemental thing so it's really not um,

not easy to put onto a little scale like that". She found this oversimplification to be frustrating and not reflective of her actual experience.

Sensitivity. Similar to the accessibility subtheme, when asked how answering the question made the participants feel, a range of responses were provided, these were categorized as positive, neutral, and negative. Participants had emotional reactions to questions, that left them feeling upset and uncomfortable. For example, when asked to reflect upon whether it was difficult to look at herself naked, *Erin* tearfully expressed, "for me, I see the scars, it brings up a lot of emotion. Even like answering the question brings up a lot of emotion." Similarly, *Barb* shared, "sometimes we focus too much on how we look, rather than how we feel, I don't know. It's okay but maybe it makes you feel negative rather than positive." She also suggested she would rather focus on confidence and self-esteem, rather than if she feels sexually or physically attractive.

3.5 DISCUSSION

Current body image literature recommends that researchers define body image and provide parameters for the aspect or dimension of body image of research interest.[34, 35] At the time of the development of the BIS, there was no consensus on the definition of body image.[12] Moreover, the concept of positive body image and insights into the dimensions of negative and positive body image emerged after the creation of the BIS.[4, 37] Thus, the BIS tool's inability to capture positive or even neutral perceptions of body image is not surprising. The original intent of the BIS was to measure body image generally; however, given the negatively phrased questions, our findings suggest the tool aligns best as a measure of negative body image. We recommend consideration be given to reframing questions to capture neutral and positive responses, or to consider the tool within the domain of body image disturbance. Figure 3 summarizes the main findings and provides future considerations for refinement of the tool for use with BCS.

A critical finding of using cognitive interviewing strategies to understand participants' thinking was that, despite the negative wording, participants reinterpreted the questions to be about confidence, self-esteem, body function, and self-acceptance, not necessarily appearance. While these attributes are more aligned with positive body image, positive body image is considered as a separate construct.[4] According to Borsboom, "a test is valid for measuring an attribute if and only if a) the attribute exists and b) variations in the attribute causally produce variations in the

outcomes of the measurement procedure" (p. 1061).[8] Without a clear explanation and without providing context on the parameters of body image being measured, participants found questions ambiguous, not aligning with their own interpretations. Expanding the introduction to this questionnaire for participants may help to clarify intent, describe the context, and outline the parameters of interest related to negative body image.

As the BIS scale was designed to be used with people with all tumour types, this generalized questionnaire may not be sensitive enough to capture concerns specific to BCS.[77] As well, a common criticism of closed-ended questions is that the answers provided may not be reflective of the respondent's attitude.[78] This was evident in the 'Accessibility' subtheme (response), as some participants stated their answer did not align with the response items provided. Including breast cancer related items would help to improve our understanding of the issues specific to breast cancer. Moreover, providing open-ended options, allowing participants to describe their experience may provide further context on the chosen response. This level of detail is critical if researchers are to provide meaningful intervention in support of participants' needs.

Body image may represent a sensitive topic for women, as the topic can be considered private, stressful to reflect upon, and generate an emotional response.[79] In performing the cognitive interviews, we found that some participants expressed discomfort when answering some question items and spoke about the distress and emotions that were triggered in doing so. Previous research on sensitive topics has proposed an 'opt out' method, where eligible participants are given the survey prior to consenting to the study in order to make an informed about joining the study.[80] Similarly, participants in our study suggested including a "prefer not to answer" option would help address this issue of discomfort. This is a key ethical consideration but also critical to ensuring participants are answering questions in keeping with their experiences, rather than forced choices that lead to misinterpretation by researchers, ultimately limiting knowledge generation.

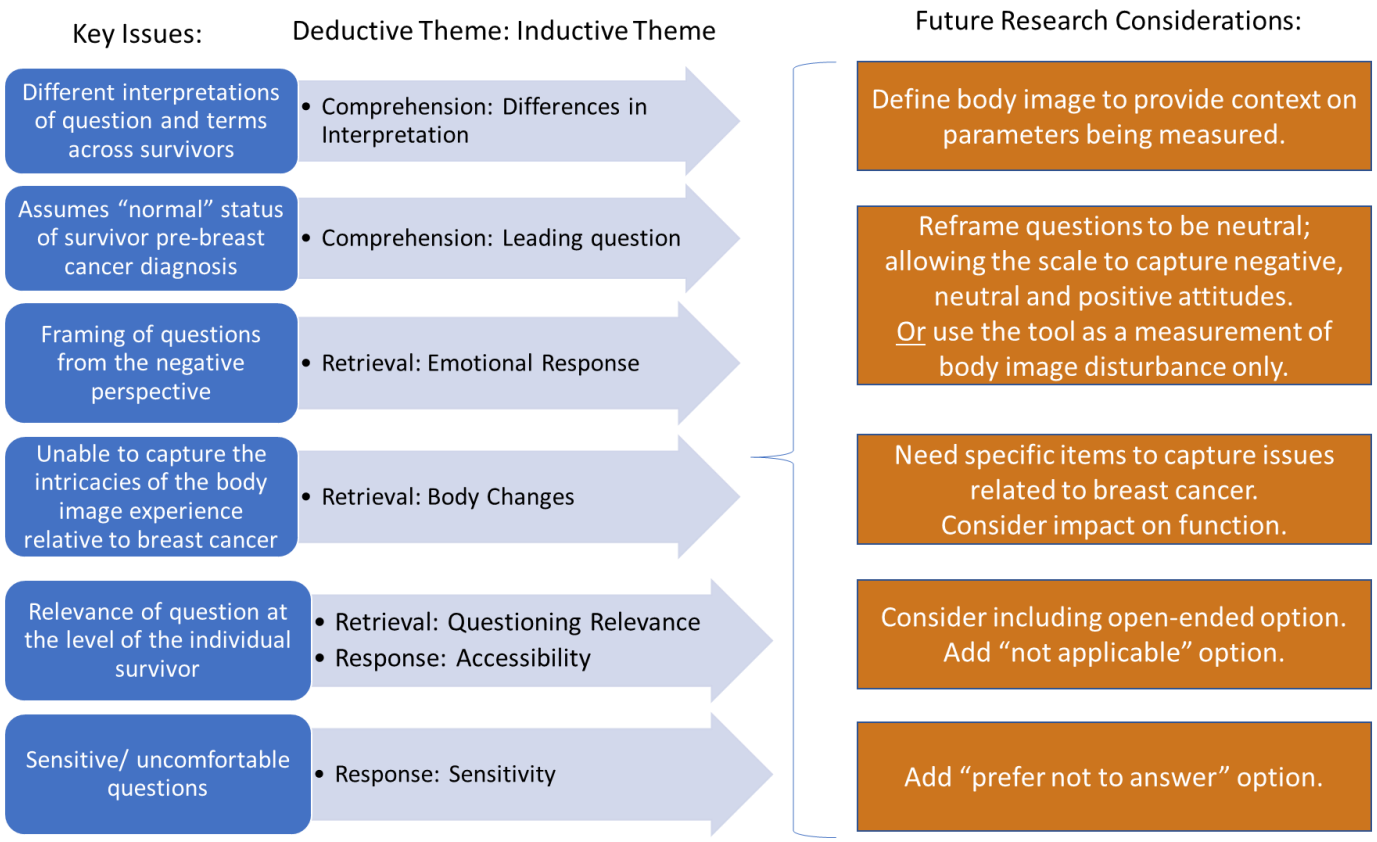

Figure 3: *Key Issues and Future Research Considerations*

3.5.1 Limitations

The majority of participants in this study scored low on the BIS scale (median of 6; range 4-19). While some studies have proposed that a BIS score of 10 points or lower indicate body image satisfaction,[58, 81, 82] the absence of negative body image does not equate to having positive body image.[38] All the participants in this study reported having concerns with body image and/or weight due to their cancer treatment prior to entry.

Women in this study were all greater than one year from completion of curative cancer treatment, and thus, time since surgery was likely is a factor in the adjustment of body image concerns. This may partly explain the focus on function and physiology rather than appearance-related concerns. While previous research has focused primarily on appearance-related concerns, new research is emerging to include function as part of body image, as positive psychology pushes researchers to define body image holistically.[4, 37, 83]

A final limitation is that we did not have the interviewers take field notes during interviews, which would have been beneficial in providing an additional source of data related to non-verbal responses. Nevertheless, the primary interviewer was actively involved in each phase of the analysis process, confirming, or providing insight into the interpretation of the transcripts.

3.6 CONCLUSIONS

The purpose of this study was to explore the construct validity of the BIS tool using cognitive interview methods. This study revealed several issues with construct validity, highlighting the need to make changes to the BIS in keeping with the emerging field of body image. Much has changed in our understanding of body image over the last two decades with the introduction of positive body image, and the shift in focus away from appearance to healthy lifestyle behaviours, self-compassion, and body functionality.[4] The findings of this study provide insight and suggestions on potential areas of questionnaire revision to improve the validity and relevance of the BIS for use with BCS.

CHAPTER 4: RESTORING BODY IMAGE AFTER BREAST CANCER THROUGH EXERCISE AND ART SCULPTURE "RISE UP" AFTER BREAST CANCER: A PILOT FEASIBILITY STUDY

Authors: Corrie Effa, Nancy Spencer, Lesley Pritchard, and Margaret McNeely

4.1 ABSTRACT

Introduction. Breast cancer is the most diagnosed cancer among Canadian women. Treatments for breast cancer are invasive, often causing visible changes to the physical appearance of the breast cancer survivor that can lead to body image concerns and psychological distress.

Objectives. The aim of this study pilot feasibility study was to examine the combination of a resistance exercise training program with an art sculpting program to promote positive body image in women diagnosed with breast cancer. Feasibility outcomes included recruitment, attendance, and completion rates, as well as cost tracking, and safety. Preliminary efficacy was determined by examining point estimates and measures of variability for objective and self-reported outcomes.

Methods. A single-group pre, -post-test design was used. Thirteen breast cancer survivors enrolled in the study, and 12 completed the intervention. Participants were asked to perform resistance exercise twice weekly for 12-weeks and attend an art sculpting class once a week for 8-weeks. Fitness measures and self-reported measures were taken before and after the intervention. Objective outcomes included anthropometric (height, weight, BMI) and fitness testing (sit-to-stand test and plank endurance test). Self-reported measures included the Body Appreciation (BAS-2), Physical Activity Stages of Change, health-related quality of life (FACIT-G), and the GODIN Leisure Time Exercise Questionnaire.

Results. The findings support feasibility, with high recruitment (87%), attendance (92%), and completion (92%) rates. Significant improvements were found in change scores from baseline to post scores for the BAS-2 scale ($p=0.02$) and strength (sit-to-stand $p=0.003$ and plank $p=0.005$). No significant differences were found for quality of life (FACT-G) or anthropometric measures (weight). No serious adverse events occurred.

Conclusion. The combination of resistance exercise training and art sculpting is feasible, and findings support preliminary efficacy for improving positive body image and body appreciation in breast cancer survivors. The findings support the feasibility of a future larger scale randomized trial.

4.2 INTRODUCTION

Breast cancer is the most commonly diagnosed cancer among Canadian women, with one in eight women estimated to be diagnosed with breast cancer in their lifetime.[1] The treatments for breast cancer include surgery, radiation, chemotherapy, and hormonal therapy. The treatments for breast cancer have a number of long-term side-effects that include partial or total loss of one or both breasts, scarring, lymphedema, weight gain, skin, hair and nail changes, and result in early onset menopause.[22, 23, 26, 41, 84] These treatments can impact the breast cancer survivor's (BCS) physical appearance and overall function, and can lead to body image concerns and psychological distress.[22, 85]

While there has been progress in addressing body image in breast cancer, there are gaps that need to be addressed. Currently, many of the studies use a narrow unidimensional approach to address body image issues.[39] This approach often only focuses on concerns relating to the disease and treatment (for example, purchasing a wig to reduce upset due to hair loss), when there is a need to take a broader, more holistic approach that additionally targets the psychological and sociocultural influences on body image.[39] Second, traditional research on body image tends to focus on reducing negative perception.[22, 36] Limiting one's research to focus solely on eliminating negative feelings rather than also measuring positive body image has prevented further growth and understanding in the field.[37] Positive body image is defined as having love and respect for one's body, which includes: a) appreciating the function of one's body; b) accepting one's body despite not matching societal ideals; c) feeling confident and happy with one's body; d) shifting focus on one's body assets rather than imperfections; e) being mindful of the needs of one's body; f) filtering information so that negative information is rejected and positive information is accepted.[4] Future research measuring positive body image will provide researchers and clinicians greater insight in understanding how to promote body acceptance and self-love, rather than merely reducing symptoms of negative body image.[4]

In this study, resistance exercise training (RET) and an art sculpting class were combined to target the physical, social, and psychological aspects of the construct of body image. The RET component was used to target the perceptual component of body image. The perceptual component refers to physical characteristics of the body - such as improving muscular strength, which may in turn improve confidence, attention to self-care, and body appreciation. The second

modality was a group art sculpting program to target the subjective component of body image, which relates to how an individual thinks and feels about their body. This was addressed through art, as the BCS sculpted a human form out of clay while reflecting on how their diagnosis of breast cancer may have impacted their body image. Both the RET and art programs had a group-delivery format, so that the participants in the study could relate socially with one another and learn together. The purpose of this study was to determine the feasibility of the study processes and preliminary efficacy of combining RET and art sculpting to promote positive body image in BCS.

4.2.1 Objectives

1) Feasibility of the processes:

- Recruitment rate (the number of consenting participants divided by the total number of participants asked to join project).

- Attendance to protocol by looking at the attendance at all sessions (RET and art sculpting).

- Completion rates (number of participants that completed the study divided by the number of participants that started the study).

- Cost tracking of the interventions (costs associated with running of the program eg. personnel, equipment costs).

- Reporting of any minor or serious adverse events (any unanticipated or unfavourable outcomes related to the study).

2) Secondary Objectives: Preliminary Efficacy Measures

- Changes in body image questionnaires (BAS-2)

- Changes in health-related quality of life (FACT-G)

4.2.2 Hypothesis related to feasibility

1. Combining RET with art sculpting will be feasible for BCS.

2. A combined intervention of RET with art sculpting will demonstrate an attendance rate of 80%

4.2.3 Hypothesis related to preliminary efficacy

1. A combined intervention of RET and art sculpting will demonstrate a trend towards improved body image and body appreciation post-intervention.

4.3 METHODS

4.3.1 Overview of Study

RISE UP or "Restoring Body Image after Breast Cancer through Exercise and Art Sculpture" was a feasibility study that was carried out at the University of Alberta in Edmonton, Alberta, Canada from January 2020 to May 2020. Participants who met the eligibility requirements were enrolled in a 12-week RET program, twice per week, as well as an 8-week art sculpting class, that started at week five, once per week for the remainder of the study.

Interruption: At week eight of the study, all research studies at the University of Alberta were suspended due to the COVID-19 pandemic. The study was modified to meet COVID-19 physical distancing restrictions and as such, the program ended up being 14 weeks of RET and nine weeks of art to accommodate the move to virtual programming.

4.3.2 Ethics Approval

Ethics approval was received from the Health Research Ethics Board of Alberta: Cancer Committee (HREBA) on October 7, 2019. The study was registered at www.clinicaltrials.gov (Identifier: NCT04088877). Informed written consent was obtained from each participant which included details on confidentiality, the benefits of participating, the risks related to participation, and the right to withdraw at any time for any reason. All paper files were stored in a locked filing cabinet in the Cancer Rehabilitation Clinic in Corbett Hall at the University of Alberta. Refer to Appendix C and E to see the consent form and ethics approval, respectively.

4.3.3 Participants

Potential participants were identified through the Cancer Rehabilitation Clinic at Corbett Hall in Edmonton. A convenience sample of recent graduates of the Alberta Cancer Exercise program (ACE) who met the eligibility criteria for the study, and had consented to being informed about

future studies were sent an email with information about the study. If an individual was interested in taking part in the study, they were required to initiate contact with the RISE-UP research team. Final determination of eligibility was performed prior to study enrollment (Appendix G).

4.3.4 Inclusion Criteria

1) Women 18 years of age and older;

2) Diagnosed of breast cancer stage I-III;

3) Identified issues with body image on the ACE intake form (Winter, Spring or Fall 2019);

4) Cleared by the exercise physiologist for unrestricted physical activity as per the PAR-Q+;

5) Participants must have completed their cancer treatments;

6) Participants must have completed the ACE initial 12-week exercise program and all follow-up testing.

4.3.5 Exclusion Criteria

1) Presence of active cancer or metastatic disease;

2) Serious or uncontrolled co-morbid disease or injury that would be deemed unsafe to exercise (e.g. Uncontrolled diabetes, heart failure);

3) Has undergone breast reconstruction surgery;

4) Indicated no concerns with body image;

5) Unable to provide consent;

6) Unable to commit to, and/or comply with the intervention due to personal reasons (e.g. vacation planned during the intervention period).

4.3.6 Study Design

This study was a prospective single-group before and after pilot feasibility study. We chose a pilot study design to determine feasibility of the study intervention and recruitment strategy to inform a future larger scale trial. The feasibility focus allowed us to specifically assess the interest in, and potential benefit from the combined intervention and group delivery format.

4.3.7 Data Collection

Participants were required to provide signed informed consent prior to baseline testing. Baseline data collection included completing the Program Intake Questionnaire (Appendix H), Contact Information Questionnaire (Appendix I), and Demographics (Appendix J). All participants were screened for exercise safety using the PAR-Q+ (Appendix K). Questionnaires were administered through REDCAP data management system. Medical data was obtained through participant self-report and by accessing participants' health record (Appendix L). Questionnaires were administered at baseline and again at the end of the intervention, including the Body Appreciation Scale-2 (BAS-2), the Self-Reported Physical Activity Questionnaire (GODIN), Physical Activity Stages of Change Questionnaire, and the Functional Assessment of Cancer Therapy-General, which is a health-related quality of life measure (FACT-G). Fitness assessments included muscular strength and endurance tests including grip strength, sit-to-stand test, one-repetition maximum for bench and leg press, and the plank endurance test (Appendix M for full protocol, Appendix N for Fitness Testing Sheet). Costs and adverse events were tracked throughout the intervention.

4.3.8 Surveys

Body Appreciation Scale-2 (BAS-2). The BAS-2 is rooted in positive psychology with the intention of providing clinicians the opportunity to measure positive body image characteristics, rather than assessing only negative perceptions.[11] It has been modified from the original 13-item to a 10-item questionnaire. Participants are asked to rank from a scale of 1 (never) to 5 (always), how much they relate to each item.[11] The psychometric properties of the BAS-2 were determined through three studies, which estimated reliability, validity and used confirmatory factor analysis with a total of 820 women and 767 men.[11] The BAS-2 has demonstrated internal consistency, test-retest reliability, and construct validity. The tool is recommended for research, clinical, prevention and educational use.[11] This tool has not yet been validated in cancer populations (see Appendix O).

FACT-G. The FACT-G version 4 is a 27-item questionnaire that uses as five-point Likert type scale (ranging from 0 "not at all" to 4 "very much so") to measure health-related quality of life (Appendix P).[13] This survey consists of four subscales: Physical Well-Being, Social/Family

Well-Being, Emotional Well-Being, and Functional Well-Being.[13] This survey has been validated and considered appropriate for the use with patients with any cancer type.[14]

GODIN. The Godin-Shephard Leisure-Time Physical Activity Questionnaire is a short survey that is frequently used to assess leisure-time physical activity in oncology research (Appendix Q).[16, 86] This self-administered questionnaire has three questions about how often one engages in mild, moderate, and strenuous activity for more than 15 minutes at a time over an average week.[86] The score can then be recorded in units with a highest number given to the strenuous sessions, and the lowest number to the mild intensity sessions.[16] The larger the final score, the more active the individual is.[16]

Physical Activity Stages of Change Questionnaire. This questionnaire was adapted with permission from the book "Motivating People to be Physically Active" by Marcus and Forsyth, 2003.[15] This questionnaire asks four questions that are to be answered yes or no regarding whether the participant is currently active, engages in regular physical activity, and whether the participant intends to be active in the next six months (Appendix R). Scoring determines which behaviour change category a participant is currently classified in (pre-contemplation, contemplation, preparation, decision/action, or maintenance), which provided us with some insight on their views towards exercise prior to the program starting.

2.3.9 Fitness Testing

One-Repetition Maximum (1-RM). Muscle strength was assessed with the one-repetition maximum (1-RM) method for bench press and leg press. The 1-RM is the gold standard for assessing muscle strength in a non-laboratory setting, as it is simple to administer and requires minimal equipment.[87, 88] The 1-RM is the greatest weight that can be moved through full range of motion with control, and proper technique.[87] The 1-RM has been tested and deemed reliable for both untrained and trained individuals.[88]

Grip Strength. Grip strength is an acceptable tool used to estimate overall muscle strength in the body.[89] Grip strength is a method where participants grip a hand dynamometer, and upon exhalation squeeze as hard as they can over a three second duration. The Jamar hand dynamometer is commonly used and has an established test-retest, inter and intra-rater

reliability.[90] The protocols and type of dynamometer used vary largely across settings, and there is a need for a globally standardized method.[90] For the purpose of this study, the Jamar was used.

Plank Endurance Test. The plank endurance test is a measure of core endurance, where participants hold a forearm supported plank position for as long as they can. Participants experiencing any pain or discomfort during the test were asked to stop immediately.

Sit to Stand (Muscular Endurance). The sit to stand test is a measurement of muscular endurance, where participants do as many sit-to-stands as they can in 30 seconds.[91] A wide range in abilities can be measured, as some may have a challenge to complete more than five and others may be upwards of 20 repetitions.[91] This test has been deemed reasonable and a valid indicator of lower body strength among the active older adult.[91]

Cost Tracking. Throughout the intervention, information was collected on the costs associated with both sculpting and RET interventions.

Adverse Events. Any minor or serious adverse events that occurred during the program were tracked by the exercise physiologist and psychologist for the RET and art program respectively and were included in the final report to inform safety of the intervention. These included any physical injury from the RET program, or any psychological disturbance as a result of focusing on body image.

5.6.10 Procedures

The RET group personal training exercise sessions and the group sculpting sessions took place at Wellspring, Edmonton and the group circuit exercise sessions took place in the Prevention and Return to Activity Centre (PRAC) at the University of Alberta in Edmonton. Wellspring is a non-profit community-based centre that offers supportive programming to cancer survivors. The RET program began on week one of the study, and the following paragraph will describe the intervention details.

RET Protocol. Participants were asked to attend the RET twice weekly over a period of 12-weeks. All sessions were completed under the supervision of a clinical exercise physiologist and the duration of each session ranged from one to one and a half hours. Participants who attended the one-hour weekly group class at Foote Field participated in a full-body circuit

training including 8-10 stations comprising cardiovascular, upper body strength, lower body strength, flexibility, balance, and coordination exercises. After a 10-minute warm-up, participants rotated through a series of exercise stations. Each station involved performing the exercise for a one-minute interval period, with a 30 second break between stations. Each participant went through two rounds of the circuit during each exercise class. Options for different intensities were provided to accommodate ability levels, with often three or more options at each station. Following the completion of the two rounds of the circuit, the class finished with 5-10 minutes of core exercises and 5-10 minutes of static stretching exercises. Refer to Appendix S for an example of a circuit exercise class.

The RET group personal training exercise sessions at Wellspring included a warm-up on an aerobic exercise machine, followed by a full body progressive RET program. Participants would follow their own personalized program using a combination of resistance exercise machines and dumbbells. Participants were encouraged to attend one group circuit class and one session at Wellspring. If a participant could not attend the circuit class, they exercised at Wellspring twice per week. Refer to Appendix T for an example of an individual's RET program.

Sculpting Protocol. Sculpting started on the fifth week of exercise. The sculpting program took place once a week for two and a half hours at Wellspring Edmonton. The artist instructor provided direction on technique and instructed participants on how to sculpt a human form using clay. The art class along with the social interactions provided participants a medium to convey and communicate their feelings on the impact of breast cancer on their body. In addition to sculpting, each group session was facilitated by a registered psychologist for 30 minutes of each class. During these sessions, the psychologist distributed a quote relating to self-acceptance, art, and/or body image and the participants were asked to reflect and share their experiences and opinions related to the topic of the day. These quotes were distributed at the start of each session.

Changes due to COVID-19. COVID-19 resulted in a suspension of in-person study activities. The study was stopped for a one-week period to prepare for delivery in a virtual format. Participants were provided with resistance bands for exercise via a safe pick up location, and the group exercises and art class were offered virtually through an online platform. The format remained the same for the group circuit class, where 8-10 exercises were completed twice

over a one-minute interval, followed by 5-10 minutes of core and 5-10 minutes of stretching. For the second exercise session, participants completed a modified home version of their Wellspring program. The program consisted of exercises that targeted the same muscle groups as the individual program at Wellspring and was adapted based on the equipment each participant had at home. We asked participants to log their exercise record for attendance purposes. A second group virtual exercise session was offered to provide participants flexibility and more exercise support given the pandemic.

The sculpting class was re-initiated after a two-week hiatus. Participants picked up their artwork (clay sculpture) and art equipment from a safe pick up location at Wellspring. Weekly group art classes were resumed via the online platform, where the art instructor connected virtually with the participants to provide feedback on their sculpture. During the session, the psychologist facilitated the group sharing and discussion. An additional sculpting class was offered to participants for finishing their sculptures.

Due to COVID 19, the intervention period was extended by two weeks longer than originally planned to make up for the cancelled weeks of programming. This extended the exercise portion of the study to 14 weeks and the art program to nine weeks. At the end of the intervention, fitness testing was done virtually, and as a result, waist and hip circumference, 1-RM bench and leg press, and the grip strength tests were not able to be administered. However, we were able to complete the following tests: weight (for individuals who had a home scale), sit-to-stand test, and the plank endurance test. All questionnaires were online after the intervention.

Deviations from Protocol. It is important to note there were some additional deviations to the protocol. One participant wanted to participate in the study but was concerned about the time commitment, as she had committed to a dragon boat racing team training. As the exercises from the dragon boat team were strength-focused and comparable to the RET study protocol, to accommodate to her schedule, she was allowed to count one dragon boat session a week as part attendance to the RISE UP study.

Another participant was accepted into the study despite having stage four cancer. This exception was made as her Oncologist determined that her health was stable and that she would benefit from the exercise program.

Upon moving the study virtually, one participant, who was 80 years of age, struggled with the group virtual environment. To accommodate for this, she was provided with one-to-one virtual RET sessions through the platform. That way, she was able to ask any questions she had about the exercises, and we were able to modify exercises and support her participation more easily. A solution was also found to address her issues with participating in the group art sculpting class. A community artist volunteered to complete the sculpture based on the participant's shared inspiration and feedback. The participant subsequently continued to participate in the sharing portion of the sculpting sessions but did not do the actual hands on sculpting. By making these changes, she was able to continue in the study, while still feeling included in the process.

4.3.11 Statistical Analysis

Demographic and medical information are presented using median and range and percentage for interval and nominal data, respectively. The primary analysis compares the surveys BAS-2, FACT-G, and GODIN before and after the intervention to measure any change in positive body image, cancer-specific health-related quality of life, and weekly reported exercise sessions, respectively. The fitness tests consisting of the sit-to-stand and the plank endurance test were analyzed to determine whether there was a statistically significant improvement in fitness outcomes. By doing these calculations, preliminary efficacy objectives will be met of the study; to determine whether the intervention demonstrates a trend towards improved body image. Analyses of outcomes were performed using non-parametric tests (Wilcoxon signed rank). Point estimates and measures of variability to inform future research were calculated from parametric statistics using a paired t-test. Descriptive data on accrual rates included the number of participants screened for eligibility, the number eligible, the number agreeing to participate, and reasons for refusal to participate. Data on attendance was collected from all participants throughout the study period.

4.4 RESULTS

4.4.1 Participants (Demographics)

A total of 13 BCS were recruited to the study. The mean age of the participants was 59.2 with a standard deviation of 10.9 years. Further information on the demographic and medical characteristics of the participants are provided in Table 8.

Table 8: *Participant characteristics and demographics*

Variable	**Participants (N =13)**
Age (years)	Mean: 59.2 (10.9)
Marital Status	**Frequency**
Never Married	(2) 15%
Married	(7) 54%
Widowed	(1) 8%
Divorced	(3) 23%
Education (highest level attained)	**Frequency**
Some High School	(1) 8%
Some University/College	(1) 8%
Completed University/College	(8) 62%
Completed Graduate School	(3) 23%
Annual Family Income	**Frequency**
Between 20-59,999	(4) 31%
Between 60-99,999	(3) 25%
>100,000	(6) 46%
Current Employment Status	**Frequency**
Disability	(1) 8%
Retired	(3) 23%
Part-Time	(5) 38%
Full Time	(4) 31%
Ethnic Origin or Ancestry	**Frequency**
Caucasian (White)	(12) 92%
East and Southeast Asian	(1) 8%
Smoking	**Frequency**
Never Smoked	(7) 54%
Ex-Smoker	(5) 38%
Drinking	**Frequency**
Never Drank	(2) 13%
Ex-Drinker	(2) 13%
Occasional Drinker	(4) 41%
Social Drinker	(5) 38%
Physical Activity Stage of Change	**Frequency**
Contemplation	(5) 38%
Preparation	(1) 8%
Decision/Action	(2) 15%
Maintenance	(5) 38%
Cancer Stage	**Frequency**
Stage 1	(6) 46%
Stage 2	(3) 23%

Stage 3	(3) 25%
Stage 4	(1) 6%
Type of Surgery	**Frequency**
Breast Conserving	(8) 62%
Radical Mastectomy	(5) 38%
Lymph Node Biopsy & Lymphedema	**Frequency**
Axillary Lymph Node Biopsy	(9) 69%
Sentinel Lymph Node Biopsy	(4) 31%
Lymphedema	(4) 31%
Treatment	**Frequency**
Chemotherapy Only	(2) 15%
Radiation Only	(2) 15%
Chemotherapy and Radiation	(8) 62%
Biological	(1) 8%
Surgery	(13) 100%
Endocrine	(6) 46%
Currently on Treatment	Frequency
Chemotherapy + Endocrine	(1) 8%
Endocrine	(5) 38%
Anthropometry	**Median (Range)**
Body Mass Index (BMI)	30.8 (23.3-46.7)

4.4.2 Primary Feasibility Outcomes

Recruitment Rate. Recruitment of participants occurred between October 2019 to January 2020. Fifty-one BCS were contacted that had previously identified issues with their body image on the ACE intake form (Winter, Spring, or Fall 2019). Of those, 14 did not respond and 37 participants expressed interest in the study. Twenty-three participants did not meet the inclusion criteria for reasons related to: having had reconstruction surgery, having active metastatic disease, conflict with the schedule of the intervention due to work or vacation, a comorbid medical condition deeming unsafe for exercise, not completing the ACE program, and an unknown reason. Fifteen participants were deemed eligible and a total of 13 participants (87%) were enrolled in the RISE UP study (See Figure 4: Study Flow).

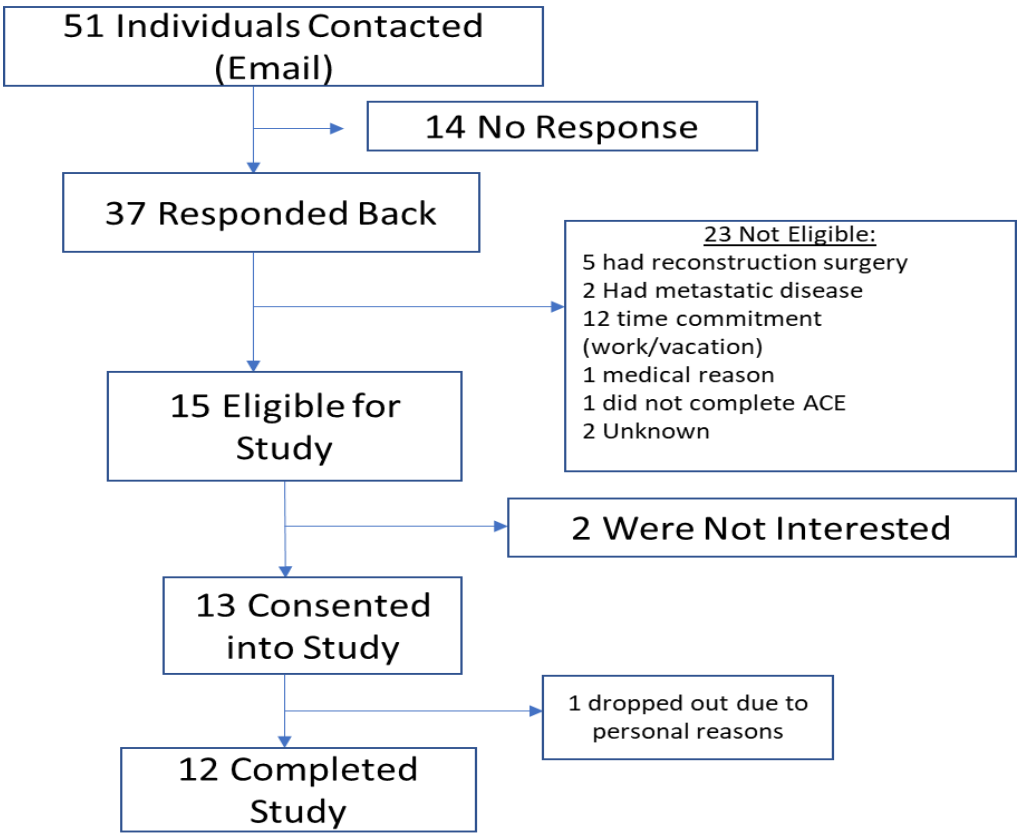

Figure 4: *Study Flow*

Completion Rate. Twelve out of 13 participants (92%) who started the RISE UP study completed the program. One participant withdrew due to personal reasons not related to the study after completing the fitness testing but before the RET or sculpting interventions began.

Attendance. All the participants completed the baseline questionnaires, anthropometric measures, and fitness testing measurements. The attendance of the program has been divided up into overall, RET, and art (both in person and virtual). It is important to note that makeup sessions were offered to participants for both exercise and art sessions due to the interruption from COVID 19. The total program attendance was 91.7%, with participants completing 352/384 sessions (Table 9 Feasibility Outcomes). Of the 12 participants, seven had 100% attendance for both the RET and art interventions. One participant stopped attending the RET and art sessions at week four of the program due to personal reasons; however, she completed the final assessment.

Attendance for RET sessions was 93%, with nine participants achieving 100% attendance. In-person attendance was high, at 87%. The group virtual exercise sessions along with the modified individual home exercise sessions displayed a similar high attendance rate of 85%.

The sculpting program had an overall attendance rate of 88%. The attendance was higher in the virtual program compared to the in-person program. One participant was unable to participate in the in-person sessions due to a change in her work schedule; however, because of the COVID-19 restrictions, she was able to attend the virtual sculpting class. Eight participants achieved 100% attendance in the sculpting program. Refer to Appendix U to see photos of participant's sculptures.

Table 9: *RISE UP Study Attendance*

	In Person Exercise	Virtual Group and Individualized Home Program	Total Exercise Attendance %	Art In Person	Art Virtual	Art Attendance %	Total Program Attendance
Total	146/168 - 92 sessions from Wellspring - 54 sessions from group circuit class	122/144 - 48 sessions from group virtual - 74 sessions from individualized home program	268/288 = 93%	38/48	46/48	84/96 = 87.5%	352/384 = **91.7%**

Adverse Events. Two participants experienced minor adverse musculoskeletal injuries as a result of the RET program including one shoulder injury and one mid-back injury. Both were given modifications to the exercises, and in both cases, the conditions resolved within a few weeks. In terms of adverse psychological events, some participants reporting feeling anxious about sharing during the group art sculpting sessions. This was addressed by reminding participants that sharing was optional, and by providing the topic of reflection at the start of class so that participants had the entire duration of the sculpting class to reflect upon what they may or may not want to share with the group.

Cost Tracking. The total cost for the 12-week program would have been approximately $9,480. However, with the additional weeks added on to accommodate the transition to virtual programming, the approximate cost of the program was $10,525. The extra costs were due to lengthening the program, and the cost of resistance exercise bands that were purchased for each participant for the virtual classes. A further breakdown of the costs associated with the RISE UP study can be found in Table 10.

Table 10: *RISE-UP Cost Tracking*

ITEM	ESTIMATED COST FOR 12-WEEK PROGRAM	APPROXIMATE actual COST DUE TO COVID-19 PROGRAM EXTENSION	EXPLANATION
Psychologist	$760 • $190/hr x 0.5 hrs/week for 8 weeks = 4 hours	$855 • $190/hr x 0.5 hrs/week for 9 weeks = 4.5 hours	• Facilitate discussion on body image topic during art class.
Sculpting Instructor	$900 • $45/hr x 2.5 hours/week x 8 weeks = 20 hours	$1013 • $45/hr x 2.5 hours/week x 9 weeks = 22.5 hours	• Instruct and Facilitate techniques for sculpting class.
Certified Exercise Physiologist	$4320 • $45/hour* x 8 hours/week for 12 weeks = 96 hours	$5040 • $45/hour* x 8 hours/week for 14 weeks = 112 hours	• Supervises exercise program.
Research Assistant (Graduate Student)	$2400 • Estimated 8 hours/week for 12 weeks = 96 hours x $25/hr		• Assist with exercise class supervision.
Fitness Assessor	$600 • $25/hour x 24 hours		• Independent assessor who will perform baseline and end program fitness testing.
Art Equipment	$250		• Clay for 13 participants.
Office Supplies	$250		• Exercise program sheets • Photocopies and pens for participants.
Exercise Equipment		$117 • $9/person x 13 persons	• Purchased 3 resistance bands per person when moved to virtual environment.
TOTAL	$9480	**$10 525**	

*Alberta Health Services (AHS): Kinesiologist average pay is $37.30 to $49.65 per hour.

4.4.3 Secondary Outcomes

The secondary outcome of this study was to look at the preliminary efficacy of improving positive body image and appreciation in BCS. By using the Wilcoxon Signed Rank non-parametric test, we were able to determine significance from baseline to post-intervention for the survey tools, the anthropometric tests, and the fitness testing measures (Table 11).

Table 11: *Non-Parametric Tests for Secondary Outcome*

Outcome Measure	Baseline Median	Baseline Range	Post-intervention Median	Post intervention Range	Δ Median	Δ Range	Effectiveness Two-tailed p<0.05
BAS-2 (n=12)	3.5	2.6-4.3	3.7	3.2-4.5	0.2	-0.5-1.6	0.0208*
FACT-G (n=12)	78.5	53-92	81	62-93	4	-30-14	p>0.05
GODIN Leisure (n=12)	23.5	0-67	45.5	0-68	17	-11-64	O.0099*
Plank (seconds) (n=10)	67.95	17.9-436	91	28-543	16.75	4-317	0.0051*
Sit-to-Stand (reps) (n=12)	17.5	8-35	20.5	9-39	2	0-6	0.0034*
Weight (kg) (n=9)	79.5	57.1-130.3	80.1	55.8-129	-1.3	-4.3-4.6	p>0.05

*****statistically significant result.

Anthropometric and Fitness Testing Outcomes

Plank. The plank test significantly improved (p=0.0051) for all 10 participants that completed both the pre, and post-tests. One participant did not complete the plank post-test due to an ongoing chronic shoulder injury, and the other did not complete the post-test as she was unable to go on the ground (participant did the baseline plank on a plinth). There was a large variability in the range of improvement, with the lowest score being an increase of four seconds, with the longest improvement of 317 seconds, and an average improvement of 56.4 seconds.

Sit to Stand. Due to the fact that the follow-up tests were done virtually, a different chair was used and as a result, the average seat height for the baseline test was 17 inches, and the average height of the chair at the end of the intervention was approximately 17.8 inches. This discrepancy in seat height may have influenced the scores. Of the 12 participants that did both the pre and post measurements, all either stayed the same or improved from baseline. The lowest score change score was zero, and the largest change was an increase in six sit-to-stands. The mean average improvement across all participants was 2.4 repetitions, the median improvement was two repetitions and a statistically significant improvement was found from baseline to post-intervention ($p=0.0034$).

Weight. Nine participants had a home scale that they used to measure their weight post-test. Of those nine participants, there was no significant change in weight from the beginning of the program to the end ($p >0.05$).

Survey Outcomes

BAS-2. A total of 12 participants completed this survey before and after the intervention. The BAS-2 scores showed a significant improvement from baseline to post-intervention ($p=0.02$).

FACT-G. A total of 12 participants completed this survey before and after the intervention. The FACT-G scores did not show a significant improvement and remained relatively similar from baseline to post-test with a mean change of 2.33 ($p >0.05$).

GODIN. A total of 12 participants completed this survey before and after the intervention. The GODIN Leisure Time Physical Activity survey showed a significant improvement in scores ($p=0.009$), indicating that participants reported a higher number of vigorous, moderate, and light activity in an average week.

4.4.4 Determination of protocol feasibility-sample size:

Based on a mean change in the BAS-2 score of 0.38 and SD 0.53 (effect size of 0.66; representing a medium effect size according to Cohen's d values)[92] from baseline to post-intervention in favour of the combined intervention group over standard care, and a p-value of

0.05 and power of 80%, we estimate the sample size for a future efficacy study would require 36 participants per group for a total sample size of 72.[93]

4.5 DISCUSSION

4.5.1 Hypothesis related to feasibility

1. Combining RET with art sculpting will be feasible for BCS.

2. A combined intervention of RET with art sculpting will demonstrate an attendance rate of 80%.

The findings of the RISE UP study support the above hypotheses. The recruitment, attendance, completion rates, cost tracking, and no serious adverse events support the feasibility and safety of the intervention combining RET with art sculpture to improve body image in BCS despite delivery in both in-person and virtual group formats.

Feasibility of the process: Recruitment. The RISE UP study had an overall recruitment rate of 87%. This is on the higher range when comparing to other RET interventions looking at body image in BCS. Of the four RET studies from the scoping review that reported on recruitment, the overall average was 77%.[48, 50, 52, 53] It is possible that there was a higher recruitment rate in RISE UP because the participants that were contacted for the study had already participated in a previous exercise study (ACE) and understood the benefits and barriers of both exercise and study participation. As a side, it is important to note that 12/23 participants declined participation due to time constraints. A consideration for future research was that the time commitment for the combined intervention was considerable and proved challenging for working survivors.

Feasibility of the process: Attendance. The overall attendance of the RISE UP study was 91.7%. While there are no known studies combining both RET and art sculpting, attendance will be compared separately for each program.

RET Attendance. The RET portion of the RISE UP study had an attendance rate of 93%. Past studies examining RET interventions to improve body image in BCS typically report a wide range of attendance rates. The average percentage of these attendance rates was around 79%.[47-52]

The lowest attendance in the six papers reviewed was a 12-month RET study that reported an overall attendance of 49%.[49] The highest was an 8-week RET program, reporting 98% attendance.[50] Despite the challenges of COVID 19, and the change in format from in-person to virtual, the RISE UP study was able to retain a high attendance rate. This was partly due to the need to extend the RET program by two weeks to allow for make-up sessions and providing multiple options for virtual exercise (having two group virtual classes a week and a home program available). We were able to accommodate participants' schedules by providing multiple avenues and options for exercise. Additionally, we tailored the exercise programs for each participant, aligning to personal goals and prescribing exercise accordingly. For example, when the study moved virtual, the exercise physiologist took an inventory of each participants' home exercise equipment to ensure that they could do each of the exercises. This may have contributed to a higher attendance rate, as we strived to ensure each participant felt supported throughout the program.

Art Attendance. Similar to the RET attendance, the art program had an overall attendance of 87.5%. Only one study has been reported examining art therapy for body image in breast cancer.[54] In the study, no data was reported on attendance at art therapy sessions.[54] The attendance in our study suggests the intervention is feasible for participants.

Feasibility of the process: Completion. The completion rate of the RISE UP intervention was 92%. As there are no known studies combining both exercise and art therapy, they will be discussed separately below.

RET Completion. The seven RET studies from the scoping review had quite a range of completion rates, with the average of the studies having an overall completion rate of 78%.[47-53] One interesting finding was that the studies that had an unsupervised at home exercise delivery format had the lowest completion rates, with the range between 38-80%;[47-49] whereas the studies with either supervised group or supervised individual exercise sessions had the highest completion rate, reporting a range of 78-90%.[50-53] With the move to virtual exercise programming, the RISE UP study did have individual unsupervised sessions as an option for participants. However, the move to virtual programming occurred in week eight of the program, when participants were already into an exercise routine, which may have influenced the high completion rate.

Art Completion. Similar to our study, the art intervention paper by Svensk et al also reported a high completion rate.[54] The intervention group reported 100% completion, with the overall study having a completion rate of 98% (one participant from the control group was excluded due to incomplete data).[54] This study was about half the length in duration as the RISE UP study, with classes lasting an hour a week, for a five-week duration.

Feasibility of the process: Cost Tracking. No prior studies were found that tracked the total cost of their program.[47-54] As a result, we will compare the cost of standard care – which is individual therapy with a registered psychologist – to the cost of the 12-week RISE UP study.[40] The 2019-2020 Psychologist Association of Alberta recommends individual therapy costs of $200/session.[94] Based on the 12-week program, the RISE UP study would have cost $9480. Across 12 participants, this amount of money would have covered only 3.95 individual psychology sessions per participant ($9480/$200 = 47.4 sessions/12 participants = 3.95 sessions/participant). To summarize, if future research demonstrates that the combination of RET and art are effective in improving body image in BCS, it may be more cost-effective to run group programming that is similar to the RISE UP protocol.

Safety: Adverse Events. No safety issues were identified from The RISE UP study. There were two minor concerns related to the RET program, as two participants acquired musculoskeletal injuries from exercise. These findings are in alignment with the findings of our scoping review of RET studies where no serious adverse events were reported.[47, 49, 50, 53] Participants expressed some anxieties with the group sharing portion of the art sculpting class.

4.5.2 Hypothesis Related to Preliminary Efficacy

1. A combined intervention of RET and art sculpting will demonstrate a trend towards improved body image and body appreciation post-intervention.

The above hypothesis was supported as significant improvements in the BAS-2 scores and fitness testing scores from pre to post-intervention were found.

Preliminary Efficacy: Body Image Tool. The RISE UP study showed significant improvement in the BAS-2 scores from pre to post-intervention. It is important to note that this significant difference was seen despite the weight of participants remaining relatively unchanged from pre to post-intervention. The RISE UP study was not intended as a weight loss program. In

alignment with positive body image literature, physically changing the body (for example, losing weight) is not a determinant to improving body appreciation.[95] In order for an individual to feel more appreciative of their body, they must reframe their body image so that the individual appreciates, accepts, and feels confident in the way their body looks and functions, all while filtering and reframing negative messaging coming from the media and society.[38] For example, reframing of body image in breast cancer might be to take the focus away from what treatment has done to the BCS body (hair loss, weight gain), and refocus the individual's attention towards appreciating the strength of the body in withstanding cancer treatments and appreciating the ability of the body to continue to move and function in daily activities. As no prior studies were found administering both RET and art as a combined intervention, we are unable to compare results. Further research with a randomized control trial design that measures positive body image using the BAS-2 is warranted. Additionally, qualitative data on the BCS' experience in the combined intervention would shed light on the barriers and facilitators to participating in the program that were not captured in this pilot study.

Preliminary Efficacy: Quality of Life Survey. No statistically significant difference was found in quality of life using the FACT-G. Stan et al reported significant improvements in quality of life pre and post 12-week Pilates intervention using the FACT-B (which has the FACT-G as a component of the questionnaires).[52] Upon summarizing the other three quality of life tools used in the scoping review papers (EORTC QLQ BR23, EORTC QLQ BR 30, and SF-36), the results were split, with two more studies showing significant improvement in quality of life (one RET paper and one art therapy paper)[51, 54] and two showing no significant change (one Pilates and one RET).[48, 53] Further research with larger sample sizes is needed to better understand the connection between improved body image and quality of life in BCS.

Preliminary Efficacy: Fitness Testing Outcomes. All the fitness testing outcomes for the RISE UP study (Sit-to-stand and plank endurance test) showed significant improvements. Our findings are similar to those of prior studies that have measured strength as a component of fitness, where significant improvements from pre- to post-intervention were found.[47-50] Consistent with this finding, it is interesting to note that the RISE UP study along with four other studies in the scoping review had significant improvement in strength-related fitness and also demonstrated a within-group body image improvement.[47-50]

4.5.3 Limitations

There were several limitations of the RISE UP study that need to be addressed. First, the small sample size and a lack of a control group limit our ability to generalize results and assess efficacy. Second, we did not control for time since diagnosis which may influence the extent and severity of breast cancer specific body image concerns among our participants. Finally, physical distancing restrictions from COVID-19 required us to transition programming to virtual environment, compromising intervention delivery and post-intervention fitness testing.

4.6 CONCLUSION

4.6.1 Summary and Future Directives

The findings from the RISE UP study suggest the combined intervention of RET with art sculpting is feasible and shows promise in improving body appreciation. To explore efficacy further, larger sample sizes using a randomized control trial design is warranted. Additionally, collecting qualitative data on BCS experience during and following the combined program would be helpful for understanding potential barriers and facilitators to participation.

CHAPTER 5: DISCUSSION

5.1 THE RESEARCHER'S BACKGROUND AND EXPERIENCES

Personal background and experience influence the researcher's choice in philosophical position, choice in methodology, theory, and questions asked.[96] Therefore, as the researcher, I will provide context regarding how my background has shaped my research.[96] I decided to go back to school after working as a Kinesiologist teaching group exercise for individuals with chronic conditions. As much as I loved that work, I was passionate to learn more and challenge myself with new opportunities. I have always had a passion to create inclusive spaces for individuals and I was excited to expand my knowledge to cancer survivors. After my first year working with the Alberta Cancer Exercise Program (ACE), I noticed how common it was for participants in the program to talk about how they wanted to exercise in order to change their appearance – whether it be weight loss, or wanting their arms and abs to looked toned. They often would joke about how I was going to get them to transform their body into one they liked. I never knew how to respond to these comments, and they made me feel sad as there were many individuals feeling self-conscious in the gym. As someone who has struggled with body image, I felt drawn to this topic. I narrowed my topic to BCS as I have a personal connection with this tumour type.

When starting to read about body image, I was shocked to discover the multitude of body image tools. Trying to select one to use for my study was extremely challenging. I kept reflecting upon my own body image experience and felt confused as to whether someone's body image could truly be captured by filling out a survey. After some discussion with my committee, we decided to administer a cognitive interview study using a popular body image tool. This study challenged me as this was my first experience of qualitative research. Participants had so much to say, and I was surprised by how much each of them shared. I felt pressure to ensure their experiences were accurately captured in the data analysis, synthesis, and writing of the report. This portion of the study taught me about patience in sitting with the data, relying on other members of the research team for their second eyes, and trusting myself in being able to reflect the voices of my participants in my work.

For the feasibility study, we decided to have me be a participant-observer in the sculpting class, which was such an enriching experience for me. I was able to connect with my participants on a

deeper level and show my vulnerabilities through my art and group sharing, rather than just observing the participants in the program. Each sculpting class felt as if time stopped. Having intentional time to be mindful and to focus on my art made me feel refreshed after each session. I kept a reflexive journal throughout the study, challenging my own body image perspectives, while reflecting upon others.

I taught the exercise portion group class and facilitated each individual exercise session at Wellspring. By being present in all the exercise sessions, participants and I were able to continue the conversations we were having in the sculpting class into the exercise gym. I found the conversations to be positive, meaningful, and intimate. I reflected on the fact that the sculpting class may have provided space for participants to reframe some of the insecurities that otherwise would not have been addressed in exercise alone.

When COVID-19 emerged in Alberta, and the study was suspended, I was devastated. I did not know how we would be able to continue the study and move both the exercise and art virtually. However, my participants were willing to learn and with the help of my supervisor, the psychologist, and artist from Wellspring, we were able to create a solution. This experience may have drawn our group closer together, as our 3x/week virtual sessions provided structure in a very unstructured time. On numerous occasions, participants thanked me for finding ways to continue the program. In turn, I was thankful to them for staying with the study and not giving up.

I have learned so much about myself and about body image over these past two years. There is so much research that is still needed, but the progress in the field over the last decade has been exciting and promising. In the following discussion, I will integrate the findings from my scoping review, cognitive interview study, and feasibility study to shed light on three key findings.

5.2 FINAL DISCUSSION AND FUTURE DIRECTIONS

This chapter will discuss the three major findings from the scoping review, cognitive interview study, and feasibility study combining RET with art sculpting. The first section will discuss the feasibility and efficacy of the combined intervention, the second will discuss the complexity behind selecting and using a body image measurement tool, and the third will discuss future directives for positive health programming in BCS.

5.2.1 RET and Art Findings and Future Directives

The intervention combining RET with art sculpting from Chapter 4 determined that the combined intervention is feasible and that there is preliminary evidence to suggest that the multifocal approach has the potential to improve body appreciation. However, future research using larger sample sizes and a randomized control trial design are needed to determine efficacy. Qualitative research is also warranted to better understand participants' experiences in these types of programs. To expand upon how further research should be conducted, the findings from the first aim of the scoping review – to explore the nature, characteristics, and extent of the literature – will be summarized.

While the scoping review had no studies involving a combined approach of RET with art therapy, the suggestions for future research can still be applicable to these research interventions separately and in combination. First, future research should explore body image as a primary outcome so that key confounding variables are controlled, and such that eligibility includes participants who have issues with body image at the start of the study. Second, consideration to delivery formats will provide further insight on whether there is added benefit to group or individual programming. However, if a study is taking a group approach, the control group must have equal amounts of group interaction to determine the effect of delivery format on outcomes.[42] Third, the use of theory was lacking in all but one of the studies in the scoping review, limiting our understanding of how the intervention of RET, art therapy, or the combination may influence body image. This suggestion is consistent with other reviews looking at body image in both breast cancer[39] and in the general population.[42] By following the above considerations, the quality of evidence in the field of body image research among BCS will continue to develop, providing insight on how theoretically informed research will help guide

connections between the intervention (RET and/or art therapy), and the format delivery (group vs. individual) to improve body image in BCS.

5.2.2 Survey tools

This thesis had objectives related to understanding and providing practical feedback for selecting an appropriate body image tool. The findings from the scoping review in Chapter 2 and the findings from conducting the cognitive interview study in Chapter 3 will be discussed. The scoping review explored the body image objectives and the alignment to the body image tool selected. Without a clear definition of the aspect of body image of interest, the use and value of a given tool may be unclear, providing a challenge when interpreting results. This challenge is found in studies examining body image in the general population as well.[35] Future research studies need to clearly define the aspect of body image being studied, matching the objectives to a valid assessment tool.

Chapter 3 discussed the construct validity of the BIS scale through cognitive interviews. The study revealed several issues with construct validity, mostly as a result from the tool remaining unchanged despite the emerging field of body image. The interviews revealed a high level of variability in the interpretation of most question items. The lack of context and parameters provided on what the participant should consider (e.g. whether to include impact on function, or age-related body image concerns) caused ambiguity and confusion. The tool is only able to capture negative perspectives on body image, leaving out both neutral and positive body image experiences. These findings provide insight and suggestions for an updated version of the BIS tool.

Both Chapters 2 and 3 provided recommendations for tool selection and development. Creation of new tools should consider parameters around what aspect of body image is being studied in the survey tool itself, providing context and a clear understanding for the respondent. Finally, while a survey tool will never truly capture the dynamic and complex relationship an individual has with their body image, future research in breast cancer should at least capture experiences across the continuum from positive to negative body image. A reduction in negative body image does not necessarily equate to an improvement in positive body image,[4, 38] and just because an individual went through breast cancer treatment does not mean that they have a negative body

image.[22] Therefore, future studies should select more than one body image tool to ensure a more comprehensive perspective is being captured.

5.2.3 Positive Health Interventions

Our hope for breast cancer research is that more clinical programs and research interventions take a positive health approach. Through our program combining RET with art to improve body appreciation in BCS (Chapter 4), we anecdotally noticed that some participants' attitudes towards exercise were starting to shift from exercising to improve their body appearance to exercising because they felt stronger and were pro-active in taking care of their body.

Similar to our anecdotal findings, interventions among the general population promoting positive health have been found to have a greater effect on self-care compared to those merely trying to reduce negative body image.[4] Engaging in self-care practices, such as exercising regularly, intuitive eating, and participating in stress-reduction activities (journaling, art) is a consequence of having a positive body image.[4] Individuals will invest time and energy taking care of their bodies because they respect and appreciate what their body does for them, rather than partaking in these activities in attempt to change their body.[4] The Health At Every Size (HAES) paradigm has taken this to heart, as they shift the narrative from traditional weight-centric approaches and focus the individual's attention toward healthy behaviour change, psychosocial health, and overall wellbeing.[95] In fact, the core values of the program for both health professionals and clients are to: "1. Practice weight-neutral self-care, 2. Eat intuitively, 3. Move your body joyfully, 4. Nurture self-compassion, and 5. Redefine success" (p. 171).[95] Shifting the focus away from weight loss and towards positive behaviours that take care of and respect the body may produce a more lasting positive change for the individual.[4, 95]

Our suggestion for future research within breast cancer would be to add an additional component teaching intuitive eating and education on how to select nutrient-dense foods. This addition to the program would not promote weight loss, but rather encourage BCS to take care of and respect their bodies, while providing them with the education to be able to make healthy nutritional changes. This additionally has the potential to create more opportunity for conversations around weight discrimination, as balancing weight loss prescriptions from medical professionals may cause additional body image distress.[95] By taking the focus away from weight

loss to healthy behaviours, BCS are able to redirect their attention to taking care of their body, which in turn will influence the appreciation they have for their body.

5.3 LIMITATIONS

This thesis had some limitations that need to be addressed. First, the small sample size of 13 participants is not large enough to make conclusions relative to the population of BCS. Second, all but one of the participants in this study were White. This lack of diversity biases our research to White women only, despite the need for body image research to be more intersectional and diverse.[37] Additionally, we did not control for time since diagnosis which may influence the extent and severity of breast cancer specific body image concerns among our participants. Lastly, COVID-19 affected the delivery of the intervention, as partway through the program we had to move to a virtual delivery model. As a result, several fitness tests were not able to be administered and we had to deviate from the original protocol, impacting our ability to analyze results.

5.4 CONCLUSION

This thesis provides evidence that RET and art therapy interventions are promising as interventions for improving body image in BCS separately (Chapter 2) and together (Chapter 4). However, more work is needed to find a tool that is valid, sensitive, and relevant (Chapter 3). Future research must also be mindful when selecting a body image tool to ensure that the tool matches the objectives of the study, accurately reflects the respondent's perspectives, and consider measuring neutral, positive, and negative body image perceptions.

There is evidence to support the feasibility of the combination of RET with art sculpting to promote body appreciation in BCS (Chapter 4). A larger sample size using a randomized control trial is needed to determine efficacy. Further qualitative data on the barriers and facilitators to participating in this type of program would provide insight in further developing this combined program. To conclude, a focus on promoting positive health and wellness has the potential for BCS to care for, respect, and accept their changed bodies.

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APPENDIX

Appendix A: Scoping Review Search Strategies

CINAHL

1. (MH “Breast Neoplasms) or breast cancer
2. (MH “Body Image+) or (MH “Body Image Disturbance (NANDA)” or (MH “Body Image Enhancement (Iowa NIC)”) or (MH “Body Image Disturbance (Saba CCC)”) or (MH “Body Image (Iowa NOC)”)
3. (self esteem or body image or body representation or self image) or ((perception* or thought* or attitude* or feeling* or belief*) n5 (body or bodies or appearance))
4. ((MH “Art Therapy”) or (MH “Canadian Art Therapy Association) or (MH “Art Therapy (Iowa NIC)”) or art* therap*
5. (MH "Muscle Strengthening+") OR ((Resist* exercise* or weight train* or resist* training or strength train* or weightlifting or (lift* n4 weight*) or gravity resistive or isotonic or isometric))
6. 1 AND (2 OR 3) AND (4 OR 5)

PsychInfo

1. breast neoplasms/ or neoplasms/ or mammography/ or mastectomy/

2. breast.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

3. mammary.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

4. 2 or 3

5. (cancer* or oncolog* or carcinoma* or tumor* or tumour* or neoplasm* or metasta* or malignan*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

6. 4 and 5

7. 1 or 6 [Breast cancer]

8. body image/ or body image disturbances/ or body awareness/

9. body image*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

10. self-esteem/ or self-concept/ or self-confidence/ or self-perception/

11. self esteem.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

12. ((perception* or thought* or attitude* or feeling* or belief*) adj5 (body or bodies or appearance)).mp.

13. 8 or 9 or 10 or 11 or 12 [Body image]

14. art therap*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

15. art therapy/ or creative arts therapy/

16. weightlifting/

17. (Resist* exercise* or weight train* or resist* training or strength train* or weightlifting or (lift* adj4 weight*) or gravity resistive or isotonic or isometric).mp.

18. 14 or 15 or 16 or 17 [Exercise or art therapy]

19. 7 and 13 and 18

Medline

1. breast neoplasms/ or breast carcinoma in situ/ or breast neoplasms, male/ or carcinoma, ductal, breast/ or carcinoma, lobular/ or inflammatory breast neoplasms/ or unilateral breast neoplasms/ or triple negative breast neoplasms/

2. breast.mp.

3. mammary.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

4. 2 or 3

5. (cancer* or oncolog* or carcinoma* or tumor* or tumour* or neoplasm* or metasta* or malignan*).mp.

6. 4 and 5

7. 1 or 6 [Breast Cancer]

8. Body Image/

9. Body image*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

10. Body representation*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

11. Self-image.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

12. Self-esteem.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

13. ((perception* or thought* or attitude* or feeling* or belief*) adj5 (body or bodies or appearance)).mp.

14. 8 or 9 or 10 or 11 or 12 or 13 [Body Image]

15. Art Therapy/

16. art therap*.mp.

17. Resistance Training/ or Weight Lifting/

18. (Resist* exercise* or weight train* or resist* training or strength train* or weightlifting or (lift* adj4 weight*) or gravity resistive or isotonic or isometric).mp.

19. 15 or 16 or 17 or 18 [Exercise or Art Therapy]

20. 7 and 14 and 19

Appendix B: Body Image Scale (BIS)

In this questionnaire you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week. Not at all/A little/Quite a bit/Very much

Name: _____ Date: _____

Have you been feeling self-conscious about your appearance?

Have you felt less physically attractive as a result of your disease or treatment?

Have you been dissatisfied with your appearance when dressed?

Have you been feeling less feminine/masculine as a result of your disease or treatment?

Did you find it difficult look at yourself naked?

Have you been feeling less sexually attractive as a result of your disease or treatment?

Did you avoid people because of the way you felt about your appearance?

Have you been feeling the treatment has left your body less whole?

Have you felt dissatisfied with your body?

Have you been dissatisfied with the appearance of your scar?

Appendix C: Consent Form

Informed Consent Form for Participation in a Research Study

Restoring Body Image after Breast Cancer through Exercise and Art Sculpture

"RISE UP" after Breast Cancer

A study to evaluate the benefit of a community-based resistance exercise and art sculpting class on body image perception in breast cancer survivors

Protocol ID: HREBA:CC 19-0363

Principal Investigator: Dr. Margaret McNeely, PT, PhD

Department of Physical Therapy/ Department of Oncology

University of Alberta & Cross Cancer Institute

Phone: 780-248-1531

Sponsor/Funder(s): University of Alberta

Emergency Contact Number (24 hours / 7 days a week):

Cross Cancer Institute Telephone Triage Nurse:

780-432-8919 or 1-877-707-4848 (toll free)

You are being invited to participate in a research study because you have you have indicated that you are interested in participating in a community-based exercise program as well as an art sculpting class for survivors of breast cancer. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

The study staff will tell you about timelines for making your decision. You may find it helpful to discuss the study with family and friends so that you can make the best possible decision within the given timelines.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason. Deciding not to take part or deciding to leave the study will not result in any penalty or any loss of medical or health-related benefits to which you are entitled.

The principal investigator, who is one of the researchers, or the site research coordinator will discuss this study with you and will answer any questions you may have. If you do consent to participate in this study, you will need to sign and date this consent form. You will receive a copy of the signed form.

WHAT IS THE BACKGROUND INFORMATION FOR THIS STUDY?

The growing population of breast cancer survivors in Alberta has brought attention to the long term toll of cancer and its treatment on the body, mind and overall health of survivors. Treatment for breast cancer often result in a visible change in the survivor's physical appearance, which can lead to body image concerns and distress. Exercise is an effective intervention that can optimize the health and wellbeing of cancer survivors and possibly improve body appreciation and self care. Taking part in art classes has been shown as an active way to foster healing, mental wellness, and to overcome stress. Currently standard care for women with breast cancer in Alberta is to receive counseling on the value of physical activity and healthy living after the completion of cancer treatments.

The Health Research Ethics Board of Alberta – Cancer Committee (HREBA-CC), which oversees the ethical acceptability of research involving humans, has reviewed and granted ethics approval for this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to evaluate the potential benefit of combining a community-based exercise and art sculpting program for women with breast cancer. We want to see if the combination of a physical program with an art-based program facilitates survivors to adopt an active lifestyle and promote positive health practices. We hope that our study will help inform future research about body image in breast cancer.

WHAT ARE OTHER OPTIONS IF I DECIDE NOT TO PARTICIPATE IN THIS STUDY?

You do not have to take part in this study in order to receive continued medical care. You may choose not to participate in this study. Your healthcare provider will discuss lifestyle recommendations with you. Right now, the usual treatment for survivors is to receive counseling on the value of physical activity and healthy living after the completion of cancer treatments.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 12 people in Edmonton will take part in this study.

WHAT WILL HAPPEN DURING THIS STUDY?

STUDY INTERVENTION

If you agree to take part in this study, you will undergo screening to ensure that you are safe to exercise and will do fitness testing to determine your current fitness level. You will take part in a twice weekly exercise program for a 12-week period and a once weekly art sculpting program for an 8-week period. The exercise program will be tailored to your fitness level and designed to address your personal fitness or lifestyle goals. The art sculpting program will be taught by an experienced art instructor. You will use clay for your project and all supplies needed for the class will be provided. After the intervention, you will be asked to participate in another fitness test, complete the body image questionnaires and participate in a focus group. The focus group will be an opportunity for you to provide feedback on what you liked or disliked about the program.

STUDY PROCEDURES

Established Procedures

The following established procedures will be done as part of this study. Some of these procedures may be done as part of your standard care, in which case the results may be used. Some may be done more frequently than if you were not taking part in this study. Some of these procedures may be done solely for the purpose of the study. If the results show that you are not able to continue participating in the study, the principal investigator will let you know.

- Body composition measurement: We will measure your height and body weight. As well, we will take a measurement of your waist and hip size with a tape measure. These measurements take between 2 and 3 minutes to complete.

- Musculoskeletal fitness measurement: we will measure your grip strength, measure your lower body endurance (30s Sit to Stand), core endurance (plank test) and measure your submaximal/maximal strength test for your arms (bench press) and your legs (leg press).

Questionnaires

You will be provided with a questionnaire package at the start and end of the study. The purpose of the questionnaire is to see if there is a change in body appreciation and body image concerns from before the program starts to once the program ends.

- Stage of Change (at start of study only): This questionnaire asks about your readiness to take part in exercise. This questionnaire takes 1 minute to complete.
- Physical activity level: We will ask you about your physical activity level using the Godin Exercise Leisure-time Questionnaire. This 6-item questionnaire asks specific questions about the type, intensity, frequency and duration of your average weekly physical activity. This questionnaire takes around 2-3 minutes to complete.
- Cancer-related Quality of Life: We will assess your quality of life using the Functional Assessment of Cancer Therapy-Fatigue Scale. This 39-item questionnaire asks specific questions about the impact of your cancer and cancer treatment on your physical wellbeing, social/family wellbeing, emotional wellbeing, functional wellbeing and fatigue. This questionnaire takes around 10 minutes to complete.
- Body Image Scale for Cancer (BIS): We will have you answer 10-items, where you rank 1 (not at all) to 4 (very much) on how much you relate to each statement to any body image concerns. The survey will be completed twice, once before the start of the intervention, and the second time after everything has finished. The first time you do this survey, you will complete the survey with one of the researchers, and you will be asked to think about factors that influence your answers to this survey. The second time you do the survey you will answer the questions on your own.
- Body Appreciation Scale-2 (BAS-2): This is a 10-item questionnaire, where you will be asked to rank from a scale of 1 (never) to 5 (always) how much you relate to each item related to body appreciation. You will be asked to complete this survey prior to the start of the intervention and once after the intervention is complete.

The information you provide is for research purposes only and will remain strictly confidential.

Some of the questions are personal; you may choose not to answer them.

Even though you may have provided information on a questionnaire, these responses will not be reviewed by individuals not involved in this study, e.g., your health care practitioner/team. If you would like them to know this information, please bring this to their attention.

WHAT ARE THE POTENTIAL SIDE EFFECTS FROM PARTICIPATING IN THIS STUDY?

You may experience side effects from participating in this study. Some side effects are known and are listed below, but there may be side effects that are not expected. You should discuss these with the principal investigator or research coordinator. The risks and side-effects of the standard or usual treatment will be explained to you as part of your standard care. These risks are not included in this consent form.

The main side effect from exercise testing and training is secondary muscle soreness. You may notice that your muscles are sore for a couple of days after the testing session and during the first week or so of the exercise program. We expect that these symptoms will get better as you get used to the exercise. As well, the exercise program will be personalized to you to minimize excessive soreness and modified as needed if you experience any excessive muscle soreness or fatigue from your exercise sessions.

It is important that you know and understand the possible risks of the treatments given in this study. The main risk associated with exercise is musculoskeletal injury (injury to the muscles, tendons, joints or bones). Your exercise sessions will be supervised and your program designed to minimize this risk by slowly increasing the amount and intensity of your exercise over time.

There is also a very small risk of heart issues (such as chest pain, irregular heart rate, heart attack) should you exercise too intensively. To avoid any risks associated with exercise, you will be screened to ensure it is safe and appropriate for you to take part in the exercise program. All exercise will be of a moderate intensity level to minimize the stress on the heart and body, while still challenging enough to improve your physical fitness. As well, we will monitor your vital signs (e.g., heart rate, blood pressure) during the exercise testing and if needed, when you exercise. If any concerns are identified at any time, you will be referred back to your doctor for further evaluation. If any issues develop during the study period, your exercise sessions may be held or discontinued.

A second risk may be that you become more aware and stressed about your body image concerns related to your breast cancer. This will be mitigated by having a psychologist attend the art

classes to help guide group sessions in a positive and meaningful direction. If concerns are identified beyond the scope of this intervention, we will inform your doctor or healthcare professional.

If you have any side effects, you should call the principal investigator or study coordinator in charge of the study. The telephone numbers are on the last page of this form.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you. Possible benefits include improved physical fitness, better energy, and a more positive body image.

WHAT ARE MY RESPONSIBILITIES AS A STUDY PARTICIPANT?

If you choose to participate in this study, you will be expected to:

- Tell the study research coordinator about your current medical conditions;
- Tell the study research coordinator about all prescription and non-prescription medications and supplements, including vitamins and herbals, that you may be taking and check with the research coordinator before starting, stopping or changing any of these. This is for your safety as these may interact with the intervention you receive on this study;
- Tell the study research coordinator if you are thinking about participating in another research study;
- Attend all scheduled study visits, undergo all of the procedures described above and complete the questionnaires;
- Inform the study research coordinator of any injuries, side effects or health problems that you may be experiencing.

HOW LONG WILL I BE PARTICIPATING IN THIS STUDY?

The study exercise program will last for about 12 weeks. You will be asked to complete a second fitness assessment at 12-weeks. Each testing session will take around an hour and a half (90 minutes) to complete. As stated above, you will be invited to attend a focus group session to allow us to hear about your experience with the program.

WILL THERE BE ANY LONG-TERM FOLLOW-UP INVOLVED WITH THIS STUDY?

You give permission to the study research coordinator or member of the study team to attempt to obtain study-related information about your health status to further evaluate the safety or efficacy of the community-based cancer exercise program. This may include contacting your care physician, or by contacting you by phone or letter (i.e., future contact).

☐ Yes ☐ No Participant's Initials: _____

Name/phone number of care physician: _____

CAN I CHOOSE TO LEAVE THIS STUDY EARLY?

You can choose to end your participation in this research (called early withdrawal) at any time without having to provide a reason. If you choose to withdraw early from the study without finishing the intervention, procedure or follow-up, you are encouraged to contact the principal investigator or research coordinator. If you decide to stop participating in the study, we encourage you to talk to your doctor first. You may be asked questions about your experience with the study intervention.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the research coordinator know. However, this would also mean that you withdraw from the study. Information that was recorded before you withdrew will be used by the researchers for the purposes of the study, but no additional information will be collected or sent to the sponsor after you withdraw your permission.

CAN MY PARTICIPATION IN THIS STUDY END EARLY?

In discussion with you, your doctor , either at his/her own initiative or at the request of the sponsor of this study, may withdraw you from the study at any time if it is in your best

interests.The principal investigator may stop your participation in the study early, and without your consent, for reasons such as:

- You are unable to tolerate the exercise or sculpting class.
- You sustain an injury as a result of participation.
- You experience an adverse effect during or after the combined program.
- Your doctor no longer feels this is the best treatment for you.
- The sponsor decides to stop the study.

If this happens, it may mean that you would not receive the study intervention for the full period described in this consent form. If you are removed from the study, the principal investigator will discuss the reasons with you and plans will be made for your continued care outside of the study.

HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the principal investigator and study staff will only collect the information they need for this study.

Records identifying you, including information collected from your medical files/records, such as your Electronic Medical Records (EMR), Netcare, charts, etc., will be kept confidential to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your identifiable medical/clinical study records at the site where these records are held for quality assurance purposes and/or to verify that the information collected for the study is correct and follows proper laws and guidelines:

- The Health Research Ethics Board of Alberta – Cancer Committee, which oversees the ethical conduct of this study.
- Members of the Regulatory/Audit team at the Cross Cancer Institute, for quality assurance purposes.

Authorized representatives of the above organizations may **receive** information related to the study from your medical/clinical study records that will be kept confidential in a secure location

and may be used in current or future relevant health research. Your name or other information that may identify you will not be provided (i.e., the information will be de-identified). The records received by these organizations will be coded with a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with your study and will not be released. To protect your identity, the information that will be on your assessment forms and questionnaires will be limited to your study ID and initials.

Any disclosure of your identifiable health information will be done in accordance with federal and provincial laws including the Alberta Health Information Act (HIA). The organizations listed above are required to have organizational policies and procedures to protect the information they see or receive about you, except where disclosure may be required by law. The principal investigator will ensure that any personal health information collected for this study is kept in a secure and confidential AHS facility as also required by law.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during the study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential. It is expected that the study results will be published as soon as possible after completion. This information may also be used as part of a submission to regulatory authorities around the world to support the approval of this intervention.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. Every effort will be made to keep your identifiable information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information.

Data collected will be entered into the secure RedCap server held at the University of Alberta and data will only be used for research purposes.

Studies involving humans sometimes collect information on race and ethnicity as well as other characteristics of individuals because these characteristics may influence how people respond to different interventions. Providing information on your race or ethnic origin is voluntary.

WILL MY HEALTHCARE PROVIDER(S) BE INFORMED OF MY PARTICIPATION IN THIS STUDY?

Your family doctor/health care provider may be informed that you are taking part in a study so that you can be provided with appropriate medical care. If you do not want your family doctor/health care provider to be informed, please discuss with your study team to find out your options.

WILL THERE BE ANY COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

You will not have to pay for the exercise or art program you receive in this study. Costs associated with attending the 12-week exercise and 8-week art scultping program in the community will be covered. There may be additional costs to you for taking part in this study such as:

- Transportation.
- Meals.
- Babysitting, etc.

Possible Costs After the Study is Complete

You may not be able to receive the study intervention after your participation in the study is completed. There are several possible reasons for this, some of which are:

- Your caregivers may not feel it is the best option for you;
- You may decide it is too expensive and insurance coverage may not be available;
- The intervention may not be available free of charge.

The principal investigator will discuss these options with you.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study. However in the case of research-related side effects or injury, as a direct result of participating in this research, you will receive all medical treatments or services recommended by your doctors.

Although no funds have been set aside to compensate you in the event of injury or illness related to the study treatment or procedures, you do not give up any of your legal rights for compensation by signing this form.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of these results, please contact the principal investigator.

The results of this study will be available on a clinical registry; refer to the section titled "Where can I find online information about this study?". Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the hospital, investigators, sponsor, involved institutions for compensation or their agents, nor does this form relieve these parties from their legal and professional responsibilities.

IS THERE CONFLICT OF INTEREST RELATED TO THIS STUDY?

There are no conflicts of interest declared between the principal investigator and sponsor of this study.

WHAT IF RESEARCHERS DISCOVER SOMETHING ABOUT ME AS A RESEARCH PARTICIPANT?

During the study, the researchers may learn something about you that they didn't expect. For example, the researchers may find out that you have another medical condition.

If any clinically important information about your health is obtained as a result of your participation in this study, you will be given the opportunity at that time to decide whether you wish to be made aware of that information.

WHERE CAN I FIND ONLINE INFORMATION ABOUT THIS STUDY?

A description of this clinical trial will be available on http://www.clinicaltrials.gov, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

The study registration number to use this website is: NCT04088877

WHO DO I CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, or if you suffer a research-related injury, you should talk to the project coordinatior or principal investigator. These person(s) are :

Dr. Margaret McNeely, PT,PhD	780-432-8716 or 780-248-1531
Principal Investigator	Telephone

Corrie Effa BScKin, CSEP-CEP, BScKin	780-492-6007
Study Coordinator	Telephone

Dr. Margaret McNeely can also be paged through the Cross Cancer Institute Switchboard at 780-432-8771

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta – Cancer Committee at:

Telephone: 780-423-5727	Toll Free: 1-877-423-5727

SIGNATURES

Part 1 - to be completed by the potential participant.

	Yes	No
Do you understand that you have been asked to take part in a research study?	☐	☐
Do you understand why this study is being done?	☐	☐
Do you understand the potential benefits of taking part in this study?	☐	☐
Do you understand the risks of taking part in this study?	☐	☐
Do you understand what you will be asked to do should you decide to take part in this study?	☐	☐
Do you understand the alternatives to participating in this study?	☐	☐
Do you understand that you are free to leave the study at any time, without out having to give reason and without affecting your future health care?	☐	☐
Do you understand who will see your records, including health information that identifies you?	☐	☐
Do you understand that by signing this consent form you are giving us permission to access your health information if applicable?	☐	☐
Do you understand that by signing this consent form that you do not give up any of your legal rights?		

☐ ☐

Have you had enough opportunity to ask questions and discuss this study? ☐ ☐

By signing this form I agree, or *allow the person I am responsible for*, to participate in this study.

Signature of Participant */Substitute Decision-Maker*	PRINTED NAME	Date

(As a Substitute Decision-Maker, you are being asked to provide informed consent on behalf of a person who is unable to provide consent for him/herself. If the participant gains the capacity to consent for him/herself, your consent for them will end.)

Part 2 - to be completed by the principal investigator or designee who conducted the informed consent discussion. Only compete this section if the potential participant has **agreed** to participate.

I believe that the person signing this form understands what is involved in the study and has freely decided to participate.

Signature of Person Conducting the Consent Discussion	PRINTED NAME	Date

Part 3 - to be completed only if the participant is unable to read or requires assistance of an oral translator/interpreter.

- The informed consent form was accurately explained to, and apparently understood by the participant*/substitute decision maker.*
- Informed consent was freely given by *or on behalf of* the participant.

Signature of Impartial Witness/Interpreter	PRINTED NAME	Date

You will be given a copy of this signed and dated consent form prior to participating in this study.

Appendix D: Cognitive Interview Probing Questions

A. Comprehension:

1. Can you explain/repeat the question in your own words?

2. Can you tell me what does this word (term) means to you?

3. Can you tell me what the question is asking you?

B. Retrieval:

1. *Can you tell me what you were thinking about when you answered this question?*

2. Can you give me an example?

3. *What time period were you thinking about?*

C. Judgement:

1. How sure are you of your answer?

D. Response:

1. How easy or hard was it to find your answer on that list? Can you tell me why?

2. How did you feel about answering that question?

Appendix E: Ethics Approval

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

Certification of Ethics Approval

This is to acknowledge that the following research has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC) I am granting approval for your site's participation in the research.

Ethics ID:	HREBA.CC-19-0363
Principal Investigator:	Margaret McNeely
Co-Investigator(s):	Karen King Jill Turner
Student Co-Investigator(s):	Corrie Effa
Study Title:	Restoring Body Image after Breast Cancer through Exercise and Art Sculpture "RISE UP" after Breast Cancer: A Pilot Multi-Methods Study
Sponsor:	University of Alberta

Effective: 3-Oct-2019 **Expires:** 2-Oct-2020

Research reviewed by delegated review on 03 October 2019.

The following documents have been approved:

- RISE UP after Breast Cancer Consent Form, Accepted Changes, September 19, 2019
- Exercise Preference Questionnaire, September 10, 2019
- Body Image Scale for Cancer, September 10, 2019
- Medical Variables Baseline, September 10, 2019
- Demographics Baseline, September 10, 2019
- PA Stages of Change Baseline, September 10, 2019
- Godin Leisure Time Questionnaire, September 10, 2019
- Body Appreciation Scale 2 Questionnaire , September 10, 2019
- FACIT-F, September 10, 2019
- PAR Q+ 2019 Baseline (Exercise Clearance) , September 10, 2019
- Study Protocol, September 12, 2019, September 12, 2019
- Fitness Testing Protocols, September 12, 2019, September 12, 2019
- Study budget, September 16, 2019, September 16, 2019
- Supervisory Committee Approval, July 5, 2019, September 12, 2019

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's *Food and Drug Regulations* (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

The committee has determined that consent must be obtained from participants for the disclosure of this information.

As a requirement of the HIA, if your study uses health information a copy of this certification will be sent to the Office of the Information and Privacy Commissioner (OIPC).

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

This approval is subject to the following conditions:

1. It is being granted only for the research described in this application.
2. Any modification to the approved research must be submitted to the Committee for approval prior to implementation.
3. Reportable events (SAE's, new safety information, protocol deviations, audit findings, privacy breaches, and participant complaints) are to be submitted in accordance with the Committee's reporting requirements.
4. A request to renew this ethics certification must be submitted and reviewed by the Committee in advance of the expiry date indicated above. Failure to submit a request will result in the file entering into an expired state, whereby all research must cease.

5. A closure request must be submitted to the Committee when the research is complete or has been terminated.

This approval does not guarantee that you will be able to access health records for research purposes. Other institutional or organizational requirements may be in place that you will be required to meet prior to initiating your research. These include approvals for the allocation of resources in support of your study. Inquiries regarding these additional approvals should be directed to the appropriate institutional or organizational body.

Please accept the Committee's best wishes for success in your research.

Approved on behalf of CC by,	**Date:**
Jackson Wu , HREBA-CC	7-Oct-2019

Appendix F: Supplemental Material

Researchers' Perspectives

As a research team we collectively come to this research through an interpretivist lens. Within this perspective, human behaviour and attitudes are formed in the social world, which is impacted by many social and cultural constructs such as ethnicity, gender, sexuality, and social class.[1] As such, the diverse backgrounds and experience an individual has, shapes their interpretation and meaning of the world.[1] As such, an individual's interpretation of a survey question is never wrong and provides insight and meaning to the question asked.[2]

Supplementary Methods:

Quality Criteria:

Quality criteria of trustworthiness and rigor were attended to throughout the entirety of the project through a variety of ways. The probing questions were trialed through a practice interview, where each probe was asked for each question item and adjustments for clarity were made accordingly.[3] In alignment with the suggestion that the interviewer must be experienced in the field and have strong interpersonal skills,[4] our team had two rehabilitation professionals with significant clinical and research experience in the field of breast cancer, administer the interviews. The data analysis was done by two individuals on the team and a clear audit trail was generated, as all coded sheets and extracted documents were kept. The first author additionally analyzed how her subjective and intersubjective experiences affected the overall research by keeping a reflexive journal throughout the entire process,[5, 6] When writing the report, the research team presented the results in sufficient detail by embedding participants' quotes to ensure that readers had enough details to draw their own postulations about the topic.[2, 7]

Supplementary Results:

Comprehension-Conceptual Variability

Participants not only struggled defining terms, but also found the broad nature of the questions confusing. For instance, *Alix* asked at the start of the interview, "are you talking, like, overall appearance?" demonstrating that she was unsure if she should be just reflecting on her appearance-related changes to breast cancer treatment, or other changes, such as aging. To add to the confusion,

some participants were unsure if they should interpret the question to be about appearance-related change only, or whether they should incorporate functional changes. This confusion was most apparent in items eight and nine. For example, *Sophia* asked, "I don't know if I should be focusing on just the appearance of it, or the function of it". The lack of parameters to the question made *Sophia* second guess how to go about answering the question.

Comprehension-Leading Questions

Focusing in on the terminology chosen for the question items had some participants feeling frustrated, as they found items to have both negative and judgmental associations. The words "dissatisfied" and "sexually attractive" were a few examples of words participants struggled with. When asked about feeling dissatisfied with what treatment has done to her body (item nine), *Sophia* stated, "I feel like to say that I am dissatisfied with my body is almost like saying like my body didn't do a good enough job of the treatment." *Krista* suggested replacing the word "dissatisfied" with "difficult", as the latter may come across as being less judgmental and negative.

Retrieval-Diverse Body Image Experiences

Coupled with changes in physical appearance, changes in function were mentioned at least once in more than half of the questions (items one, two, six, eight, nine, and ten). Some participants, like *Alix*, explicitly stated these functional changes bothered her most. For example, *Alix* responded to item eight asking about whether the treatment had left her feeling less whole by exclaiming, "not because of physical appearance, but more because of my flexibility in my shoulders especially." While the functional changes seemed to have had the greatest effect on some participants' body image perspectives, it is important to note that others explicitly left out functional examples as they understood the questions to be about physical changes only.

Retrieval-Emotional Response

As many participants expressed gratitude and positive coping strategies to deal with the emotional changes, some also expressed neutral feelings about the body changes they had experienced. Most of these examples were from participants who felt not much had changed since their diagnosis and treatment. For example, *Mary* expressed neutral feelings because she did not experience a drastic change to her body and subsequently admitted, "I don't think it was that difficult of a change." In

brief, the participants who perceived the changes to be minimal, experienced less emotional stress, taking on a positive or neutral attitude toward their body image.

On the other hand, participants who perceived the changes to be significant, spoke frequently about the emotional implications and frustrations they experienced. These examples often emphasized how the physical changes made them feel, rather than the change itself. For example, two younger women in the study talked about how the hormone treatments put them into early onset menopause, which affected their attitude towards themselves. *Sophia* disclosed, "I like getting my period because it makes me feel like a young, healthy woman" and *Natalie* stated, "I went into early menopause so that was kind of strange and I think I felt less feminine because of it." In both examples, *Sophia* and *Natalie* emphasized how going into early onset menopause challenged their identity as healthy and feminine, respectively.

Judgement-Certainty

The majority of participants demonstrated confidence that they chose the answer that best fit their personal experience. This was observed as participants responded to the probe "how sure are you of your answer?" with "very sure," "I'm absolutely sure," "pretty sure," and similar responses. Some participants seemed uncertain at first, as they switched their answer on more than one occasion. However, over time, the participants who initially appeared uncertain talked themselves into being confident in their answer. Upon reflection, it could be the think aloud process may have influenced this evaluation of certainty, as a participant would be unlikely to spend as much time evaluating question certainty when filling out the survey tool alone. Which also indicates the value of the cognitive interview process in ensuring questions are indeed accessing the information researchers intend to measure.

Response-Questioning Relevance

In response to item four which asked "if you feel less feminine/masculine as a result of the disease or treatment," *Krista* said, "I mean I see feminine/masculine as a dichotomy somewhere on a spectrum but I don't feel like I'm on, but I know I am more female and relate to that more." To summarize, this item dichotomized gender, restricting *Krista* to associate herself with feeling either masculine or

feminine, and challenged her ability to relate to the question. This also reflects the lack of identity consideration in the development of the questionnaire.

Similarly, *Natalie* struggled with item five as the question asked whether she found it difficult to look at herself naked. She was unable to relate to the question, as she said, "I never look at myself naked", providing a challenge for her to answer the question when she never participated in the behaviour in the first place.

Finally, several participants struggled with item 10, as they were more concerned with having a scar than focusing on the appearance of their scar. *Sophia* summarized this thought as she said, "I'm not dissatisfied with the appearance of my scar, um, like from a surgical skill and outcome perspective … But I don't like having it, I don't like want anyone to kind of know that it's there and I don't want like people seeing it." To her, the more relevant question was discussing her attitude towards having a scar, rather than what it looked like.

Response-Accessibility

There were a variety of reasons why some participants deemed the questions difficult to answer. We categorized these reasons as unable to answer the question due to lack of relevance, wishing there was a "somewhat" option to choose from, struggling to select an answer that summarized their experience over the past week, and struggling to match experience on the scale provided. Some participants said the answer was easy, as *Alix's* reason was because "there is only four choices," and *Erin* agreed stating, "just again the layout of it it's just right there". While feeling positive was why *Laurie* found the question easy. She said, "Um the answer was fairly easy because I feel good. I feel good about who I am right now."

While some participants struggled selecting an answer, others had a difficult time answering the question, as their responses were dependent on circumstance, location, and time. For instance, *Laurie* expressed her discomfort in needing to wear a dress for a special occasion, and that she was unable to wear the dress she wanted. Upon reflecting, *Laurie* said, "if I didn't have to do something it probably would have been different." Here, she was implying that normally she does not feel self conscious of her appearance when dressed. However, in circumstances where she needed to dress up, or was required to wear a dress, she felt more self conscious.

Aside from how hard or easy it was for participants to answer a question, it is important to mention that the only way for participants to express positive change on a particular question was to select "not at all." For example, *Sandra* responded to item seven, which asked if participants avoid people as a result of their disease or treatment, by exclaiming, "I love, I see more people now than I did before actually." Her change in seeing more people since her breast cancer diagnosis was not able to be represented fully by just selecting the "not at all" option, as that option also incapsulated individuals who had experienced no change in how many people they socially engaged with. To illustrate, *Susan* also selected "not at all", as she had "…never had a problem" being around others. Regardless of whether these questions felt accessible to the participant, these are two very different answers grouped into the same category.

Response – Sensitivity

A couple of participants responded positively to how the questions made them feel. For example, *Sandra* thought that item 10 was a good question to ask. She said, "You should be asked about it and talking about it takes it out of the secret part of it." This positive sentiment stemmed from being invited to talk about a topic that is often considered taboo.

While there were a few quotes expressing positivity towards the questions, a few participants experienced a neutral attitude. Quotes such as *Amy's,* "Oh fine", *Yvonne's* "No big deal", and *Natalie's* "I'm okay to answer it" were categorized into neutral feelings about answering question items one, two, and three, respectively. These neutral responses were more common at the start of the survey, with more adverse reactions in the second half of the survey.

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2. Willis G. *Analysis of the Cognitive Interview in Questionnaire Design*. Oxford University Press, 2015.
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4. Spencer NLI, Bouffard M and Watkinson EJ. Cognitive interviews with children as a research tool for instrument validation in adapted physical activity. *European Journal of Adapted Physical Activity* 2020; 13: 1-16.
5. Nowell LS, Norris JM, White DE, et al. Thematic Analysis. *International Journal of Qualitative Methods* 2017; 16: 1-13.

6. Finlay L. “Outing” the Researcher: The Provenance, Process, and Practice of Reflexivity. *Qualitative Health Research* 2002; 12: 531-545.
7. Tracy SJ. Qualitative Quality: Eight “Big-Tent” Criteria for Excellent Qualitative Research. *Qualitative Inquiry* 2010; 16: 837-851.

Appendix G: Eligibility Screening and Enrolment

Please complete the survey below.

Thank you!

Inclusion Criteria	
1. Woman 18 years or older * must provide value	1 ◉ Yes ○ No
2. Diagnosed with breast cancer (stages 1-3) * must provide value	1 ◉ Yes ○ No
3. Identify issues with body image on the ACE intake form (Winter, Spring or Fall 2019) * must provide value	1 ◉ Yes ○ No
4. Cleared by the exercise physiologist for unrestricted physical activity as per the PAR-Q+ * must provide value	1 ◉ Yes ○ No
5. Has completed cancer treatments (do not include hormone therapy) * must provide value	1 ◉ Yes ○ No
7. Is able to commit to a 12 week exercise and art program * must provide value	1 ◉ Yes ○ No
Exclusion Criteria	
1. Present with active cancer or metastatic disease * must provide value	0 ○ Yes ◉ No
2. Serious or uncontrolled co-morbid disease or injury that would be deemed unsafe to exercise (e.g. Uncontrolled diabetes, heart failure) * must provide value	0 ○ Yes ◉ No

3. Has undergone breast reconstruction surgery * must provide value	0	Yes ○ No ●
4. Indicate no concerns with body image * must provide value	0	Yes ○ No ●
5. Inability to provide consent * must provide value	0	Yes ○ No ●
6. Inability to commit to, and/or comply with the intervention due to personal reasons (e.g. vacation planned during the intervention period) * must provide value	0	Yes ○ No ●
Final Eligibility		
Did the participant meet the eligibility requirements for this study? * must provide value	1	Yes ● No ○
	Submit	

Appendix H: Program Intake Questionnaire

Confidential

Program Intake Questionnaire

Please complete the survey below.

Thank you!

IMPORTANT NOTE:
Please complete this entire form and hit "Submit" prior to leaving the form.
If you are not able to complete the entire form all at once, please hit "Save & Return Later" prior to leaving the form.
Doing the above will ensure the security of your information.

Cancer Diagnosis and Treatment

On which side of your body was your breast cancer found?	○ Right ○ Left ○ Both sides (Bilatertal)
Do you have any issues in the arm or shoulder on the side(s) of your breast cancer? (e.g. pain, reduced range of motion, swelling,...)	○ Yes ○ No
Please describe the issue(s) that you are having on the side(s) of your breast cancer:	_____
Are you currently receiving treatment for your cancer?	○ Yes ○ No
Which treatment(s) are you CURRENTLY receiving? Please check all that apply.	☐ Chemotherapy ☐ Radiation ☐ Hormone Therapy ☐ Biological Therapy ☐ Other
Please indicate the treatment that you are currently receiving.	_____
Do you have any complications or issues related to your current treatment(s) that may interfere with your ability to complete an exercise program?	○ Yes ○ No
Please let us know how the complication(s) or issue(s) may interfere with your ability to exercise.	_____
What treatment(s) have you COMPLETED for your cancer? Please check all that apply.	☐ Surgery ☐ Chemotherapy ☐ Radiation ☐ Hormone Therapy ☐ Biological Therapy ☐ Other

Please indicate the treatment that you received.

_____

When did you complete your cancer treatment(s)?

_____
(mm-yyyy)

Do you currently have any ongoing issues from your cancer and/or its treatments that may interfere with your ability to participate in an exercise program?

- ○ Yes
- ○ No

Please let us know how this issue(s) may interfere with your ability to exercise.

_____

Exercise has the potential to positively impact a number of the side effects from cancer and its treatments that are commonly experienced by cancer survivors.

Please select any of the listed side effects or issues that you are experiencing as a direct result of your cancer and/or its treatments.

With this information, it may be possible for ACE staff to modify your ACE exercise program to better match your specific issue(s) and potentially help you to get more out of participating in the study.

- ☐ Fatigue
- ☐ Pain
- ☐ Lymphedema (swelling)
- ☐ Peripheral neuropathy (tingling, numbness) or other nerve damage
- ☐ Osteoporosis or bone loss
- ☐ Muscle or joint issues (e.g. loss of mass, reduced range of motion, pain, stiffness,...)
- ☐ Cognitive challenges (learning or memory problems, chemo brain, brain fog)
- ☐ Weight maintenance issues
- ☐ Breathing issues
- ☐ Heart issues
- ☐ Other issue(s) or concern(s) that you feel exercise might specifically benefit for you

Please provide more detail regarding the fatigue you indicated above, including:
- severity of the fatigue
- things that make your fatigue better or worse
- how your fatigue might interfere with your ability to exercise

_____

Please provide more detail regarding the pain you indicated above, including:
- location in the body
- cause if known
- current management
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the lymphedema/swelling you indicated above, including:
- location in the body
- cause if known
- current management
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the peripheral neuropathy or nerve damage you indicated above, including:
- location in the body
- cause if known
- current management
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the osteoporosis or bone loss you indicated above, including:
- location in the body
- severity of bone loss
- current management
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the muscle or joint issue you indicated above, including:
- location in the body
- cause if known
- current management
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the cognitive challenge you indicated above, including:
- the specific issue you are having
- current management strategies
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the breathing issue you indicated above, including:
- the specific issue you are having
- current management
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the heart issue you indicated above, including:
- the specific issue you are having
- current management
- how it might interfere with your ability to exercise

_____

Please provide more detail regarding the other issue or concern you indicated above, including:
- the specific issue or concern you have
- current management strategies
- how it might interfere with your ability to participate in the ACE exercise program

_____

Appendix I: Contact Information

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Contact information

Record ID	_____
Name	_____
Initial	_____
Preferred Name	_____
Contact Information	
Home Phone	_____
Cell	_____
Business	_____
Email	_____
Other	_____
Preferred method of contact	_____
Best time to reach you	_____
Health Contact Information	
Alberta Health Care Number	_____
Alberta Cancer ID	_____

Emergency Contact	
Name of Emergency Contact	_____
Relationship	_____
Phone Number	_____

Appendix J: Demographic Variables

BASELINE DEMOGRAPHIC VARIABLES

Study ID: _____ Initials: _____ Date: _____

1. Date of Birth: ___ _____ _____ Age: _____

Day Month Year

2. Marital Status: Never Married _____ Married _____ Common Law _____

Separated _____ Widowed _____ Divorced_____

3. Education (check highest level attained):

Some High School _____ Completed High School _____

Some University/College _____ Completed University/College _____

Some Graduate School _____ Completed Graduate School _____

4. Annual Family Income: < 20,000 _____ 20-39,999 _____ 40-59,999 _____

60-79,999 _____ 80-99,999 _____ > 100,000 _____

5. Current Employment Status: Disability _____ Retired _____ Part Time _____

Homemaker _____ Full Time _____ Temporarily Unemployed _____

6. Location of residence/ home? _____

7. Ethnic origin or ancestry? _____ (or underline all that apply)

- British, Western European, Eastern European, French, Northern European, Southern European, Aboriginal, East and Southeast Asian, Southern Asian, Western Asian, Pacific Islands, Arab, Latin/Central and South American, Caribbean, African, Other)

8. Smoking status:

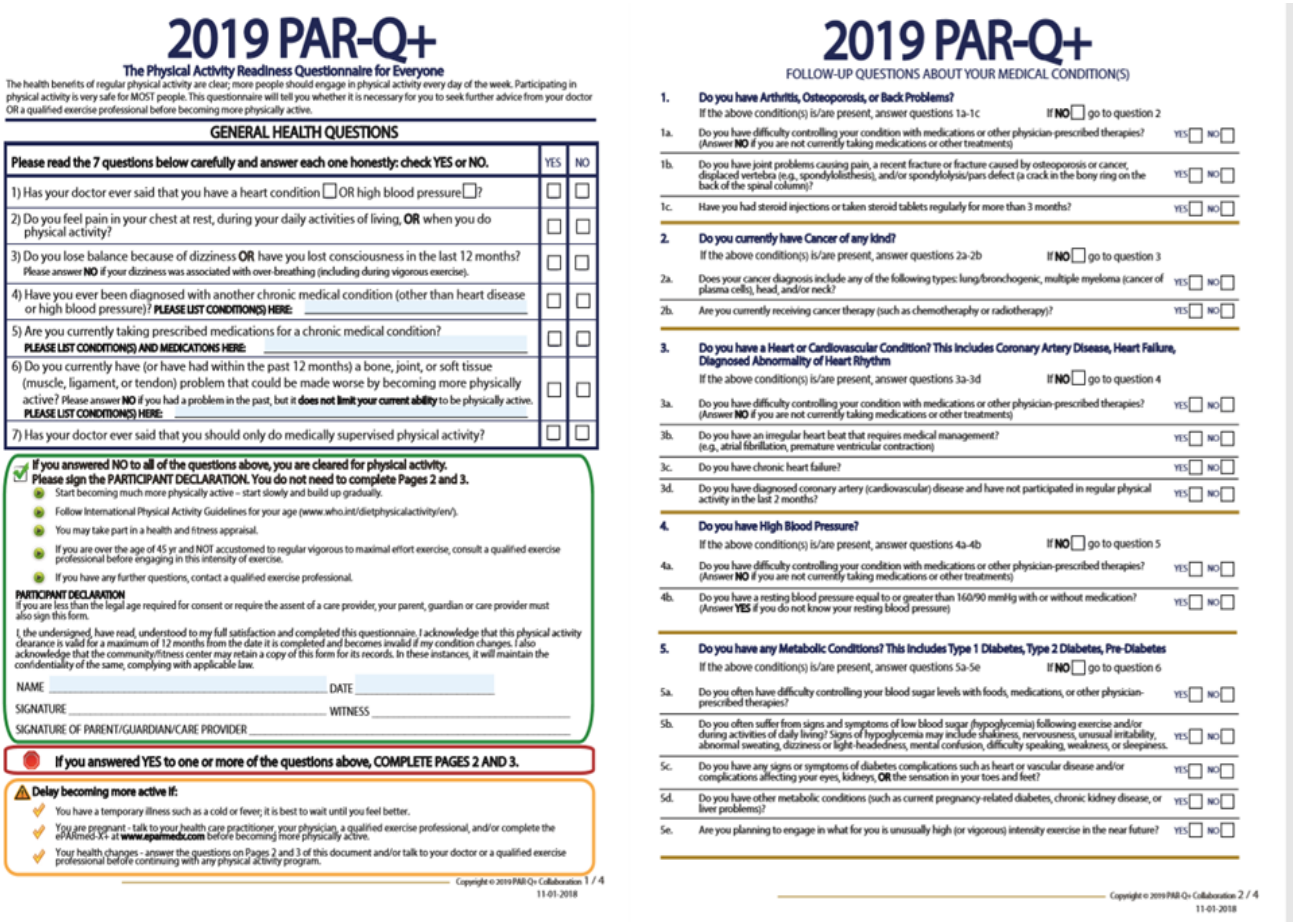
____ Never Smoked ____ Ex-Smoker ____ Occasional Smoker

____ Regular Smoker (smoke every day)

9. Drinking status:

____ Never Drank ____ Ex-Drinker ____ Social Drinker ____ Regular Drinker (drink every day)

Appendix K: Par Q+



2019 PAR-Q+

The Physical Activity Readiness Questionnaire for Everyone

The health benefits of regular physical activity are clear; more people should engage in physical activity every day of the week. Participating in physical activity is very safe for MOST people. This questionnaire will tell you whether it is necessary for you to seek further advice from your doctor OR a qualified exercise professional before becoming more physically active.

GENERAL HEALTH QUESTIONS

Please read the 7 questions below carefully and answer each one honestly: check YES or NO.	YES	NO
1) Has your doctor ever said that you have a heart condition ☐ OR high blood pressure ☐?	☐	☐
2) Do you feel pain in your chest at rest, during your daily activities of living, **OR** when you do physical activity?	☐	☐
3) Do you lose balance because of dizziness **OR** have you lost consciousness in the last 12 months? Please answer **NO** if your dizziness was associated with over-breathing (including during vigorous exercise).	☐	☐
4) Have you ever been diagnosed with another chronic medical condition (other than heart disease or high blood pressure)? **PLEASE LIST CONDITION(S) HERE:**	☐	☐
5) Are you currently taking prescribed medications for a chronic medical condition? **PLEASE LIST CONDITION(S) AND MEDICATIONS HERE:**	☐	☐
6) Do you currently have (or have had within the past 12 months) a bone, joint, or soft tissue (muscle, ligament, or tendon) problem that could be made worse by becoming more physically active? Please answer **NO** if you had a problem in the past, but it **does not limit your current ability** to be physically active. **PLEASE LIST CONDITION(S) HERE:**	☐	☐
7) Has your doctor ever said that you should only do medically supervised physical activity?	☐	☐

If you answered NO to all of the questions above, you are cleared for physical activity.
Please sign the PARTICIPANT DECLARATION. You do not need to complete Pages 2 and 3.

- Start becoming much more physically active – start slowly and build up gradually.
- Follow International Physical Activity Guidelines for your age (www.who.int/dietphysicalactivity/en/).
- You may take part in a health and fitness appraisal.
- If you are over the age of 45 yr and NOT accustomed to regular vigorous to maximal effort exercise, consult a qualified exercise professional before engaging in this intensity of exercise.
- If you have any further questions, contact a qualified exercise professional.

PARTICIPANT DECLARATION

If you are less than the legal age required for consent or require the assent of a care provider, your parent, guardian or care provider must also sign this form.

I, the undersigned, have read, understood to my full satisfaction and completed this questionnaire. I acknowledge that this physical activity clearance is valid for a maximum of 12 months from the date it is completed and becomes invalid if my condition changes. I also acknowledge that the community/fitness center may retain a copy of this form for its records. In these instances, it will maintain the confidentiality of the same, complying with applicable law.

NAME _____ DATE _____

SIGNATURE _____ WITNESS _____

SIGNATURE OF PARENT/GUARDIAN/CARE PROVIDER _____

If you answered YES to one or more of the questions above, COMPLETE PAGES 2 AND 3.

Delay becoming more active if:

- You have a temporary illness such as a cold or fever; it is best to wait until you feel better.
- You are pregnant - talk to your health care practitioner, your physician, a qualified exercise professional, and/or complete the ePARmed-X+ at **www.eparmedx.com** before becoming more physically active.
- Your health changes - answer the questions on Pages 2 and 3 of this document and/or talk to your doctor or a qualified exercise professional before continuing with any physical activity program.

11-01-2018

2019 PAR-Q+

FOLLOW-UP QUESTIONS ABOUT YOUR MEDICAL CONDITION(S)

1. Do you have Arthritis, Osteoporosis, or Back Problems?
If the above condition(s) is/are present, answer questions 1a-1c If **NO** ☐ go to question 2

1a. Do you have difficulty controlling your condition with medications or other physician-prescribed therapies? (Answer **NO** if you are not currently taking medications or other treatments) YES ☐ NO ☐

1b. Do you have joint problems causing pain, a recent fracture or fracture caused by osteoporosis or cancer, displaced vertebra (e.g., spondylolisthesis), and/or spondylolysis/pars defect (a crack in the bony ring on the back of the spinal column)? YES ☐ NO ☐

1c. Have you had steroid injections or taken steroid tablets regularly for more than 3 months? YES ☐ NO ☐

2. Do you currently have Cancer of any kind?
If the above condition(s) is/are present, answer questions 2a-2b If **NO** ☐ go to question 3

2a. Does your cancer diagnosis include any of the following types: lung/bronchogenic, multiple myeloma (cancer of plasma cells), head, and/or neck? YES ☐ NO ☐

2b. Are you currently receiving cancer therapy (such as chemotherapy or radiotherapy)? YES ☐ NO ☐

3. Do you have a Heart or Cardiovascular Condition? This includes Coronary Artery Disease, Heart Failure, Diagnosed Abnormality of Heart Rhythm
If the above condition(s) is/are present, answer questions 3a-3d If **NO** ☐ go to question 4

3a. Do you have difficulty controlling your condition with medications or other physician-prescribed therapies? (Answer **NO** if you are not currently taking medications or other treatments) YES ☐ NO ☐

3b. Do you have an irregular heart beat that requires medical management? (e.g., atrial fibrillation, premature ventricular contraction) YES ☐ NO ☐

3c. Do you have chronic heart failure? YES ☐ NO ☐

3d. Do you have diagnosed coronary artery (cardiovascular) disease and have not participated in regular physical activity in the last 2 months? YES ☐ NO ☐

4. Do you have High Blood Pressure?
If the above condition(s) is/are present, answer questions 4a-4b If **NO** ☐ go to question 5

4a. Do you have difficulty controlling your condition with medications or other physician-prescribed therapies? (Answer **NO** if you are not currently taking medications or other treatments) YES ☐ NO ☐

4b. Do you have a resting blood pressure equal to or greater than 160/90 mmHg with or without medication? (Answer **YES** if you do not know your resting blood pressure) YES ☐ NO ☐

5. Do you have any Metabolic Conditions? This includes Type 1 Diabetes, Type 2 Diabetes, Pre-Diabetes
If the above condition(s) is/are present, answer questions 5a-5e If **NO** ☐ go to question 6

5a. Do you often have difficulty controlling your blood sugar levels with foods, medications, or other physician-prescribed therapies? YES ☐ NO ☐

5b. Do you often suffer from signs and symptoms of low blood sugar (hypoglycemia) following exercise and/or during activities of daily living? Signs of hypoglycemia may include shakiness, nervousness, unusual irritability, abnormal sweating, dizziness or light-headedness, mental confusion, difficulty speaking, weakness, or sleepiness. YES ☐ NO ☐

5c. Do you have any signs or symptoms of diabetes complications such as heart or vascular disease and/or complications affecting your eyes, kidneys, **OR** the sensation in your toes and feet? YES ☐ NO ☐

5d. Do you have other metabolic conditions (such as current pregnancy-related diabetes, chronic kidney disease, or liver problems)? YES ☐ NO ☐

5e. Are you planning to engage in what for you is unusually high (or vigorous) intensity exercise in the near future? YES ☐ NO ☐

11-01-2018

2019 PAR-Q+

6. Do you have any Mental Health Problems or Learning Difficulties? This includes Alzheimer's, Dementia, Depression, Anxiety Disorder, Eating Disorder, Psychotic Disorder, Intellectual Disability, Down Syndrome

If the above condition(s) is/are present, answer questions 6a-6b — If **NO** ☐ go to question 7

6a.	Do you have difficulty controlling your condition with medications or other physician-prescribed therapies? (Answer **NO** if you are not currently taking medications or other treatments)	YES ☐ NO ☐
6b.	Do you have Down Syndrome **AND** back problems affecting nerves or muscles?	YES ☐ NO ☐

7. Do you have a Respiratory Disease? This includes Chronic Obstructive Pulmonary Disease, Asthma, Pulmonary High Blood Pressure

If the above condition(s) is/are present, answer questions 7a-7d — If **NO** ☐ go to question 8

7a.	Do you have difficulty controlling your condition with medications or other physician-prescribed therapies? (Answer **NO** if you are not currently taking medications or other treatments)	YES ☐ NO ☐
7b.	Has your doctor ever said your blood oxygen level is low at rest or during exercise and/or that you require supplemental oxygen therapy?	YES ☐ NO ☐
7c.	If asthmatic, do you currently have symptoms of chest tightness, wheezing, laboured breathing, consistent cough (more than 2 days/week), or have you used your rescue medication more than twice in the last week?	YES ☐ NO ☐
7d.	Has your doctor ever said you have high blood pressure in the blood vessels of your lungs?	YES ☐ NO ☐

8. Do you have a Spinal Cord Injury? This includes Tetraplegia and Paraplegia

If the above condition(s) is/are present, answer questions 8a-8c — If **NO** ☐ go to question 9

8a.	Do you have difficulty controlling your condition with medications or other physician-prescribed therapies? (Answer **NO** if you are not currently taking medications or other treatments)	YES ☐ NO ☐
8b.	Do you commonly exhibit low resting blood pressure significant enough to cause dizziness, light-headedness, and/or fainting?	YES ☐ NO ☐
8c.	Has your physician indicated that you exhibit sudden bouts of high blood pressure (known as Autonomic Dysreflexia)?	YES ☐ NO ☐

9. Have you had a Stroke? This includes Transient Ischemic Attack (TIA) or Cerebrovascular Event

If the above condition(s) is/are present, answer questions 9a-9c — If **NO** ☐ go to question 10

9a.	Do you have difficulty controlling your condition with medications or other physician-prescribed therapies? (Answer NO if you are not currently taking medications or other treatments)	YES ☐ NO ☐
9b.	Do you have any impairment in walking or mobility?	YES ☐ NO ☐
9c.	Have you experienced a stroke or impairment in nerves or muscles in the past 6 months?	YES ☐ NO ☐

10. Do you have any other medical condition not listed above or do you have two or more medical conditions?

If you have other medical conditions, answer questions 10a-10c — If **NO** ☐ read the Page 4 recommendations

10a.	Have you experienced a blackout, fainted, or lost consciousness as a result of a head injury within the last 12 months **OR** have you had a diagnosed concussion within the last 12 months?	YES ☐ NO ☐
10b.	Do you have a medical condition that is not listed (such as epilepsy, neurological conditions, kidney problems)?	YES ☐ NO ☐
10c.	Do you currently live with two or more medical conditions?	YES ☐ NO ☐

PLEASE LIST YOUR MEDICAL CONDITION(S) AND ANY RELATED MEDICATIONS HERE:

GO to Page 4 for recommendations about your current medical condition(s) and sign the PARTICIPANT DECLARATION.

11-01-2018

2019 PAR-Q+

If you answered NO to all of the FOLLOW-UP questions (pgs. 2-3) about your medical condition, you are ready to become more physically active - sign the PARTICIPANT DECLARATION below:

- It is advised that you consult a qualified exercise professional to help you develop a safe and effective physical activity plan to meet your health needs.
- You are encouraged to start slowly and build up gradually - 20 to 60 minutes of low to moderate intensity exercise, 3-5 days per week including aerobic and muscle strengthening exercises.
- As you progress, you should aim to accumulate 150 minutes or more of moderate intensity physical activity per week.
- If you are over the age of 45 yr and **NOT** accustomed to regular vigorous to maximal effort exercise, consult a qualified exercise professional before engaging in this intensity of exercise.

If you answered **YES** to **one or more of the follow-up questions** about your medical condition:

You should seek further information before becoming more physically active or engaging in a fitness appraisal. You should complete the specially designed online screening and exercise recommendations program - the **ePARmed-X+ at www.eparmedx.com** and/or visit a qualified exercise professional to work through the ePARmed-X+ and for further information.

Delay becoming more active if:

- You have a temporary illness such as a cold or fever; it is best to wait until you feel better.
- You are pregnant - talk to your health care practitioner, your physician, a qualified exercise professional, and/or complete the ePARmed-X+ **at www.eparmedx.com** before becoming more physically active.
- Your health changes - talk to your doctor or qualified exercise professional before continuing with any physical activity program.

- You are encouraged to photocopy the PAR-Q+. You must use the entire questionnaire and NO changes are permitted.
- The authors, the PAR-Q+ Collaboration, partner organizations, and their agents assume no liability for persons who undertake physical activity and/or make use of the PAR-Q+ or ePARmed-X+. If in doubt after completing the questionnaire, consult your doctor prior to physical activity.

PARTICIPANT DECLARATION

- All persons who have completed the PAR-Q+ please read and sign the declaration below.
- If you are less than the legal age required for consent or require the assent of a care provider, your parent, guardian or care provider must also sign this form.

I, the undersigned, have read, understood to my full satisfaction and completed this questionnaire. I acknowledge that this physical activity clearance is valid for a maximum of 12 months from the date it is completed and becomes invalid if my condition changes. I also acknowledge that the community/fitness center may retain a copy of this form for records. In these instances, it will maintain the confidentiality of the same, complying with applicable law.

NAME _____ DATE _____

SIGNATURE _____ WITNESS _____

SIGNATURE OF PARENT/GUARDIAN/CARE PROVIDER _____

For more information, please contact
www.eparmedx.com
Email: eparmedx@gmail.com

Citation for PAR-Q+
Warburton DER, Jamnik VK, Bredin SSD, and Gledhill N on behalf of the PAR-Q+ Collaboration. The Physical Activity Readiness Questionnaire for Everyone (PAR-Q+) and Electronic Physical Activity Readiness Medical Examination (ePARmed-X+). Health & Fitness Journal of Canada 4(2):3-23, 2011.

The PAR-Q+ was created using the evidence-based AGREE process (1) by the PAR-Q+ Collaboration chaired by Dr. Darren E. R. Warburton with Dr. Norman Gledhill, Dr. Veronica Jamnik, and Dr. Donald C. McKenzie (2). Production of this document has been made possible through financial contributions from the Public Health Agency of Canada and the BC Ministry of Health Services. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada or the BC Ministry of Health Services.

Key References
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11-01-2018

Appendix L: Medical Variables

MEDICAL VARIABLES

1. Date of initial diagnosis of cancer: _____

Day Month Year

2. Type of cancer: _____

Histopathological details: _____

Stage: T____; N____; M____ / Overall stage_____

TREATMENT DETAILS:

3. Surgery date:_____

a. Location of surgery:_____

b. Details of surgery:

_____

4. Systemic Therapy: **yes____ no____**

a. CT type_____Cycles; _____ Dates: _____

Day Month Year

b. Biological Therapy _____ Dates: _____

5. Radiation Therapy: **yes____ no____**

a. Location_____

b. Dosage: _____ Fractions: _____Dates: _____

MEDICAL HISTORY:

12. Relevant past medical history: _____

13. Co-morbid/ concurrent conditions: _____

_____

14. Medications:

Medication	**Indication/reason**	**Dosage/ frequency**	**Date started**

Appendix M: Fitness Testing Protocols

DETAILED PROTOCOLS FOR FITNESS ASSESSMENTS

REQUIRED Fitness Testing

1) **Resting Vital Measurements**

   a) **Resting Heart Rate**

   - Ensure the participant has followed the pre-testing instructions listed above regarding food/beverage/alcohol intake, smoking, and exercise. Also ensure the participant has proper attire/footwear and that they have taken their medication as per doctor instruction.
   - Place a heart rate monitor strap on the participant, and then ask the participant to sit quietly and comfortably in a chair with their feet flat on the floor for 5 minutes. If necessary, provide a stool to place their feet on.
   - After 5 minutes, record the heart rate monitor reading in beats per minute (bpm).
   - **If a heart rate monitor is NOT available**, complete the following steps to obtain the resting heart rate measurement:
     - After 5 minutes, let the participant know that you will be taking a 15-second count of their pulse at the wrist. Ask the participant to rest their arm on the table and continue to sit quietly during the measurement.
     - Use your index and middle finger to apply gentle pressure at the wrist proximal to the thumb.
     - If you are having difficulty locating the participant's pulse at their wrist or it is too faint to count accurately, attempt to measure with the diaphragm of a stethoscope placed on the sternum or over the second intercostal space on the left side of their chest.
     - Use a 15-second count to determine the resting heart rate. Simultaneously start the stop-watch with the heart rate and count the first beat as "0".
     - Again, record the measurement in beats per minute (bpm)
   - If the heart rate is measured at ≥100 bpm, wait 5 minutes (participant should sit quietly during this time) and take the measurement again.
   - If the resting heart rate is still ≥100 bpm, DO NOT allow the participant to continue with the musculoskeletal or aerobic fitness components of the assessment.

   b) **Resting Blood Pressure**

- This measurement is taken immediately after the resting heart rate measurement, while the participant is still seated.
- Let the participant know that you will be measuring their blood pressure.
- Ask the participant to rest their arm and sit quietly during the measurement.

  NOTE: Blood Pressure is to be taken on the left arm when possible, but if applicable should only be taken on the **non-affected arm** (e.g. non-surgical side for breast or head & neck cancer survivor).
- Choose the appropriate size cuff by measuring the circumference of the participant's upper arm.
- Wrap the cuff firmly and smoothly around their arm with the lower edge of the cuff 2-3 cm above the antecubital space. Locate and note the brachial artery.
- The participant's arm should be resting on a table or comfortably supported at an angle of 10 to 45º from their trunk with the lower edge of the cuff at heart level.
- Rapidly inflate the cuff 20 to 30 mmHg above the radial palpatory pressure and quickly place the stethoscope over the brachial artery. Release the cuff pressure at a rate of 2 mmHg per second.

  NOTE: The stethoscope should be in complete contact with the skin with minimal pressure so as not to distort the artery. Ensure that the stethoscope is not touching the cuff or its tubing.
- The systolic pressure is determined by the first Korotkoff sound (first perception of sound). The diastolic pressure is determined by the fourth Korotkoff sound (muffling of the sound).
- Record both the systolic and diastolic measurements to the nearest 2 mmHg.
- If the resting systolic blood pressure is >144 mmHg and/or if the resting diastolic blood pressure is >94 mmHg, wait 5 minutes (participant should sit quietly during this time) and take the measurement again.
- If the resting systolic blood pressure is >144 mmHg or if the resting diastolic blood pressure is >94 after the second reading, DO NOT have the participant attempt the musculoskeletal or aerobic fitness components of the assessment.

c) <u>Resting Oxygen Saturation (SpO_2) Measurement</u>

This measurement will ONLY be taken where a pulse oximeter is available.

- Take measurement immediately after the other resting measurements, while the participant is still seated.
- Let the participant know that you will be measuring their oxygen saturation.
- Ask the participant to rest their arm and sit quietly during the measurement.

- Place the oximeter on the index or ring finger until a stable measurement is obtained.
- Record the % oxygen saturation (SpO_2).

2) Anthropometric Measurements

a) <u>Standing Height</u>

- Ask the participant to remove their footwear and any wigs, hats and/or scarves.
  - Make a note on recording sheet if the participant was not willing to remove any of the above, and ensure the same is worn for subsequent measurements if possible.
- Ask the participant to stand looking straight ahead with their arms hanging at their sides and feet together. If taken against a wall, heels and back should be in contact with the wall.
- Instruct the participant to stand as tall as possible with feet flat and heels in contact with the stadiometer/floor, and take a deep breath.
- Place a set square (ensure it is level with the ground) on the head, depressing the hair if necessary to ensure contact with the head for an accurate measurement.
- Record the measurement to the nearest 0.5 cm.

b) <u>Weight</u>

- The participant's shoes should remain off after the height measurement. Ask participant to remove anything from their pockets (keys, wallet), heavy jewellery, and any unnecessary clothing (e.g. Sweatshirt).
- Ensure that the scale has been accurately calibrated and resting on a hard, flat surface. The scale should read zero when the participant is not standing on the scale.
- Ask the participant to step on the scale and stand still while looking straight ahead, with their arms hanging by their sides.
- Record weight to the nearest 0.1 kg.

c) <u>Body Mass Index (BMI)</u>

- The ratio of body weight to height squared:

  BMI = weight in kilograms (kg) / height in metres squared (m^2).

  NOTE: This will be calculated automatically when the data is entered into REDCap.

d) <u>Waist Circumference</u>

- Waist circumference is measured at the top of the iliac crest, and should be taken directly on bare skin if the participant is comfortable with this.
    - Ask the participant to roll up their shirt and/or tuck it into their bra to ensure that it is not in the way. **NOTE**: Do not have the Participant hold their shirt up, as this can affect the accuracy of the measurement.
    - If necessary, also ask the participant to lower the waist of their pants slightly to expose the top of their hips.
- Ask the participant if it is ok to feel for the top of their hip bone and make a mark with a washable marker.
- Palpate the upper right hipbone until you locate the uppermost lateral border of the iliac crest, and draw a horizontal line at this landmark in the midline of the body.
- Ensure that the bottom edge of the tape measure is level with the landmarked point, and is in a horizontal, level plane around the abdomen.
- Pull the tape measure with sufficient tension so that it is snug, but without any indentation to the skin.
- Ask the participant to relax their arms at their sides, and take the measurement at the end of a normal expiration.
- Record the measurement to the nearest 0.5 cm.

e) <u>Hip Circumference</u>

- Hip circumference is measured at the greatest gluteal protuberance.
- Ask the participant to stand with their feet together and right hip facing you.
- Ask them to cross their arms at their chest, with hands at the shoulders.
- Ensure that the tape measure is in a horizontal, level plane, and pull the tape measure with sufficient tension so that it is firmly against the clothing.
- Have participant lift long shirts or other bulky clothing or items (wallets, keys, etc.) out of the measurement area.
- Record the measurement to the nearest 0.5 cm.

f) <u>Waist/Hip Ratio (WHR)</u>

- Calculate the ratio of waist circumference to hip circumference:

    WHR = waist circumference (cm) / hip circumference (cm).

  NOTE: This will be calculated automatically when the data is entered into REDCap.

3) Musculoskeletal Fitness Measurements

a) Grip Strength (Muscular Strength)

- Explain to the participant that you will now assess their grip strength, which is a good indicator of upper body muscular strength.
- Adjust the dynamometer so that the second joint of their fingers rests on the handle.
- Ask the participant to hold the dynamometer in line with their forearm and away from their side at approximately a 45º angle (level with the thigh).
- Explain to the participant not to swing their arm or bend their elbow or wrist during the test, and that neither the dynamometer nor their arm can touch their body or any other object during the test.
- Tell the participant that they will get two trials per hand, alternating hands after each trial for a combined score of your highest score from each hand.
- Ask the participant to take a deep breath in and then squeeze as hard as they can for 2-3 seconds.
- Ensure the participant is exhaling while squeezing the dynamometer.
- Alternate hands, allowing two trials per hand. Ensure the dial is set to zero prior to each trial.
- Record the reading to the nearest kilogram. Combine the maximum score for the left and right hand.

  NOTE: The best trials will be selected and used to calculate the total score when the data is entered into REDCap.

b) Sit to Stand Test (Muscular Endurance)

- Explain to the participant they will now be doing a sit to stand test to assess the muscular endurance of their legs.
- Place a chair with the back against the wall to prevent the chair from sliding.
- Chair seat height should be as close to 17” (43.2 cm) in height as possible. Use same chair for all testing.
- The participant wears shoes for this test.
- The participant starts in the seated position with arms crossed at their chest. Their back does not need to touch the back of the chair.
- They will rise to a full stand and then return to the fully seated starting position.
  - They must stand with full hip extension and return to the seated position with

their bottom in contact with the chair for the repetition to count.

- Inform the participant that you will give them a 'ready-set- go' cue to start the test. Ensure that you start your stopwatch simultaneously with 'go'.
- The participant will complete as many repetitions as they can in 30 seconds.

NOTE: If the participant is not completing the motion as fast as possible, ask them to stop and repeat the test as fast as possible.

c) <u>Muscular Strength 1 or 8 Repetition Maximum (RM) Bench and Leg Press Tests</u>

- Explain to the participant that you will now assess their upper and lower body strength using the vertical bench and/or leg press machines.
- Adjust machine to ensure proper technique, safety, and comfort.
    - For Bench Press, set seat height to ensure alignment of hands at level of pectoralis major. Range of motion is from level (within an inch) of chest to full arm extension.

      NOTE: For individuals with shoulder impairments from cancer treatments (e.g. breast, head & neck) or a history of shoulder injury, the ROM should be reduced to begin with the elbows in line with their body.
    - For Leg Press, set seat so that knee is just below 90°. Feet should be approximately hip width apart. Range of motion is from knee starting at 90° to full extension (without hyper-extending knee).
- Ensure proper breathing with exhalation on exertion and inhalation when returning to starting position.
- Explain to participant that you are measuring the maximum weight they can lift one time (for 1RM) or eight times (for 8RM).
- Participant starts with a warm-up of 4 to 8 repetitions at a light to moderate load.
- The participant will be asked to rate the perceived load of the warm-up resistance weight on a scale of 1–5 (1 = very easy and 5 = maximal/ full effort).
- The load will be increased relative to the participant's response. Once the participant reports a score of 4 (close to maximal effort) out of 5, a small increase in weight will be added and a 1 (or 8) RM will be attempted.
- Ample rest (at least 2-5 minutes) should be allowed before each 1 (or 8) RM attempt.
- The goal should be to determine the participant's 1RM or 8RM in a maximum of 3 trials following the warm-up.
- Record the weight lifted for the final 1 or 8 RM (and the number of repetitions completed if more or less than target number of reps were completed).

d) Core Endurance

Plank Test

- Explain to the participant they will be doing a plank test to assess their core muscular endurance.
- Participant will start lying prone on a mat on the floor.
- Resting on forearms and feet dorsiflexed with weight on the balls of the toes.
- Have the participant hold his/her body in a straight line from head to heels.
- The feet should be together and legs must be straight.
- Elbows should be beneath the shoulders with their arms separated or with fingers linked.
- The participant should look straight down and brace/hold the position for as long as he/she can.
- Hips must be in line with the trunk – NOT above or sagging below.
- Instruct the participant to hold this position for as long as they can and the test will be terminated when back lowers or rises out of the position.
- Begin timing the test when the participant has taken the correct starting position, and stop & record the time (to the nearest tenth of a second) when they can no longer maintain proper form.

Appendix N: Fitness Testing Recording Sheet

RISE UP Fitness Testing Data Sheet

Testing Time Point: Baseline 12-week

Vitals

Resting Heart Rate	**bpm**
Resting Blood Pressure	**mmHg**
Resting O_2 Saturation	**%**

Body Composition

Height (to nearest 0.5 centimeter)	**cm**
Weight (to nearest 0.1 kg)	**kg**
Waist circumference (to nearest 0.5 cm)	**cm**
Hip circumference (to nearest 0.5 cm)	**cm**

Musculoskeletal

Hand Grip	**Trial 1**	**Trial 2**
RIGHT	**kg**	**kg**
LEFT	**kg**	**kg**

Function

Sit to Stand Test (# of reps in 30 sec)	

STRENGTH TESTS

Upper & Lower Body Strength	**Bench Press**	**Leg Press**
1 Repetition maximum (lbs)*		
Seat Height		
Modifications? (Blocking, other?)		

***Indicate number of reps (e.g. 8) if number other than 1 completed.**

CORE - Plank Test (to nearest 0.1 sec)	

Appendix O: Body Appreciation Sclae-2

Appendix B: Body Appreciation Scale – 2 Survey Questions

For each item, the following response scale should be used:

1 = Never, 2 = Seldom, 3 = Sometimes, 4 = Often, 5 =Always.

Directions for participants: Please indicate whether the question is true about you never, seldom, sometimes, often, or always.

1. I respect my body.

2. I feel good about my body.

3. I feel that my body has at least some good qualities.

4. I take a positive attitude towards my body.

5. I am attentive to my body's needs.

6. I feel love for my body.

7. I appreciate the different and unique characteristics of my body.

8. My behavior reveals my positive attitude toward my body; for example, I hold my head high and smile.

9. I am comfortable in my body.

10. I feel like I am beautiful even if I am different from media images of attractive people (e.g., models, actresses/actors).

Scoring Procedure: Average participants' responses to Items 1–10.

Appendix P: FACIT-G Version 4

FACIT-F (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

	PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

FACIT-F (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Appendix Q: Godin Leisure Time Exercise Questionnaire

GODIN LEISURE TIME EXERCISE QUESTIONNAIRE

We would like you to recall your average weekly exercise over the past month. How many times per week on average did you do the following kinds of exercise over the past month? When answering these questions please remember to: Consider your average weekly exercise over the past month Only count exercise sessions that lasted 15 minutes or longer in duration Only count exercise that was done during free time (i.e. do not included occupation or housework) Note the main difference between the three categories is the intensity of the exercise Write the average frequency on the first line and the average duration on the second line

STRENUOUS EXERCISE (Heart beats rapidly, sweating) (e.g., running, jogging, hockey, soccer, squash, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance bicycling, vigorous aerobic dance classes, heavy weight training) In an average week I was involved in strenuous exercise _____ times/week for an average duration of _____ minutes/each session.

MODERATE EXERCISE (Not exhausting, light perspiration) (e.g., fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing) In an average week I was involved in moderate exercise _____ times/week for an average duration of _____ minutes/each session.

MILD EXERCISE (Minimal effort, no perspiration) (e.g., easy walking, yoga, archery, fishing, bowling, lawn bowling, shuffleboard, horseshoes, golf, snowmobiling) In an average week I was

involved in mild exercise _____ times/week for an average duration of _____ minutes/each session.

RESISTANCE TRAINING EXERCISE (e.g. exercises with dumbbells, body weight, bands, such as squats, bicep curls, etc.) In an average week I perform resistance training activities_____ times/ week for an average duration of _____ minutes/session.

FLEXIBILITY TRAINING EXERCISE (e.g. yoga, stretching) In an average week I perform flexibility training activities_____ times/ week for an average duration of _____ minutes/session.

Appendix R: Stages of Change Questionnaire

Confidential

Physical Activity Stages of Change

Please complete the survey below.

Thank you!

RM 1-FM: Physical Activity Stages of Change-Questionnaire

For each of the following questions, please circle Yes or No. Be sure to follow the instructions carefully.
Physical activity or exercise includes activities such as walking briskly, jogging, bicycling, swimming, or any other activity in which the exertion is at least as intense as these activities.

1)	1. I am currently physically active.	◯ Yes ◯ No
2)	2. I intend to become more physically active in the next six months.	◯ Yes ◯ No

For activity to be regular, it must add up to a total of 30 minutes or more per day and be done at least five days per week. For example, you could take one 30-minute walk or take three 10-minute walks for a total of 30 minutes.

3)	3. I currently engage in regular physical activity.	◯ Yes ◯ No
4)	4. I have been regularly physically active for the past six months.	◯ Yes ◯ No

Appendix S: Group Exercise Circuit Training Example

*Modifications provided as needed

Warm-up: Cha Cha Slide line dance

Stations: 1 minute at each station, 2x around

Cardio:

1. Pylon shuffle
2. Mountain Climbers (off wall, off chair, or off the floor)
3. Modified Burpees

Lower Body:

4. Deadlift
5. Curtsy squat with lateral leg lift
6. Glute bridge

Upper Body:

7. Holding light weight straight out in front, forward pulses while seated on ball
8. Chest push-up (wall, bench, knees or from toes)
9. Standing pullback with resistance band

Core – Tabata format 20 seconds on/10 seconds off

1. Reverse curls
2. Side leg lift or side plank
3. Superman alternating arms and legs or bird dog
4. Bicycles
5. Side leg lift or side plank
6. Front plank

Flexibility of major muscle groups – Hold each stretch 20-30 seconds

1. Seated hamstrings stretch
2. Standing quadriceps stretch
3. Seated glutes stretch
4. Standing calf stretch
5. Hip flexors stretch
6. Pectoralis Major/Minor stretch
7. Child's pose
8. Triceps stretch

Appendix T: Individual Resistance Exercise Program Template

Group Personal Training

Study ID: __

First Name: Location: Wellspring Session:

Warm–up: 3–5 mins of light aerobic exercise (treadmill, walking, bike).

Exercise Type: Wks 5-8			Date:		Date:		Date:		Date:		Date:		Date:		Date:		Date:	
Aerobic		Type																
		Duration (minutes)	10-15		10-15		15-20		15-20		15-20		15-20		15-20		15-20	
		Intensity level																
		RPE																
Muscle Group	**Machine OR Exercise**	**Exercise Details (machine settings, etc)**	Sets x Repetitions															
			2x10		2x12		3x10		2x10		2x12		3x10		2x10		2x12	
			lbs	✓	lbs	✓	lbs	✓	lbs	✓	lbs	✓	lbs	✓	lbs	✓	lbs	✓
Chest/ Triceps	Vertical Bench (#1)	Seat:																
Back	Vertical Row (#3)	Seat:																
Legs	Seated Leg Press (#4)	Seat:																
Shoulders	Shoulder Press (#2)	Seat:																
Biceps	Bicep Curls																	
Balance	Single Leg Balance with Hip Flexion																	
Core	Plank																	
Core	Deadbug																	
Core/Glutes	Clamshells																	
Other																		
Stretch	**Muscle Groups: Hamstrings, Quads, Calves, Pecs, Triceps. 2 × 20-30sec**																	
RPE																		

Rating of Perceived Exertion (RPE) SCALE

0	0.5	1	2	3	4	5	6	7	8	9	10
None	Very, Very Light	Very Light	Light	Moderate	Somewhat Strong	Strong		Very Strong			Maximal

Trainer Comments/Notes:

Appendix U: Photographs of Participants' Sculptures

Holding my Heart

"My sculpture is a robust, compact piece, which shows a vulnerability and thoughtfulness that lends it gravity. I tried forcing it into something gendered and aesthetically pleasing; however, it came out as an androgynous and peaceful representation instead. I had expectations and ideas for this piece which didn't come to fruition. Instead, it is its own being. I am grateful for the guidance from Pat who saw something in this that I couldn't and encouraged that essence to the surface. The result is a strong but vulnerable piece. It is holding and protecting its heart with strength and compassion. I think there is a lesson in there somewhere".

CHILD POSE

Journey thru cancer
Leads Inward to Love Myself
Stronger and Alive

“Thinking about the sculpture, I think I made it in the image of how I see myself in the past and how I want to see myself moving forward. I am relaxed, fit and calm. I am holding a blob, which represents the part that was cut away with the tumour from my lumpectomy. I thought I am still me and this is just a blob that is no longer attached to me. I was feeling like I can handle this, I can just toss it away and be free of it. I am not defined by a missing piece of flesh, I define myself by so much more, like my resilience, my determination and my strength”.

GRATITUDE

Creativity leads me to Calm and Peace

Peace and Calm leads me to Creativity

“I wanted my piece to be something positive, something that represents hope. My piece represents me sitting on the floor getting ready to do mat exercises. Getting down and back up from the floor are hard for me. Yet, there is hope in it; if you can get down-you can get back up. Exercise is so beneficial, and is what keeps me moving daily.
The modelling of the clay allowed us to see the strength, weaknesses and flexibility in building our pieces: much like the flow in our daily lives.
To quote Hillsong: ‘take me as you find me, all my fears and failures, fill my life again...’.
That is where exercise and art bring me.”